



Technological University Dublin  
**ARROW@TU Dublin**

---

Dissertations

School of Computing

---

2012

## Accessible Information: Advocating the Use of Technology for Individuals with Intellectual Disability on their Path to Individualised Services

Michelle Moloney  
*Technological University Dublin*

Follow this and additional works at: <https://arrow.tudublin.ie/scschcomdis>

 Part of the [Computer Engineering Commons](#)

---

### Recommended Citation

Moloney, M. :Accessible Information: Advocating the use of Technology for Individuals with Intellectual Disability on their Path to Individualised Services.Masters Dissertation. Technological University Dublin, 2012.

This Dissertation is brought to you for free and open access by the School of Computing at ARROW@TU Dublin. It has been accepted for inclusion in Dissertations by an authorized administrator of ARROW@TU Dublin. For more information, please contact [yvonne.desmond@tudublin.ie](mailto:yvonne.desmond@tudublin.ie), [arrow.admin@tudublin.ie](mailto:arrow.admin@tudublin.ie), [brian.widdis@tudublin.ie](mailto:brian.widdis@tudublin.ie).



This work is licensed under a [Creative Commons Attribution-Noncommercial-Share Alike 3.0 License](#)



**Accessible Information: Advocating the  
use of Technology for Individuals with  
Intellectual Disability on their Path to  
Individualised Services**

**Michelle Moloney**

A dissertation submitted in partial fulfilment of the requirements of  
Dublin Institute of Technology for the degree of  
M.Sc. in Computing (Assistive Technology)

**July 2012**

I certify that this dissertation which I now submit for examination for the award of MSc in Computing (Assistive Technology), is entirely my own work and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

This dissertation was prepared according to the regulations for postgraduate study of the Dublin Institute of Technology and has not been submitted in whole or part for an award in any other Institute or University.

The work reported on in this dissertation conforms to the principles and requirements of the Institute's guidelines for ethics in research.

***Signed:*** \_\_\_\_\_

***Date:***                    ***16 July 2012***

## ABSTRACT

Providing people with an intellectual disability (ID), opportunities for social integration have been shown to have a reliable positive influence on their well-being (Wehmeyer *et al.*, 2006; Bunning, 2009). A large percentage of individuals with ID are unable to read and write. For this reason in order for the person to make an informed choice the person needs to have good information presented in a way that they can understand. They may need to see tangible visual aids (video, role play, film, photographs). It may need to be demonstrated to them a number of times. This assists a person in making choices and decisions so that they can actively participate not just in their own lives but in the community. Otherwise the person cannot make the decision, and other people are making it for them.

Therefore this research will investigate the viability of developing an internal web-based learning and communication tool for people with an ID. The tool will focus on providing accessible information through image to image navigation and by providing choice of modality when receiving information. (Who, 2011) state that two of the biggest barriers to living an ordinary life are the lack of accessible information and being able to advocate. A person cannot be an active citizen if they cannot access the information or understand the way it is presented. It effects every part of your life.

The experiment also evaluated if video conferencing communication tools are accessible for the participants who reside in different locations to communicate with each other. The key issues that must be explored around the development of such a system will be factors such as; Accessible Information, Web Accessibility and Universal Design. The pilot system will involve individuals with mild to moderate ID who attend one of seven training centres in disparate locations. This research will also explore these issues in the context of social models, such as Wolfensberger's theory of Social Role Valorization.

**Key words:** *accessible information, intellectual disability, web accessibility, cognitive design, individualised services*

## ACKNOWLEDGEMENTS

A sincere thank you to Dr. Michael Collins, my supervisor, for all his help and guidance along the way. The Big Bang Theory will never be the same again. To my advisors (Ollie, Bre, Ed, Sushi, Eamon & Taz) who got this carcass over the finish line, particularly at the last hurdle, you have been brilliant. A virtual pat on the back to all. Eddie, I could have done with your sharp criticism and keen eyes. You are absolutely missed. Sabrina, with your facilitator hat on, it was an education. Dad, it is hard to believe that you have finally retired. Mum, it's harder to believe you let him! Enjoy all the travels ahead.

A huge thank you is offered to the participants who partook in this research. Your willingness to engage, your enthusiasm, and your absolute frankness at times was refreshing. Without doubt, the interaction with you was the best part of this whole process.

# TABLE OF CONTENTS

<b>ABSTRACT .....</b>	<b>II</b>
<b>TABLE OF FIGURES .....</b>	<b>IX</b>
<b>TABLE OF TABLES .....</b>	<b>XI</b>
<b>TABLE OF ABBREVIATIONS.....</b>	<b>XII</b>
<b>1. INTRODUCTION .....</b>	<b>1</b>
1.1 INTRODUCTION.....	1
1.2 BACKGROUND .....	4
1.3 RESEARCH PROBLEM .....	4
1.4 RESEARCH OBJECTIVES .....	6
1.5 RESEARCH METHODOLOGY .....	7
1.6 RESOURCES .....	8
1.7 SCOPE AND LIMITATIONS.....	8
1.8 ORGANISATION OF THE DISSERTATION .....	9
<b>2 INTELLECTUAL DISABILITY IN AN ICT WORLD .....</b>	<b>10</b>
2.1 INTRODUCTION.....	10
2.2 UNDERSTANDING INTELLECTUAL DISABILITY .....	10
2.2.1 <i>What is Intellectual Disability?</i> .....	10
2.2.2 <i>Prevalence Levels</i> .....	10
2.2.3 <i>Terminology</i> .....	12
2.2.4 <i>Employment</i> .....	13
2.3 LITERACY LEVELS OF PEOPLE WITH AN ID.....	14
2.3.1 <i>Reading</i> .....	14
2.3.2 <i>Writing</i> .....	15
2.3.3 <i>Digital Literacy</i> .....	15
2.3.4 <i>Literacy Strategies</i> .....	15
2.4 LEARNING CHARACTERISTICS OF PEOPLE WITH ID .....	17
2.5 WHAT DO PEOPLE WITH ID USE ICT FOR? .....	18
2.5.1 <i>Daily Tasks</i> .....	18

2.5.2	<i>Social Inclusion</i> .....	20
2.5.3	<i>Gather Information</i> .....	20
2.5.4	<i>To Learn</i> .....	21
2.5.5	<i>Leisure Activities</i> .....	21
2.6	HOW DO PEOPLE WITH ID USE ICT? .....	23
2.6.1	<i>Assistive Technologies</i> .....	23
2.6.2	<i>Mobile Computing</i> .....	25
2.6.3	<i>Virtual Environments</i> .....	29
2.6.4	<i>Game Development</i> .....	31
2.7	BENEFITS FOR PEOPLE WITH ID USING ICT.....	31
2.8	CONSTRAINTS FOR PEOPLE WITH ID USING ICT .....	32
2.8.1	<i>Access to ICT, Awareness and Basic Interest</i> .....	32
2.8.2	<i>ICT Skills and Training</i> .....	33
2.8.3	<i>Costs</i> .....	34
2.8.4	<i>Assistive Technology (AT) Needs</i> .....	34
2.8.5	<i>Accessible Information</i> .....	35
2.8.6	<i>Authentication</i> .....	35
2.8.7	<i>Cognitive Capability</i> .....	37
2.8.8	<i>Vulnerable Adults</i> .....	39
2.9	CONCLUSION .....	39
<b>3</b>	<b>ACCESSIBLE INFORMATION, ADVOCACY AND THE ROAD TO INDIVIDUALISED SERVICES .....</b>	<b>41</b>
3.1	INTRODUCTION.....	41
3.2	INSTITUTIONAL MODEL .....	41
3.3	COMMUNITY LIVING MODEL.....	42
3.3.1	<i>Benefits from a service provider perspective</i> .....	42
3.3.2	<i>Benefits to the Individual</i> .....	42
3.3.3	<i>Measuring Integration</i> .....	43
3.4	INDIVIDUALISED SERVICE MODEL.....	44
3.4.1	<i>United Kingdom Model</i> .....	45
3.4.2	<i>Direct Payments</i> .....	46
3.4.3	<i>Assessment Tools</i> .....	47
3.4.4	<i>Reframing Disability Service Provision in Ireland</i> .....	47

3.4.5	<i>Smart Homes</i> .....	48
3.5	THE ADVOCACY MOVEMENT TOWARDS INDIVIDUALISED SERVICES .....	49
3.6	HEALTH INFORMATION AND QUALITY AUTHORITY .....	50
3.6.1	<i>About the Health Information and Quality Authority</i> .....	50
3.6.2	<i>The impact of HIQA on ID</i> .....	51
3.6.3	<i>HIQA and Accessible Information</i> .....	52
3.6.4	<i>Care Quality Commission - CQC</i> .....	53
3.7	CAPACITY.....	54
3.8	ACCESSIBLE INFORMATION IN AN ID CONTEXT .....	56
3.8.1	<i>Symbol Sets</i> .....	56
3.9	CONCLUSION .....	57
<b>4</b>	<b>COGNITIVE DISABILITY AND ITS IMPACT ON DESIGN.....</b>	<b>58</b>
4.1	INTRODUCTION.....	58
4.2	STANDARDS .....	58
4.2.1	<i>Web Content Accessibility Guidelines Version 1.0</i> .....	58
4.2.2	<i>Web Content Accessibility Guidelines Version 2.0</i> .....	60
4.2.3	<i>Section 508</i> .....	61
4.2.4	<i>Digital Accessible Information SYstem</i> .....	62
4.2.5	<i>Organisational Standards</i> .....	62
4.3	HUMAN COMPUTER INTERACTION .....	63
4.3.1	<i>User Centered Design</i> .....	65
4.4	G3ICT.....	67
4.5	LEGISLATION.....	67
4.6	UNIVERSAL DESIGN .....	67
4.7	WEB ACCESSIBILITY TOOLS.....	68
4.8	CONCLUSION .....	69
<b>5</b>	<b>DESIGN PROCESS.....</b>	<b>70</b>
5.1	INTRODUCTION.....	70
5.2	REQUIREMENTS GATHERING .....	70
5.3	DESIGN CONCEPT .....	71
5.4	DESIGN PRINCIPLES.....	73
5.5	TOOL SELECTION.....	74



5.5.1	<i>Why PhotoSymbols?</i> .....	75
5.5.2	<i>Why Moodle?</i> .....	75
5.6	ONLINE LEARNING RESOURCE AND ID .....	76
5.7	ENVIRONMENT CONTENT SELECTION .....	77
5.8	ENVIRONMENT CONTENT DEVELOPMENT .....	78
5.9	DESIGN EVALUATION .....	79
5.9.1	<i>Paper Prototype</i> .....	79
5.9.2	<i>Content Evaluation</i> .....	80
5.9.3	<i>Interface Evaluation</i> .....	81
5.9.4	<i>Web Accessibility Considerations</i> .....	83
5.10	ACCESSIBLE DOCUMENTATION .....	84
5.11	MOVING FORWARD .....	85
5.12	CONCLUSION .....	85
<b>6</b>	<b>IMPLEMENTATION .....</b>	<b>86</b>
6.1	INTRODUCTION .....	86
6.2	ABOUT THE SERVICE PROVIDER .....	86
6.3	ABOUT THE PARTICIPANTS .....	87
6.4	MATERIALS .....	87
6.5	PROCEDURES .....	87
6.5.1	<i>Procedure One for Group A</i> .....	88
6.5.2	<i>Procedure Two for Group A</i> .....	89
6.5.3	<i>Procedure Three for Group B</i> .....	90
6.6	OTHER FACTORS FOR CONSIDERATION .....	90
6.7	CONCLUSION .....	91
<b>7</b>	<b>EVALUATION .....</b>	<b>93</b>
7.1	INTRODUCTION .....	93
7.2	PARTICIPANT DEMOGRAPHICS .....	93
7.2.1	<i>Group A</i> .....	94
7.2.2	<i>Group B</i> .....	94
7.3	ETHICAL CONSIDERATIONS .....	95
7.4	ENVIRONMENT SETTINGS .....	96
7.5	ASSESSMENT PROTOCOL .....	97

7.6	DATA COLLECTION .....	98
7.7	DATA ANALYSIS METHODS.....	99
7.8	RESULTS.....	100
7.8.1	<i>Group A Results</i> .....	100
7.8.2	<i>Group B Results</i> .....	102
7.8.3	<i>Results Applicable to Both Groups</i> .....	106
7.9	LIMITATIONS .....	109
7.10	CONCLUSION.....	109
<b>8</b>	<b>CONCLUSION .....</b>	<b>110</b>
8.1	INTRODUCTION.....	110
8.2	RESEARCH OVERVIEW.....	110
8.3	EXPERIMENTATION, EVALUATION AND LIMITATION .....	111
8.4	CONTRIBUTIONS TO THE BODY OF KNOWLEDGE .....	112
8.5	FUTURE WORK AND RESEARCH .....	113
8.6	FINAL REFLECTIONS.....	116
	<b>REFERENCES .....</b>	<b>119</b>
	<b>APPENDIX A - EXPRESSION OF INTEREST FORM.....</b>	<b>126</b>
	<b>APPENDIX B - INFORMATION SHEET .....</b>	<b>127</b>
	<b>APPENDIX C - CONSENT FORM.....</b>	<b>130</b>
	<b>APPENDIX D - RESEARCH ETHICS APPLICATION FORM.....</b>	<b>132</b>

## TABLE OF FIGURES

Figure 1.1	HIQA Seven Dimensions of Individual Quality Care	2
Figure 2.1	Distribution of Subcategories of Disabilities in EU	11
Figure 2.2	Terminology Used to Refer to ID	13
Figure 2.3	A Typical ATD Selection Framework	24
Figure 2.4	Problems Experienced by Persons with ID using a Touch Screen	26
Figure 2.5	iPhone Screenshot of MARTi app	27
Figure 2.6	EZ Tune Interface	27
Figure 2.7	iPod Touch Example for Person with ID	29
Figure 2.8	Sample On Screen Keyboard	35
Figure 2.9	Internet Access Controls	36
Figure 2.10	Symbol Log in Suggestion	37
Figure 2.11	Intelligent Model for Rating Cognitive	38
Figure 3.1	HIQA Values	51
Figure 3.2	Assessment Pathway	55
Figure 3.3	Example of Different Symbol Sets	57
Figure 4.1	Definitions of Concepts of Accessibility, UD & Communication	62
Figure 4.2	Summary of Difficulties Experience by Children with DS	65
Figure 4.3	SymbolChat Interface	66
Figure 5.1	Sample SMH Newsletter	72
Figure 5.2	Moodle Prompt - Insert an Image without Description	76
Figure 5.3	Moodle Prompt - Screen Reader during Installation	76
Figure 5.4	Site Map	78
Figure 5.5	Easy Read Document Sample	79
Figure 5.6	A Paper Prototype Sample Presented for Evaluation	80
Figure 5.7	Sample Prototype Interface	81
Figure 5.7	Prototype Initial Images	83
Figure 5.9	Prototype Revised Images	83
Figure 6.1	Other Prototype Implementation Considerations	91
Figure 7.1	Number of Participants with Level of ID per Group & Overall	93
Figure 7.2	The Percentage Level of ID per group, by Gender & Overall	95

Figure 7.3	Computer Usage by Group A	100
Figure 7.4	Sample of Skype Interface	102
Figure 7.5	Computer Access for Group B	103
Figure 7.6	Mouse Usage Analysis of Group B	105
Figure 7.7	Group B Analysis if Too Easy or not	106
Figure 7.8	Analysis of First Preference Modalities	107
Figure 7.8	Analysis of Second Preference Modalities	107
Figure 7.8	Analysis of Third Preference Modalities	108

## TABLE OF TABLES

Table 2.1	Degree of ID	12
Table 2.2	Experiences of Students Victimised or Bullied via the Internet	39
Table 5.1	Web Accessibility Considerations	84
Table 6.1	Organisation Overview of ID Levels	86
Table 6.2	Task Breakdown of Open Shortcut	89
Table 7.1	The Mean Age and SD by Gender and Group	94
Table 7.2	Summary of Gender & Age Composition of Participant Groups	95

## TABLE OF ABBREVIATIONS

AT	Assistive Technology
ATD	Assistive Technology Device
CAD	Cognitive Assistive Device
CQC	Care Quality Commission
CRPD	Convention on the Rights of Persons with Disabilities
DRC	Disability Rights Commission
DS	Down Syndrome
EEA	European Economic Area
EU	European Union
GPS	Global Positioning System
HCI	Human Computer Interface
HIQA	Health Information and Quality Authority
ID	Intellectual Disability
IQ	Intelligence Quotient
IS	Intelligent System
ICT	Information and Communication Technology
NHS	National Health Service
NIDD	National Intellectual Disability Database
PDA	Personal Digital Assistant
RFID	Radio-frequency Identification
SD	Standard Deviation
SMH	Saint Michaels House
SSI	Social Services Inspectorate
UD	Universal Design
UK	United Kingdom
URL	Uniform Resource Locator
VLE	Virtual Learning Environment
VR	Virtual Reality
W3C	World Wide Web Consortium
WAI	Web Accessibility Initiative

WCAG

Web Content Accessibility Guidelines

WHO

World Health Organisation

# 1. INTRODUCTION

## *1.1 Introduction*

The backdrop for caring for those with an Intellectual Disability, henceforth referred to as ID, has changed dramatically in the past three decades. There has been a growing movement away from an institutional set up to a community based setting (Lakin & Stancliffe, 2007). In recent times, the biggest change is the advent of a personalised budget. This system has existed in the United Kingdom (UK) since 2008. Essentially it denotes that each individual with ID who has the capacity (Oldreive & Waight, 2011) to choose their own services will now be able to do so. In an Irish context this is expected to happen in the next five to ten years. It presents a massive departure from current workings in that in effect the person with ID can tender for services, and the private sector can now become involved. Therefore service providers need to effectively communicate these changes to their service users. ID service providers traditionally concentrate their efforts on providing Information and Communication Technology (ICT) services to their staff not service users, or consumers as they are now. It is expected that this service model will have to change.

For some perhaps this alternative path is viewed as a potentially very lucrative market opportunity. It opens up a once closed market to a tendering process. For some services who traditionally received a funding allocation regardless of the level of service that was provided, this could be the wake up call that benefits all. Staff may be reignited to pull together to provide the best service, as their previous captive customer has just been given parole. No customer, no service, no jobs.

With all the potential benefits that personalised budgets can bring to an individual they are not a panacea. This was highlighted in a BBC Panorama expose broadcast in May last year (Undercover Care, The Abuse Exposed). Essentially in one of the first private care home facilities set up to care for individuals with ID, following the introduction of private budgets, extensive physical and verbal mistreatment of individuals was taking place. So much so that as a result of the undercover investigation, thirteen people were fired and four arrested. The Care Quality



Commission (CQC), the UK equivalent of the Health Information and Quality Authority (HIQA), had visited the location several times, and having failed to respond to three calls from a whistle blower detailing the abuse, the care home remained open (Guardian, 2011). The whistle blower in this case, was a former member of staff who had previously brought the issue to management and CQC. After being relieved of his position for being regarded as a trouble maker he approached Panorama. This programme highlighted the best and worst of staff. In HIQAs Seven Dimensions of Individual Quality Care the individual is placed at the centre of the process. However, if staffing is wrong it impacts on all the other items, for example quality of life, which has been aptly demonstrated in this case.

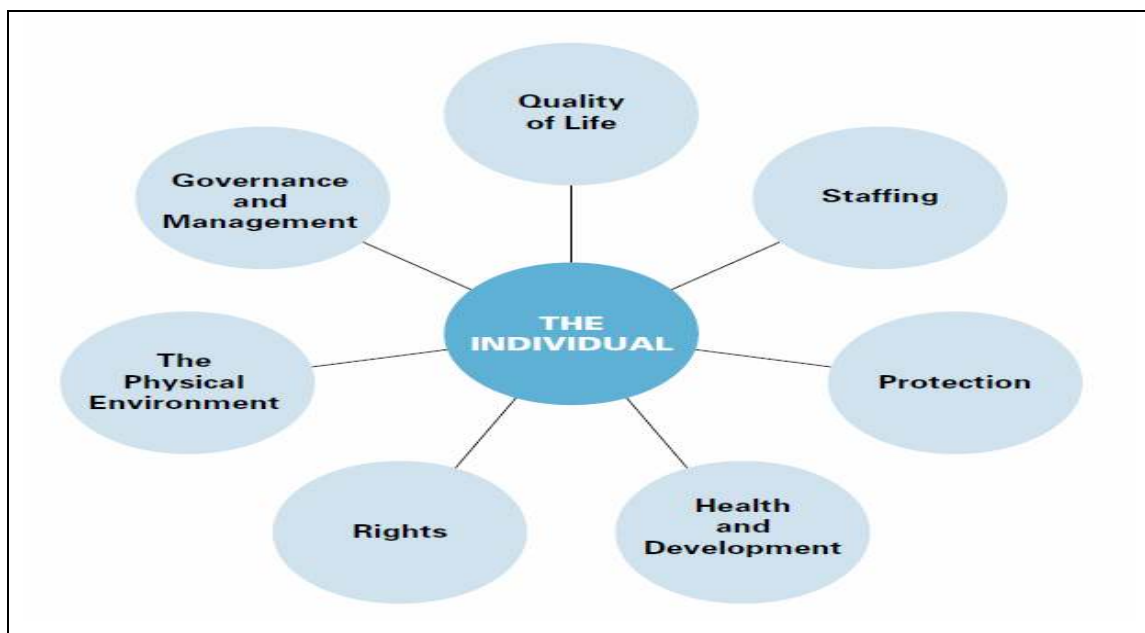


Figure 1.1 HIQA Seven Dimensions of Individual Quality Care (Source: HIQA Draft National Quality Standards: Residential Services for People with Disabilities, pg 7)

Clearly this is an example of a system breakdown. Following the airing of the programme, CQC undertook one hundred and forty five unannounced inspections, where its findings were that forty eight percent of locations did not meet the necessary welfare standards. A further finding established that privately run services were twice as prone to failure, as those operated by the National Health Service (NHS) (Child Protection Agency, 2012).

It is detrimental to an individual's well being if they are unable to act in service of their own objectives without the adequate support systems in place to facilitate their actions. Support workers need to carefully evaluate the needs (type, level, intensity and duration of support) of an individual while respecting their right to dignity, and respect and act in service of the individuals' goals. These support structures should ensure that the individuals needs and interests are met and result in substantive gains for the individual.

The value of decision making to an individual with an ID is enriching and conducive to socially positive behaviour (Reyer & Sturme, 2009). The individual's degree of ID should not be a measure for self determination; rather the state and community need to facilitate the additional steps, for example enhanced communication, which will allow the individual to function. To help an individual with ID make decisions the provision of accessible information is crucial. HIQA will monitor this and as part of their governance state that it is obligatory that service providers supply information in the appropriate accessible format. This places a huge focus on having accessible communication to ensure the service users understand the path that lies ahead. Advocacy groups are hot on their heels to ensure that ID service providers do just that.

In their World Report on Disability, (WHO, 2011) state that the lack of accessible information and the ability to advocate are two of the main barriers for a person with ID to live an ordinary life. ICT may facilitate the exchange and circulation of information, but it also acts as a means of augmenting human rights and advocating the move toward individual service. As the cost of ICT has reduced it has become more widely obtainable. Universal Design (UD) and web accessibility guidelines have promoted user-friendly designs, which in turn have encouraged individuals with ID to use the technology. Nevertheless, to partake in this digital revolution, individuals with ID need to learn how to complete basic ICT skills. The ability to use a mouse, keyboard or alternative Assistive Technology Devices (ATDs) as an input device is central. Once a connection to the Internet is established, aptitude in opening and searching an Internet browser is an important aspect of connecting to a whole new world. These skills can help an individual to become more socially and economically included.

Technology cannot claim to fully offset the problems that individuals with ID come upon. However ICT can hugely impact their lives. (Franklin, 1991) remarked that the upsurge in technology:

*“Has redefined their abilities to successfully learn, work, live, and play in their communities” .*

## ***1.2 Background***

Historically persons with ID have been denied the same rights as those of the non-disabled. They have been refused the entitlement to live within the community with the equivalent constitutional rights afforded to a non-disabled citizen (Stewart & Ward, 2007). With regards to those who have ID it has proven necessary for structures to be put in place, to a certain degree by agencies, to assist individuals with such issues as decision-making. Society is required to remember that those with ID are to be equated the same rights, and that structures be implemented to allow them have value and inclusion in our society. With policy development, the principle of “normalisation” for those with ID in today’s society must take the following into account; individual needs and supports, community inclusion, social value and greater satisfaction and fulfilment. Society is ethically obliged to ascertain the needs of the individual. A human rights focus is empowering for those with ID and their support network.

## ***1.3 Research problem***

Lack of accessible information and the ability to advocate have been listed as the top barriers to living an ordinary life for those with ID. Many studies been carried out that have indicated the benefits of ICT for people with an ID (Wehmeyer et al, 2006; Bunning, 2009). ID service providers themselves view ICT for their service users as not a priority. Equipment may not be available in the first place, and if available the individual may never get to use it due to lack of supports. (Li-Tsang et al, 2005) relate that traditionally, regular ICT training is not a common feature in ID service providers. Another consideration is that the types of files that individuals with ID tend to prefer are multimedia, which can be large in size and therefore have great impact on network activities.

With budgets consistently being cut in recent years, staff training itself is suffering. With the latest budget delivering a cut of five and a half percent services will be reduced as opposed to being added or extended. Juxtapose this with the requirement of The Disability Act of 2005 that necessitates all government agencies to produce content that is where possible compatible with ATDs prior to 2015.

With the onset of personalised budgets and HIQA requesting accessible communication in many of its policies, IT departments in these organisations need to consider its service delivery. For many, access to the Internet is an essential part of their daily existence. If an individual desires access to the Internet in their residential home, this should be facilitated, as this affects their quality of life. HIQA will advocate on the individuals behalf and bring this matter to the attention of the service provider. If the service provider responds that it is their policy not to give their service users access, HIQAs viewpoint is simple, the service provider needs to change their policy.

Irish ID service providers are required to submit a specific dataset about their service users to the National Intellectual Disability Database (NIDD). This dataset takes into account elements such as an individuals current and future day and residential service requirements, as well as list the clinical inputs a service user has had each year. At present it is deemed that an individual receives a clinical input if a clinician, such as a physiotherapist or social worker, has given four or more inputs within a year. Note that a phone call is perceived as an input as is a group talk. There are some changes required ahead as moving towards personalised budgets requires that every element of the service provided is recorded and costed. At present we operate with a blunt instrument as opposed to measuring the individuals needs. For instance respite is recorded in terms of half day blocks which often does not accurately depict the service level given.

Also on the NIDD there is no requirement to record the language or understanding level of the individual. Language in this instance refers to the verbal functioning of the individual. It could depict if the individual communicates using signs, short words or whether they are verbally adroit. Understanding in this context refers to the level of instruction an individual can follow. For instance, simple in context, simple instruction

or where details are no problem. The literacy level of the individual is also not captured; this should not only include reading, writing and maths but also digital literacy. The preferred modality for an individual to receive information is not retained anywhere. Furthermore, nor are any ICT skills or Assistive Technology (AT) requirements captured. If this data was required as part of the national dataset for the NIDD it would ensure that organisations focus a little more attention on carrying out this skill audit. Through capturing this dataset the style of information an individual likes to be communicated with can be identified. This information could then be disseminated at a national level to provide and promote communication strategies.

A lack of accessible communication and information is recorded in vital areas such as education, health care, local government and justice. Following on from that, (Who, 2011) reports that there is no accessible information provided for individuals with ID in the case of ante natal care or following their arrest after being involved in a crime.

A lot of research work has been carried out in the realm of ID, though the majority of it is clinical based. (Wehmeyer et al, 2008) states that the dearth of empirical studies with regard to technology in the realm of ID needs to be addressed.

#### ***1.4 Research objectives***

The research objectives outlined at the beginning of this research were:

- To apply for and achieve ethical approval from the ethics research committee of the chosen partner organisation.
- To gain a further understanding of what ID is.
- To investigate how individuals with ID use ICT and what they use it for.
- To investigate the change in service model provision and its impact if any on the necessity for accessible information.
- To review research in the areas of web accessibility, with particular focus on design impacts for cognitive impairments.
- To involve members of the target group, individuals with ID, in the design process.

- To design an interface that supports picture to picture navigation, with minimal text used throughout to support literacy difficulties.
- To provide information in an accessible format to help the participants understand what they have to do and aid decision making.
- To gain informed consent off the participants.
- To implement a prototype specifically designed for and with individuals with ID.
- To test the prototype and complete experiments facilitated by the advocacy lead.
- To collect, analyse and evaluate the results.
- To make recommendations for future research in the area.

These objectives have been achieved throughout the dissertation and contributed to the overall outcome. The aim of this research is to firstly determine if and secondly measure how web communication tools can improve the communication between clients with mild to moderate intellectual disability who reside in different locations.

### ***1.5 Research methodology***

The research methodologies used formed a mixture of quantitative and qualitative research methods. Semi structured and structured interviews were held with the advocacy lead, the SMH EVOLVE team, members of the IT department as well as most importantly the target group themselves. A research proposal was submitted to the SMH ethics research board, a copy of which is located in Appendix D. The advocacy lead and the participants in Study A were involved throughout the design, testing and evaluation stages of the project.

It is evident when reviewing the online literature that the majority of articles with reference to ID are from a clinical standpoint as opposed to a technical one. Online database searches were conducted once suitable criterion was established. A comprehensive review of the literature began with the term ID. A pertinent issue here is the many terms ID is known as, for instance mental retardation, cognitive disability, learning disability, developmental disability and mental handicap. These keywords were searched in combination with ICT, computer, technology and web accessibility to

try and capture the widest result set. To try and portray similar organisations the search was interchanged with organisation, institution, community, agency, voluntary and non-profit when searching via online journals and electronic databases.

With respect to the experiment the quantitative aspect will refer to the measurement of verbal and physical prompts required to access the various aspects of the technology. The qualitative component will involve open-ended questions to the group after they have used the technology. This will involve adopting a participatory approach to the research. The sampling method used will include participants who meet the following inclusion criteria – (1) an adult with mild or moderate ID (18 years of age or above) (2) verbal communication skills sufficient to provide information about their thoughts and experience of using the technology.

### ***1.6 Resources***

In order to carry out this research the author liaised with the chosen partner organisation, speech and language therapists, the advocacy lead, the IT department, the experiment participants and their key workers. Specialist websites who use new forms of media to alter the lives of individuals with ID, as well as recommended IT solutions in the area, were consulted. Online journals and databases were accessed right the way through. Technical resources such as training laptops, dongles and webcams were utilised for the experiment part of this study. The assigned supervisor had an input to the project throughout.

### ***1.7 Scope and limitations***

The scope of the experiment evaluation is limited to adults with mild or moderate levels of ID. Initially the system will be internal and therefore participants will only be able to interact with participants they know or with participants that are known of. One drawback is this could be considered non inclusive. A major limitation is that there is no record of the participants ICT skills, their computer usage or whether they require assistive technology to use ICT. A further constraint was the recommendation that a time limit of a maximum of forty five minutes to an hour, be used at any one sitting when evaluating with the experiment participants. Although the correct process, it does

not equate to a lot of time when gaining informed consent also has to be taken into consideration in the same sitting.

### ***1.8 Organisation of the dissertation***

This dissertation falls mainly into three sections. Firstly it has a beginning and an end. The second section that follows covers the literature review aspect, with the remaining section detailing the experiment. So to begin, the opening chapter introduces the key areas of discussion for this dissertation, and expresses the objectives and methodology used. It also highlights the problems existing in the area.

The second chapter commences the literature review section. It provides a review of the existing literature on the characteristics of ID as related to computer usage. ID, its definition and prevalence will be discussed. The constraints, ranging from ICT skill levels, access controls and AT are further developed. The progression from an institutional set up, to community setting to individualised service via personalised budgets will be outlined in the third chapter. HIQA and its stance on accessible information will be further analysed. The fourth chapter outlines the guidelines and elements that need to be taken into account when designing for the cognitively impaired. The factors that need to be considered when deploying accessible information via the web to an individual with ID will be depicted.

The next section, which comprises of three chapters, sets out the design, implementation and evaluation of the experiment. The fifth chapter describes the design of the prototype, outlining the iterations and the considerations employed. It discusses the reasoning for tool selection and the development of accessible documentation. The following chapter, discusses the implementation of the experiment, the environment and the procedures that were involved. Chapter seven starts with a description of group demographics, ethical considerations and the assessment protocol. It follows on with the data analysis and collection methods before producing the results recorded during the experiment.

The dissertation concludes with a summation of views following research and experiment analysis and offers thoughts on future development.



## 2 INTELLECTUAL DISABILITY IN AN ICT WORLD

### *2.1 Introduction*

This chapter describes what ID is, the terminology used to describe it and its prevalence. The literacy levels, literacy strategies and learning characteristics of individuals with ID are depicted. How an individual uses ICT and what they use it for is outlined. The perceived benefits and constraints for people with ID using ICT are discussed.

### *2.2 Understanding Intellectual Disability*

#### 2.2.1 What is Intellectual Disability?

(Felce, 2006) reports that although the conditions that give rise to ID are common, how ID is modelled, evaluated, classified and responded to, varies greatly between nations, cultures and economies. Almost eighty percent of the ID population have mild impairments in intellectual functioning, with an IQ falling within the range of fifty five to seventy (Mengue-Topio, 2011). (WHO, 2001) describes ID as being:

*“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”.*

It is important to note that as well as being intellectually disabled these individuals may also have physical difficulties or have sensory deficits which may further prohibit traditional methods of accessing information.

#### 2.2.2 Prevalence Levels

In their World Report on Disability, (WHO, 2011) approximate on a global scale that six hundred and fifty million people have some form of disability. The report states that nigh on eighteen percent of the America population have disabilities, roughly speaking in the region of fifty one million people. Within the European Union (EU)

and European Economic Area (EEA) it is estimated that in excess of eighty four million have some form of disability, including sensory, physical , mental or conditional disability. Figure 2.1 below provides an indication of the distribution of subcategories of disabilities within the EU.

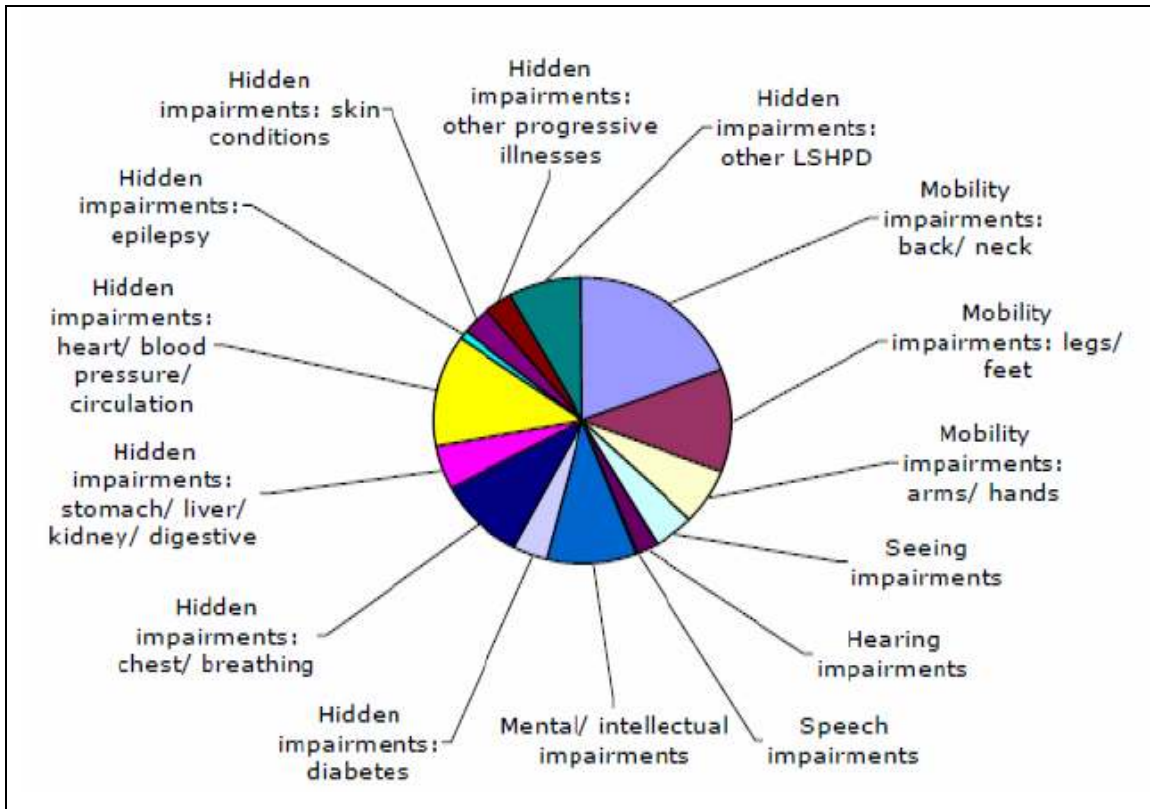


Figure 2.1: Distribution of subcategories of disabilities in EU (Source: Ojasalo, 2010)

Studies suggest that occurrence rates of ID demonstrate sizeable variation (WHO, 2007; Fujiura, 2003). (Gillberg & Soderstrom, 2003) report that ID affects between one to two and a half percent of the general populace of the Western World.

As of December two thousand and ten, in the Republic of Ireland , twenty six thousand, four hundred and eighty four people, (56.9% male and 43.1% female) were recorded on the NIDD. The NIDD is used to plan future services for those with ID. The NIDD outline six levels of ID which comprise of: (1) Normal, (2) Borderline, (3) Mild, (4) Moderate, (5) Profound and (6) Severe. However it is generally only individuals that range from mild to severe ID that attend a service. The prevalence recorded during this period is noted as being 2.09 per thousand of population. It is felt that this number should actually be higher as individuals with mild ID are under

reported (Kelly et al, 2010). Table 2.1 below depicts the level of ID and number of people registered as having ID on the NIDD as of two thousand and ten.

	<b>People with ID</b>	<b>%</b>
Mild	8,841	33.4
Moderate	10,564	40.0
Severe	4,065	15.3
Profound	998	3.7
Not verified	2016	7.6
<b>All levels</b>	<b>26,484</b>	<b>100.0</b>

Table 2.1. Degree of ID. (Kelly et al, 2010)

### 2.2.3 Terminology

A pertinent issue here is the many terms ID is known as, for instance mental retardation, cognitive disability, learning disability and developmental disability. The label mental retardation, which is used widely in the United States, conjures up a negative stereotype that can both offend and constrain individuals. The favoured term in the United Kingdom and Australia is Learning Disability, while Japan and Ireland prefer the term Intellectual Disability.

In 2001 the American Association on Mental Retardation (AAMR) decided to remove the words 'mental retardation' from their name. However, there was much debate as to what to change it to as an assortment of labels were being used around the world. They finally changed their name in 2007 to American Association on Intellectual and Developmental Disabilities (Stewart & Ward, 2007). To further highlight the international sway toward the terminology of ID (Panek, 2005), President Barack Obama in October 2010 signed into law, Rosa's Law. This necessitates that the terms 'mental retardation' and 'mentally retarded' are to be removed from federal policy. They are to be exchanged with 'ID' and 'individual with an ID' (Community Counselling Services).

WHO launched its first ever World Report on Disability in 2011 and in a slight variance, within that report they use the term intellectual impairment throughout. What

is an interesting aspect here, is that in a table referencing the terminology used to describe ID that was created by WHO in two thousand and seven, there is no reference to intellectual impairment on the list. Further analysis of this terminology can be viewed in Figure 2.2 below.

	World		Africa	Americas	South-East Asia	Europe	Eastern Mediterranean	Western Pacific	N
	Proportion of countries	Number of countries							
Developmental disabilities	22.6%	33	14.7%	16.0%	20.0%	29.8%	23.1%	27.3%	146
Intellectual disabilities	56.8%	83	47.1%	60.0%	80.0%	59.6%	46.2%	63.6%	146
Learning disabilities	32.2%	47	35.3%	32.0%	60.0%	27.7%	23.1%	36.4%	146
Mental deficiency	17.2%	25	26.5%	12.5%	60.0%	19.1%	0%	4.5%	145
Mental disability	39.0%	57	55.9%	44.0%	0%	34.0%	46.2%	22.7%	146
Mental handicap	39.7%	58	61.8%	16.0%	80.0%	34.0%	46.2%	31.8%	146
Mental retardation	76.0%	111	82.4%	80.0%	80.0%	70.2%	92.3%	63.6%	146
Mental subnormality	11.6%	17	11.8%	12.0%	60.0%	6.4%	23.1%	4.5%	146

Figure 2.2 Terminology used to refer to intellectual disabilities (percentages of countries by WHO regions) (WHO, 2007)

(Yuker, 1988) explored levels of acceptance by ranking twenty four types of disability and asking people to rate which disability they found most acceptable. The research was framed within the context of who would the person like as a neighbour, and asked the person to rate their preference. Mental retardation (an American study hence the term) placed twenty second on the disability hierarchy. That reflects that for the people surveyed, for them their third least favourite potential neighbour would be someone with ID. What is important to note here, is that merely changing the term to learning disability or ID or intellectual impairment, will not tackle the negative mind-set focused on individuals with ID (Wolfensberger, 2002).

#### 2.2.4 Employment

The support needs of individuals with ID who are seeking or who wish to maintain existing employment are highly individualised. This factor is reflected in the high rates

of unemployment experienced by this group, which is a concern for themselves and their families. Traditional forms of employment for this group vary from supported employment programs, sheltered workshops to regular employment with non disabled peers. (Donnelly, 2010) suggests that for people with ID an optimum approach may be to facilitate direct experience in various jobs in order for the person to self determine a preference. Employment can offer many benefits. It can not only provide an income, but it can also enhance a persons welfare, heighten a persons sense of identity, raise esteem and offer a social outlet .

### ***2.3 Literacy levels of people with an ID***

#### **2.3.1 Reading**

Many individuals with ID experience difficulty reading. The reckoning why, is not as simple as saying the individuals do not possess the cognitive capability to learn to read. Often the case is that people have not had the educational supports that they would have needed in the past. They may have had poor and negative educational experiences. For individuals with ID who are now in the forty to sixty age bracket, traditionally when they left school at eighteen they would enter employment in a workshop setting in a service. Therefore any reading skills that they may have developed would not have been further cultivated.

The size of the font and perception impacts on reading ability. In that the individual may be able to read but the font is too small, placed too closely together, or the information is too compacted on the page. Some individuals who are unable to read have developed good social sight-reading. This is the ability to identify signs that are familiar in social settings, for instance toilet and exit signs. However, if the images or even style of writing was to change, this causes confusion. The images need to be consistent.

(Oldreive, 2011) reports that in a two thousand and one study of one hundred and thirty two students with mild to moderate ID, twenty two percent were able to distinguish words and understand a passage of text.

### 2.3.2 Writing

There is limited research available regarding teaching individuals with ID basic written expression skills. Teaching individuals with ID written communication faces many challenges. Firstly they generally take longer to attain proficiency in any skill set, than the average populace. Common strategies such as conceptualising, rehearsing and planning are often found to be difficult to use. Nevertheless some studies have shown that individuals with ID can learn to communicate through different forms of writing and benefit from doing so. Strategy instruction such as the Self-Regulated Strategy Development (SRSD) model was found to yield the best writing outcomes for people with ID (Joseph & Konrad, 2009). What is missing to date though is a report amalgamating effective forms of writing instruction for individuals with ID.

### 2.3.3 Digital Literacy

Communication platforms have changed. Sending an email, a text or instant messaging has in many cases replaced the traditional phone call. However these new forms of communication require written expression. Accordingly the ability to produce written expression makes it possible for a person to be included in the social mainstream (Joseph & Konrad, 2009). For any user who does not possess technical know-how, the use of computers can prove stressful. The level of computer literacy within the ID community is in the main low. However, technology such as multimedia can make it more viable for an individual with ID to be able to express themselves in writing (Strum, 2000). In previous research (Abbott, 1991) reports that individuals with mild levels of ID felt more assured of their abilities through the use of word processing software, spell checkers and on screen word lists.

### 2.3.4 Literacy Strategies

There exists a wide spectrum of literacy abilities within the ID community. Some individuals may have functional literacy skills. A lack of incentive and misunderstanding may restrict access to written information. Group instruction is not just more efficient, it can be just as successful as one to one instruction for the general populace. However this would need to be observed within an ID context to determine how effectively individuals learn in small and large groups as opposed to one on one.

A key aspect is the detection of what instructional elements work best for individuals with ID when learning to read and write. Elements such as reinforcement and corrective feedback need to be considered. If the instruction is clear and logical it will help individuals with ID learn, and thus expand their means of communication. This new skill of written communication can be exploited in this digital age. It can open up opportunities with regards to seeking employment and expand social circles that perhaps previously went unnoticed.

Strategies such as story maps and interactive writing that have been found to be effective for people with learning difficulties should be evaluated with individuals with ID. Similarly strategies that are known to have been successful for other individuals may likewise become so for individuals with ID if the suitable accommodations are put in place. This might be through the use of ATDs or increasing an individual's opportunity to write.

A crucial element in a child's pedagogic development in such areas as mathematics and reading is Working Memory (WM). WM is the capacity to maintain and process information while concurrently conducting a cognitive task and is a necessary component to flexible intellect and decision-making ability. Teenagers with a mild to borderline ID, with an IQ score ranging from 55-85 are found to have a significant number of working memory problems and by and large do not perform well in the academic arena. As a result these teenagers will need additional learning supports than their fellow counterparts.

A study by (Van der Molen, et al, 2010) was conducted on the effects of memory training programmes in individuals with ID. It focused specifically on verbal short-term memory exercises. In general the memory training programmes were effective and demonstrated an increased ability in the subjects to repeat items accurately. This study demonstrates that WM is a key mental process and with correct application, adolescents with mild to borderline intellectual disabilities can be trained to enhance their short-term memory function

## ***2.4 Learning characteristics of people with ID***

(Mengue-Topio, 2011) reports that for the most part individuals with mild to moderate levels of ID can acquire rudimentary academic skills. (Li Tsang, 2004) states that previous studies demonstrate that people with ID can obtain different skill sets by following step-by-step training. However, the individuals display patterns of weak retention over skills that they have learnt. Due to this, it is proposed that to augment learning follow up training should be provided (Li Tsang 2004). (Brandao, 2010) describes how individuals with Down Syndrome (which falls under the ID umbrella), learn best when activities are both repetitive and engaging and suggests using music as a form of intervention. As music is rhythmic and repetitive it can focus an individuals attention. It can also act as a reminder mechanism as the words and gestures can be slotted around the music in a more fun way to learn.

Children with ID often find it more challenging to sustain their attention over extensive intervals of time than their peers without ID. (Bray et al, 1997), contend that the education of individuals with ID should make the most of their cognitive capabilities as opposed to concentrating on their level of impairment. (Hayes & Conway, 2000) suggest that the focus should be on providing strategies that promote the learning of typical, habitually occurring information.

(Hayes & Conway, 2000) relate that the learning ability of an individual with ID may depend to some extent on their level of functioning when carrying out rudimentary cognitive tasks. (Doyle & Arnedillo -Sanchez, 2011) suggest stepping away from just verbal reasoning and using learning strategies that employ pictures, physical prompts and exact representations. (Chang, 2009) reports that photos rather than text or speech are the preferred modality for individuals with ID when receiving directions via a user interface. This is important with respect to task prompting systems and wayfaring solutions.

Technology can broaden horizons and lead to creative and engaging methods of learning. Multimedia can be developed to suit the needs and preferences of an individual with ID. Developmental age, modality preferences, language ability as well as favoured learning style can all be designed for. Social stories have been developed



using multimedia tools, photos and music to assist individuals comprehend text (Doyle & Arnedillo -Sanchez, 2011).

(Golledge et al, 1983) investigated the spatial knowledge of individuals with mild and moderate ID in their own environment. Individuals were invited to identify the areas known to them in their locality. They were then asked to assign pictures in sequential order to a habitual route. Lastly, it was requested that they place key landmarks on a neighbourhood map. The results suggest that individuals with ID had acquired one dimensional knowledge of areas in their locality, that is, they could recognise landmarks in their own locality. On the other hand haphazard representations were produced when trying to assimilate the diverse routes onto a coordinated map which would signify difficulties in two dimensional constructions.

In a further study investigating route planning, undertaken with individuals of moderate ID, the individuals were guided along an unfamiliar route and afterwards they were asked to retrace their route. “Route knowledge” was measured by the number of correct turns and “Relational knowledge” was assessed by accuracy in a pointing task (pointing to non-visible landmarks located along the route). Results showed that individuals with moderate ID could learn a route, but performed poorly at the relational knowledge task. The two experiments described above led to similar conclusions: individuals with ID can learn route knowledge, but they have difficulties in developing survey knowledge of their environment (Mengue-Topio 2011).

### ***2.5 What do people with ID use ICT for?***

In a study by (Wehmeyer, 1998), the findings reported that individuals with ID use ICT for communication, educational activities, household finances or budgeting, leisure activities and for work-related activities. This has been broken down here to daily tasks, social inclusion, gathering information, to learn and for leisure activities.

#### **2.5.1 Daily Tasks**

The quality of life for individuals with ID can be greatly hindered due to struggles in completing daily living tasks. The method of successful task engagement is believed to benefit persons with ID in the following areas; reduced deviant behaviour, reduced

boredom, increased physical activity and increased domestic and community based employment. Acquiring this level of task engagement with minimal support supervision is most desirable.

Prompting aids have long been employed to assist individuals with ID in carrying out their daily living tasks. Task engagement can be devised using the following methods; self – instruction, pictographic cards and computer aided system. The use of self-instruction is not ideal as it requires the individual to memorise a sequence of words, whilst pictographic cards need to be used in a specific order. The computer aided system allows the task to be relayed to the individual with ID with efficiency and can be developed to include prompts to pre-empt distractions on the part of the individual.

According to (Lancioni et al, 1999) the key factors for the successful implementation and efficacy of task management on a computer aided system are:

- the expansive nature of the computer system
- the frequent system prompts
- the simplicity of a one stroke response (i.e. a key press)
- the accurate system coding to compensate for compulsive key pressing
- the limited human interaction which could have mishandled the instructions

What is clear is that this method can bring enrichment to activity centres, work shelters and assisted living environments.

For many individuals with ID, issues re wayfaring have a negative effect on their quality of life as it radically reduces their independence. The individual may encounter difficulties remaining oriented in their home, at their place of work or at their leisure, for example whilst out shopping. The individual may struggle taking public transportation. (Chang, 2009) discusses the Clever Project which uses on board Global Positioning System (GPS) devices to transmit prompts via a Personal Digital Assistant (PDA) which remind the individual with ID when to get off the bus.

### 2.5.2 Social Inclusion

Computer-mediated support environments are conducive to social inclusion for those who suffer with ID as the issue of physical environment and time requirements are eliminated. The success of social networking and shared virtual worlds on the Internet has merited research into the value of computer-mediated support interventions. However, (Forman et al, 2011) reports that the research surrounding the use of social media by people with disabilities, is rather meagre. The majority of studies to date into computer-mediated support interventions have been text based investigations, due to the level of forthright and intimate data that can be obtained due to the anonymous method of communication (Shpigelman et al, 2009).

The non-intimate nature of e-relationships can be helpful and can ultimately be as supportive to an individual if real world relationships are inaccessible or unavailable. Emotional development and empowerment can be enhanced via the Internet due to the anonymity which allows for individuals to be seen as people without disabilities should they so wish. In tandem, the level of intimate detail exchanged between users can provide a method of coping with disabilities or issues. The user and their criteria for using the Internet solely drive the level of information.

Two models that inform social participation are the International Classification of Functioning, Disability and Health (ICF) Model and the Disability Creation Process (DCP) Model. Although autonomous, they are complimentary in many aspects. The ICF analyses participation by identifying a persons involvement in life situations. This is viewed through their usual performance environment and in a generic place as opposed to in a local context. The ICF also appraises a persons competence to participate. The DCP adds the context of 'life habits', which consist of valued daily activities and social roles. (Baker et al, 2012) point out that while an individuals physical and mental capabilities have a part to play in the level of social participation, they suggest that functional capacity is not the entire picture.

### 2.5.3 Gather Information

Certainly, individuals with ID through using ICT, can gain access to a wealth of resources. Many exist in an acceptable format and can provide information regarding

health and accessible services. ICT advancements during the late twentieth and early twenty first century have enabled daily tasks such as shopping, banking, and personal communications to now occur online, often within virtual environments. Online communities of practice can provide a supportive environment for learning and developmental activities (Baker et al, 2012).

(Li-Tsang et al, 2004) found that effective access to the Internet was beneficial to individuals with ID in terms of information access, and consequently empowered them to become better-informed consumers. The study found that in fact the use of computer technology had the effect of minimizing the effect of the disability, leading to an improved quality of life, which in turn enhanced social inclusion. Furthermore, (Davies et al, 2004) stated that the benefits of computer use mirrors that of the general populace especially with the benefits in areas of self esteem, productivity and efficiency.

#### 2.5.4 To Learn

(Li-Tsang, 2004) remarks that ICT can transform the way an individual with ID learns. It is recognised that ICT can greatly improve the quality of life as well as employment options for individuals with ID. The digital divide is a term often bandied about. This refers to the disparity between those that have access to and training of ICT and those that do not. Individuals with ID fall into the latter group. This can hinder their integration into society as having access to ICT and the necessary ICT skills are a central part of life in today's world. Conversely it is felt that this disparity can be diminished if adequate training opportunities are provided. Studies have shown that with sufficient support individuals with ID have the ability to learn ICT skills (Li-Tsang, 2004).

#### 2.5.5 Leisure Activities

For various reasons, many individuals with ID are not involved in sufficient physical activity necessary to maintain a healthy lifestyle. Active participation in physical activities has benefits in terms of physical fitness, coping mechanisms and stress reduction in particular. The lack of participation puts individuals with ID in the risk bracket for health issues generally. Unfortunately, the majority of leisure activities

available to individuals with ID are quite limited, with a focus on more sedentary activities. As a second consequence of the gap in availability of required leisure pursuits, this may also lead to other behavioural dependencies and depression. Listed below are common barriers to partaking in physical activity prevalent among people with ID:

- Environmental. Adults living in a nursing home for example are less likely to participate in physical activities, as it is not set up to provide these services.
- Motivational. As a result of current poor health, it has a knock on effect to not seeing the benefits of exercise. Therefore, set programs should be set to appeal to the target audience. Poor health status is seen by sixty percent of women and thirty eight percent of men as the main reason for not participating in the exercise (Lotan et al, 2011).
- Limitations regarding Support Personnel – Several studies have demonstrated that carer and family involvement has a major influence on the ID participant. Participation would likely be increased with the active involvement and support of these personnel.

Virtual Reality (VR) based invention addresses the barrier stated above. To summarise, VR typically refers to the interaction of an individual, or individuals to a technology based program in which there is a simulated effect of a real life scenario. For example, in the case of video capture, the user stands or sits in a marked area in front of a large video screen. Users can see themselves on the screen, and their movements in reality direct the virtual task displayed in front of them. This enables viewing of functional tasks such as catching a ball.

VR addresses the barriers that a physical environment can impose, as the virtual environment can replace the physical one very easily. It can be customized according to a users needs. For example, take the case of an individual with ID who shares the same environment with an individual who has an entirely different set of support requirements. In this instance, a customised VR environment can be created for both with relative ease. Studies have shown that users have found this to be an enjoyable experience and this adds to the motivational requirement needed to progress. Support

personnel benefit from this as the requirement for resources is reduced, and hence they have more of a reason to promote this method.

## ***2.6 How do people with ID use ICT?***

### 2.6.1 Assistive Technologies

Assistive Technology (AT) is any item that can maintain or improve a person's lifestyle. It can also be referred to as enabling technology, access technology and adaptive technology. It enables and promotes independence, in some cases permitting an individual to manage completely independently. AT can range from low-tech devices, such as a walking stick to high-tech such as environmental control devices. AT is often associated as something people with disabilities use. However, many everyday items, such as a pair of glasses, offer the same functionality, but do not have the same associations. Consider this point made by (Wanderman, 2003):

*“If you are dyslexic and you use a computer to write it is assistive technology, but if you are not dyslexic and you use a computer to write with, it is not?”*

For some users there is a large stigma attached to using AT and thus the match between the user and the AT item is pertinent to successful adoption. In many cases the AT is not the answer to everything and is instead just a tool that empowers people.

As well as possessing a level of ID, in numerous cases the individuals may also have a sensory or physical disability. These facets support an individual centred deployment (Mirza & Hammel, 2009). Therefore they may need access points other than the traditional mouse such as trackballs and switches. Figure 2.3 depicts a proposed ATD Selection Framework (Scherer et al, 2007).

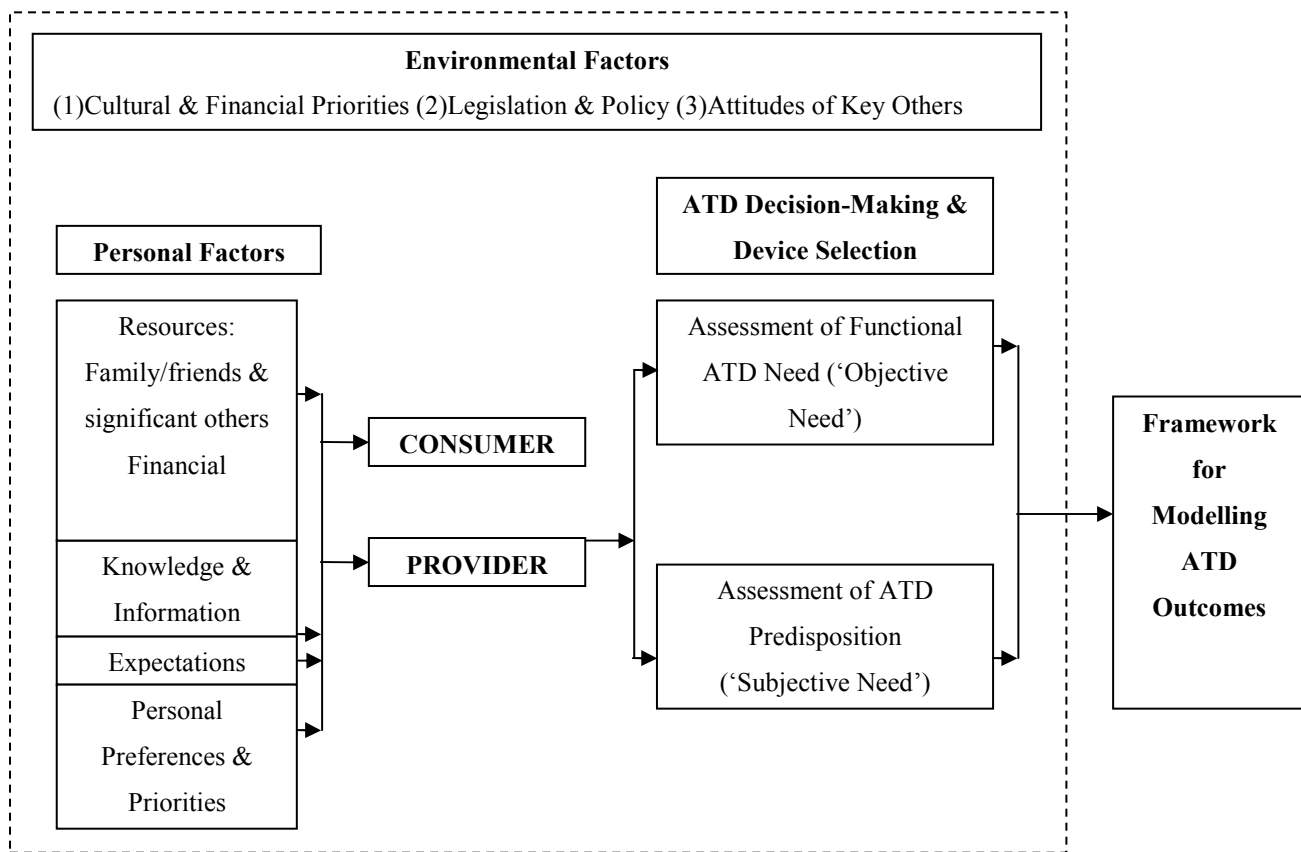


Figure 2.3: A Typical Assistive Technology Device (ATD) Selection Framework. (Scherer et al, 2007)

Jaeger (2006) reports that many ATDs remain incompatible with ICTs thus rendering the ICT inaccessible or at best difficult to use, and suggests that accessibility not just usability should be considered in the design process of ICT. It is important to note that a persons mood can negatively impact the employment of ATDs as they may serve as a constant reminder of the individuals disability.

The function of Cognitive Assistive Devices (CAD) is to enhance mental process and enable the individual a greater degree of independence in daily activities and self determination. While adults with ID may be able to read and write, they may experience difficulty in dealing with complex problems, finding solutions, comprehending certain situations or managing their finances. The selection of a cognitive assistive device for those with an ID has been in practice in Sweden since the 1990's where CAD (predominantly used as a time aid) has been employed as an assistive tool in day to day living. In order for the device to be beneficial to the individual, the evaluation(s) undertaken by the occupational therapist(s) must take into

consideration the supports already in place for the individual and select the most appropriate device to compliment their supports and enable their goal of self determination (Wennberg & Kjellberg, 2010).

(Standen et al, 2011) explored the possibility of using the Wii Nunchuk as an alternative ATD for people with ID, highlighting the potential cost savings. A number of ATDs are being explored to aid with cognitive tasks (LoPresti et al, 2008).

### 2.6.2 Mobile Computing

Many daily tasks involve frequent movement and the introduction of a context aware prompting system would serve to reduce cognitive load on the user. For instance, with individuals who operate at a high functioning level, they could then be prompted for tasks that they missed or failed to complete, in comparison to a prompt for all tasks. (Chang, 2009) discusses a study of this which employed Radio-Frequency Identification (RFID) tags that were attached to elements of the designated tasks. The individuals with ID wore wrist scanners which linked to the RFID tags and the results were fed back via PDA prompts.

Mobile phone usage is ubiquitous in today's society. The European broadband and telecommunications company, Telefonica, claim that nearly seventy four percent of individuals with ID, who are aged between fifteen and sixty four, own or use a mobile phone (Urturi Breton et al, 2012). Furthermore there has been considerable growth in both the number of touch enabled smartphones and the applications available for them. For individuals with an intellectual disability the growing range of features and options available can at times make the phone itself less accessible (Jaeger, 2006). In a small study (Urturi Breton et al, 2012) evaluated the issues individuals with ID experienced when using a touch screen mobile phone. These findings are indicated in Figure 2.4.



Item	Problem
Buttons	Some are too small, do not click when pressed and therefore provide no feedback to whether or not the associated number had been dialled or pressed.
Menus	Too many, most of them unnecessary, difficult to understand and recall.
Text size	Too small to read (even with corrective lenses).
Touch screens	When interacting with a tactile component, the user presses on the component and waits until some feedback is received, instructing them how to proceed or to remove their finger from the screen. In other cases, if two components need to be pressed, one after other, (for instance when introducing text) the finger is not retracted to interact with both, but is dragged across the screen until the second component is reached. Multi-Touch events: Users are unable to instinctively use the gestures required to zoom, however given sufficient assistance they can learn to generate the required finger movements.

Figure 2.4 Problems experienced by individuals with ID when using a touch screen mobile phone (Source: Urturi Breton et al, 2012)

The usage of Apps is ubiquitous in today's world. There are not many apps specifically developed for the ID population, as each users cognitive, physical and sensory impairments are unique. Even so those with ID have been mostly underserved by this market. More so when you consider the high percent of mobile phone ownership for this group. Nonetheless, two examples of such apps are MARTi and EZ Tune. MARTi is the result of a collaboration between a research team (researchers in ID and pervasive developmental disorders) and an ICT partner. It was developed with individuals with ID and provides visual and audio clues to assist an individual in completing the steps in a task. A free version is available that permits the individual to trial two tasks while the full version is obtainable for a cost of €31.99 . A sample of the MARTi interface can be viewed in Figure 2.5.



Figure 2.5 Marti App Interface (Source: <http://itunes.apple.com/us/app/marti/id489615229?mt=8>)

The second app, EZ Tunes, is essentially a simplistic music player and assists people who find it difficult to play music on their mobile device. The interface consists of three buttons through which the user can access their music as well as view a picture of the album art. The two interface screens viewable in Figure 2.6 present the user with the option of pressing a green or red button to play or stop a song. To choose another song the users selects the yellow button. Finally to move to another album the user chooses the blue button.



Figure 2.6 EZ Tune Interface (Source: <http://itunes.apple.com/us/app/ez-tunes/id401572732?mt=8>)

iPads with their graphical prowess, intuitive operational style and countless accessibility features, are being gradually introduced into the ID population. Nevertheless, the cost of the technology as well as not being able to attach ATDs rule it out as an option for many. There is also the fear of them being dropped and breaking. There are cases available that prevent iPads from breaking when dropped or from excessive drool.

(Ford, 2011) describes the process of identifying a technology solution to suit an individual with ID and their unique needs. After deciding on an iPod Touch (in essence an iPhone without the mobile phone capability), the search began for appropriate apps. Anything promising was downloaded for free trial or if the app was inexpensive it was purchased for evaluation. The short list was then reviewed with the individual and their natural supports. Their solution comprised of:

- Proloquo2Go (icon based text to speech communication for individuals with difficulty speaking)
- Pocket Informant (easy to use calendar)
- Emoji Emoticons (keyboard character set comprised of small icon pictures as an alternative to letters)
- Google gMail calendar to synchronise to iPod Touch (allowed natural supports such as family to edit calendar even if iPod Touch not around)

(Ford, 2011) found that the individuals sense of time improved as alarms for upcoming events acted as alerts. The technology itself was discrete, age appropriate, portable, perceived as cool and most importantly could be used with minimal support. One unanticipated gain from the study was the individual felt more attached to family and friends. An example of such was the individuals access to Facebook where they could quickly get a sense of what their friends and family were up to through the pictures. Other visual sites also ensured the individual with ID could access information independently. Overall it was an empowering solution that fostered independence. A snapshot of the tools used for this solution can be viewed in Figure 2.7.

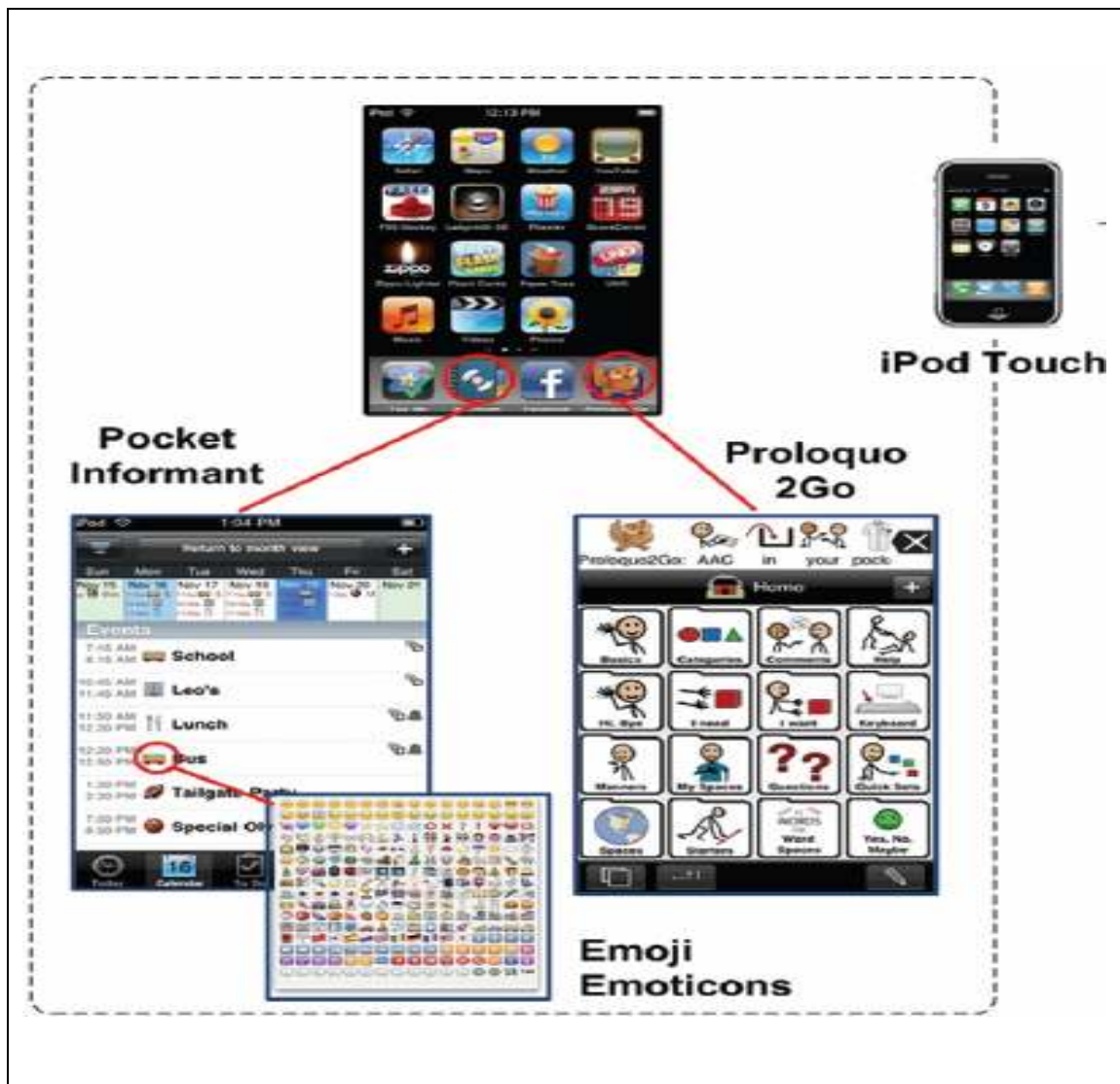


Figure 2.7 iPod Touch Solution for person with ID ( Source Ford, 2011)

### 2.6.3 Virtual Environments

Virtual Environments (VE) provide users with repeated and active exploration. They stimulate the same cognitive mechanisms in individuals that would be used in a real-world scenario, but the time constraints are greatly reduced. Experimental evidence has revealed that the spatial knowledge acquired in a VE, transfers successfully to the equivalent real-world space. Virtual technology has been employed by numerous researchers for development and training skills and they have found that the learnt skills did transfer to a real-world environment. (Mengue-Topio, 2011) proposes that a VE offers a safe and interesting method for appraisal of the navigational aptitudes of individuals with ID and suggest it as a technique to coach wayfaring strategies.

The purpose of a study by (Lotan et al, 2011) was to assess suitability of a VR exercise for adults with severe ID. According to reports by caregivers, most but not all participants found the exercise beneficial and hence motivational. Participation in leisure activities for this category of participant is at the extreme end of remaining unsupported. The general leisure characteristics tend to be watching television or arts and crafts type work.

The technology availed of was a GestureTek IREX video capture VR system. The participants sat in a marked area, which captured and projected their images onto a large video screen in front of them. The screen also displayed an option to choose from seven simulated games. They were entitled; “Birds and Balls”, “Soccer”, “Drums”, “Car Racing”, “Juggler”, “Ocean” and “Parachute”. These specific games were chosen in advance by the caregivers to suit individuals who had high levels of cognitive and motor skill limitations. The participant chooses the game they wish to play, and the caregivers operate the program as directed by the participant, usually by means of facial expressions or gestures. In terms of playing the game, the participants moved their hand and upper body to control the interaction with virtual objects within the virtual environment.

The caregivers were selected from a particular residential home and were chosen to participate in the above program based on various characteristics. For example, their role at the facility and their IT literacy level had an influence on their suitability for selection. The caregivers themselves recommended the most significant features to successfully participate in the study were as determined below:

- Motivation to participate
- Personal ability and positive outlook towards VR technology
- Ability to work with a broad range of residents
- Interest in technology and ability to operate computer based systems.

The conclusion arrived at was that when an individual with limited opportunity for leisure activity is provided with a customised accessible opportunity, then it enables them to become more physically active. The VR game environment is one such

example of an accessible and appropriate leisure opportunity. The findings also support a theory that involving individuals with ID in exercise programs and activities that attract them acts as a re-enforcement of the benefits that participating in such a program can bring. Despite certain technical problems, the care giving staff were able to help the residents with ID participate and enjoy physically challenging activities. Therefore, this technology widens the choice of available activities for individuals with a severe level of ID. Furthermore, implementing VR technology at a local level such as residential units was found to be feasible and beneficial to caregivers and participants.

#### 2.6.4 Game Development

For many children, the first time they use ICT is generally for the purpose of playing a game, usually with an educational element. Digital games are envisaged as a fun thing to do, either on your own or with other players. (Brandao, 2010), suggests that through play, children can learn and expand their social skills. In spite of this, adapted play opportunities are sparse for children with ID. This is especially interesting, given one aspect of digital “life” where more than twenty percent of gamers are believed to have some degree of functional limitation (Ingham, 2008).

### ***2.7 Benefits for people with ID using ICT***

Use of ICT by individuals with ID can be a powerful way to augment their self determination, their self direction, their autonomy and their productivity (Davies, Stock and Wehymeher 2004). Computer use can build esteem. ICT can also promote fun, and enhance a persons leisure time through the use of music, video games and video capture. With this the person can be at the centre of things and chose the music they want to listen to, the game they wish to play or the environment setting they desire within video capture.

So, while use of computers to enhance autonomy (software to assist money management, apps to break down the steps of a task), increase productivity (word processors, CAD prompting systems, graphics software), or for recreational or leisure activities (video games, genealogy software) has been increasing for the general

public, there is only limited evidence that similar gains have been made for people with ID.

Another example of the benefits of ICT is the micro technology element. For example, sensors and activators have tangible benefits to the user, which have been gradually introduced to organisations such as day care centres, social service departments, and many care organisations. However, there has been little research into the area of accessibility and the study of the drivers and process behind facilitating this technology provision to end-users.

In his research (Arnott, 1999) highlighted the importance of the 'Locus of Control'. This essentially refers to how much control a cognitive aid has over an individual should the individual necessitate a great deal of counsel and support. The discussion rests on the fact an individual may be willing to yield a lot of control to a device for large time frames if it means they do not relinquish that power to another human and thus remain independent from human care givers. This can augment an individuals self worth and quality of life. Albeit, it does raise the question of who is the master and who is the slave.

## ***2.8 Constraints for people with ID using ICT***

### **2.8.1 Access to ICT, Awareness and Basic Interest**

Access to ICT can be hampered by a general lack of awareness regarding what technologies exist and the access options that are available. Needless to say for an individual with ID to accrue benefits from using ICT they need access to ICT in the first place. (Wehmeyer, 1998) conducted a survey (N = 1218) of ICT access by individuals with ID. At that stage thirty three percent stated that the individual with ID had access to a home computer, a figure that has surely steadily increased with the decreased costs involved in purchasing a computer. For some, using ICT and having access to the Internet is a form of status.

### 2.8.2 ICT Skills and Training

Many people, not just those with an ID, may encounter difficulties comprehending information presented to them via a web page. Suggestions such as uncluttered pages and use of audio to aid navigation can assist those striving to understand what is in front of them. Mouse and pointer settings can be adjusted to suit the user. Alternative input devices such as a trackball or touchpad should be facilitated. The use of keyboard overlays can prove helpful when an individual is trying to access web links.

(Li-Tsang et al, 2007) noted the effects of ICT training on people with ID. The outcomes were found to be beneficial, instilling a sense of self empowerment. However, having a computer and training is not enough to ensure usage. The overall culture of the organisation as well as staff beliefs plays a huge part in the uptake of ICT by people with ID (Parsons et al, 2008). A keyworkers or family members support was noted as key in enabling the daily use of ICT(Li-Tsang et al, 2007).

(Li-Tsang, 2004) notes that a key aspect to the success of an ICT training program for individuals with ID is to ensure that the trainer to trainee ratio remains low. (Davies, Stock & Wehymeyer, 2004) discuss how important it is for this group to receive computer training, based primarily on the potential benefits this skill can bring. They also promote independent use of computer software to support self paced, self directed learning. CompSkills is a package designed specifically for individuals with ID that provides audio and offers visual prompts to errors. It introduces the user to basic computer tasks in incremental steps and allows for repetition. The results of the study conducted by (Li-Tsang, 2004) indicate that individuals with ID can learn to use a computer more independently if the suitable training supports are put in place.

(Davies, Stock and Wehymeher 2004) report that ICT has been used to teach individuals with ID anti-bullying training, language acquisition, budgeting and money management, menu planning and independent Internet access.



### 2.8.3 Costs

The cost of a computer, of online access and of ATDs if required, are a prohibiting factor for many. The cost of high speed broadband makes it unattainable for countless (Davidson & Santorelli, 2009).

### 2.8.4 Assistive Technology (AT) Needs

There exist constraints when applying ICTs directly into the AT domain mainly due to the difficulty that comes with integrating individuals with ID into social and working environments. To help tackle this challenge certain Intelligent Systems (IS) have been developed to help this integration (Martinez et al, 2010). The IS device is designed to interact with the user to overcome personal disabilities to increase performance, individual autonomy, personal safety and help to create a healthy environment within work and socially.

It is common that an individual with ID can have blockages which means that they are unable to make a decision or respond to a stimulus. Due to the difficulty with adapting these technologies, it is extra important that a designer must consider their needs accurately. Choosing a bad design may in fact further enhance the already high levels of social exclusion seen in the ID world.

ATDs for example voice synthesisers, magnifiers, alternate keyboards (a sample of which can be viewed in Figure 2.8), trackballs, voice activated software and keyboard pointers, can help people with a range of disabilities to use ICTs. However, many ICTs have been developed without regard to accessibility thus marginalising people with ID as they effectively create more barriers for them.



Figure 2.8 A sample on-screen keyboard. (Wobbrock & Myers, 2007)

### 2.8.5 Accessible Information

Many of the cutting edge GPS devices that display locations have not taken into account the requirements of individuals with ID with regard to the navigational interface. GPS devices can become inoperable when satellite coverage is inadequate. Therefore the language set has to be reasonable to the individual, whether it be text (letters, words, phrases) or symbols (icons, photos). Icon sets have traditionally been used with individuals with ID.

### 2.8.6 Authentication

(Parsons et al, 2006) reported that ICT was used to facilitate internal rather than external communication for individuals with ID. Therefore authentication issues would impact mostly on locally installed systems, such as games. A method of dual authentication is common in this area, particularly when individuals are accessing the Internet. This means log on is required by both the individual with ID and another nominated person.

If access is going to be filtered for the individual, on what terms should this be done? Some would suggest stratifying based on the level of ID. However other elements such as the individuals capacity, language awareness, their level of understanding and their ICT skill set should be considered. In some instances specialised browsers have been used to limit Internet access for individuals with ID. In other cases content selection

software is applied in order to filter the online material that can be viewed. This can be observed in Figure 2.9.

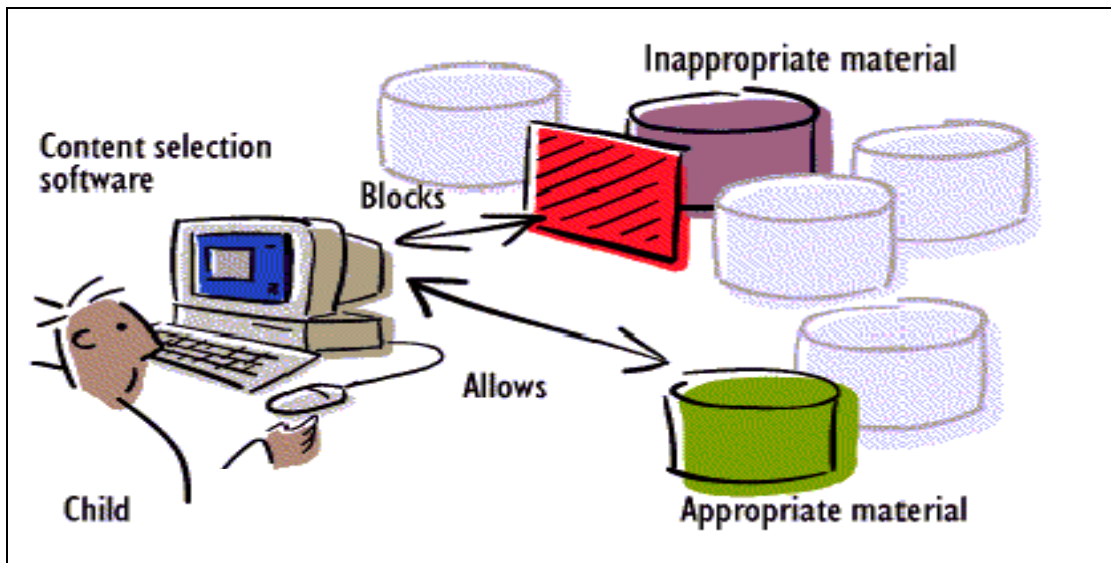


Figure 2.9 Internet Access Controls (Source; W3C, 1996: PICS: Internet Access Controls without Censorship).

Traditional log on methods may be difficult for individuals with ID to use. Firstly many have literacy issues and secondly the mapping set, which is generally text or words, can be difficult for the user. Thirdly individuals may have difficulty recalling their password, particularly if they do not frequent the same sites often. A suggested alternative is that the individual picks images to represent their password. An example of such an option is presented in Figure 2.10.

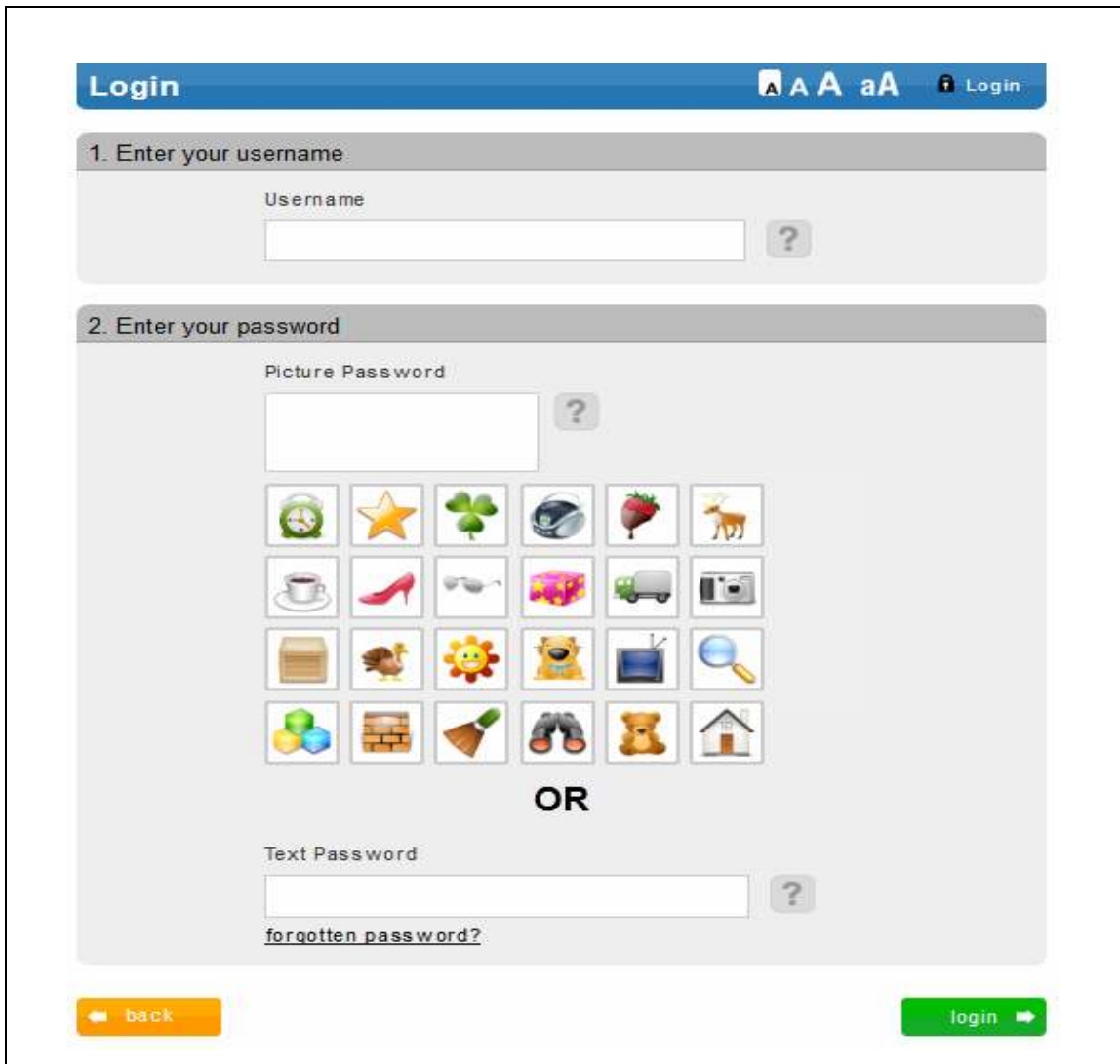


Figure 2.10 Log in suggestion Source (<http://www.klikin.eu/user/login>)

### 2.8.7 Cognitive Capability

There is a difficulty in determining the capability of a user due to the complexities of determining the particular hardware and software requirements that meet their needs. This complexity requires fuzzy logic techniques to deal with the vagueness of measurement, in order to arrive at a more suitable solution. An intelligent model consisting of four grouped levels for rating cognitive ability is displayed in Figure 2.11.

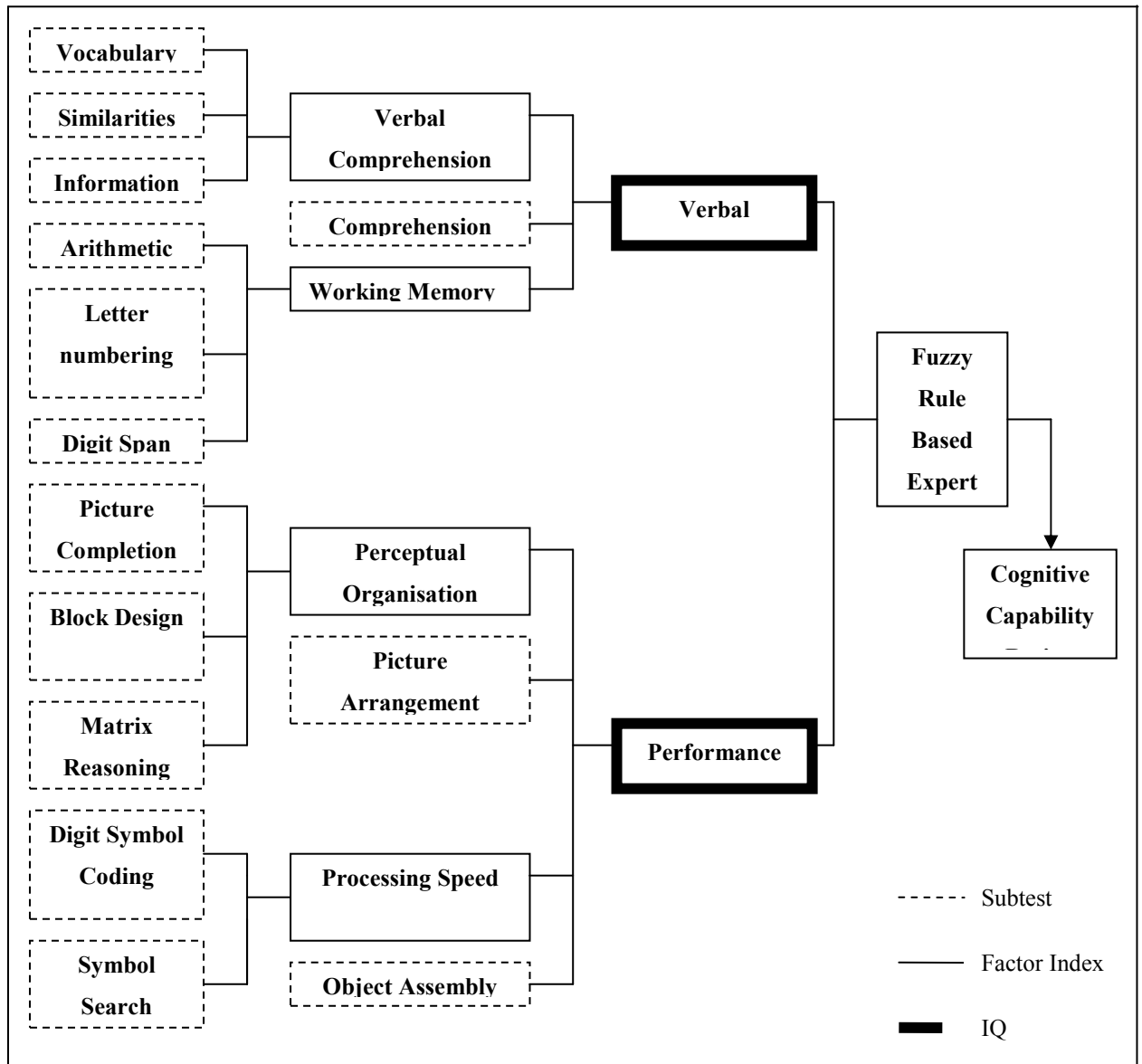


Figure 2.11 Intelligent Model for Rating Cognitive Capability (Source: Pushchak & Sasi, 2004)

This cognitive rating model is a combination of verbal Intelligent Quotient (IQ) and performance IQ. The verbal IQ is based on verbal comprehension, the comprehension sub test and the working memory index. The performance IQ is based on the perceptual organization index, the picture arrangement subtest, the processing speed index and the object assembly subtest. The fuzzy logic principles are then applied to simulate the cognitive capability rating, using rules formed as a combination of both the verbal and performance IQ. (Pushchak & Sasi, 2004) provide an example of a few of the fuzzy rules used for rating verbal comprehension index and the working memory index 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.

### 2.8.8 Vulnerable Adults

Cyber bullying is an issue amongst those with ID. Bullying in its traditional form, can be extrapolated out as challenging behaviour. (Didden et al, 2009) discovered a correlation between frequency of Internet usage and cyber bullying and states that those with ID are at risk and people need to work together to ensure the issue of cyber bullying is addressed and where possible, controlled. Table 2.2 illustrates the experiences of students victimised or bullied via the Internet.

Experiences on the Internet	Victim		Bully	
	Occurred about once a month	Once or more times a week	Occurred about once a month	Once or more times a week
Hurting	19%	5%	6%	4%
Harassing	21%	12%	14%	1%
Insulting	21%	8%	13%	2%
Name calling	27%	6%	18%	5%
Making fun of	29%	9%	22%	5%
Ignoring	14%	12%	24%	8%

Table 2.2 Experiences of Students Victimised or Bullied via the Internet (Didden et al, 2009)

## 2.9 Conclusion

This chapter introduced the reader to ID. It provided a definition, and verified the prevalence levels and the issues surrounding the terminology of the label itself. The literacy issues and learning strategies as well as learning styles were developed. A depiction of what an individual with ID uses ICT for ( daily living, social inclusion, to gather information, to learn and for leisure activities) and how they use ICT (AT, mobile computing, virtual environments and game development) were laid out.

Following that the benefits and constraints (access and awareness of ICT, skill level and training, costs, AT needs, accessible information, authentication, cognitive capability and vulnerable adults) were discussed.

The next chapter introduces the change in service provision within an ID context, from institution to community living to individualised services. The role that advocacy and accessible information play in this path are discussed.

### **3 ACCESSIBLE INFORMATION, ADVOCACY AND THE ROAD TO INDIVIDUALISED SERVICES**

#### ***3.1 Introduction***

This chapter introduces the rise and fall of service models in the context of service provision for individuals with ID. The role of advocacy with respect particularly to individualised services is discussed. The provision of accessible information is a prerequisite in assisting the individual in their decision making process.

#### ***3.2 Institutional Model***

After centuries of social exclusion people with an ID have only recently had their rights to social inclusion recognised. Historically they have been on the margins of society. The barriers to their social inclusion included legislation, asexualisation and institutionalism. It was not until the nineteen hundred and seventies that the disability rights movement received sufficient consideration in many aspects of society, including telecommunications policy (Jaeger, 2006). Social perceptions to some extent have changed through changes in legislation and policies that acknowledge the rights of persons with disabilities to be integrated into society.

(Anderson, 2005) predicts a future with reduced numbers attending an institutional setting. He expects the population in this setting to age, as younger people with ID will prefer to remain in the community. This move out of institutional settings to community care, marks a move to a smaller number of people with ID residing in each residential setting. (Lakin & Stancliffe, 2007) report that this produces more advantageous outcomes. Service providers are in a period of transition from institutionalised care to supporting people with ID living in an integrated community setting (Taber-Doughty, 2010).



### ***3.3 Community Living Model***

Institutions, with their exclusive enclaves of social interaction are far removed from the service model that is seen as desirable. Integration (that is dispersing people geographically in the community) is seen as more conducive to individuals engaging in community living activities. This is an area of concern for service providers as many people with ID have low levels of integration within the rest of their community (Cummins, Lau 2003). Even though most people are now located physically within the general community they are often not socially a part of their community.

#### **3.3.1 Benefits from a service provider perspective**

There are several reasons why a service provider would propose as a positive that community integration benefits an individual with an ID. However, these points may not be from the viewpoint of the individual with ID as the study found that people have a natural affinity towards integration with people that they can identify with, as opposed to with the community in general. For example new migrants in a country may choose to settle within their own community.

#### **3.3.2 Benefits to the Individual**

As has been argued, people regard their integration on a social perspective as opposed to the community in general. People just do not see this as relevant or important to them. A Comprehensive Quality of Life Scale (Cummins 1997a, b) was performed to garner exactly this information and it has been shown that community ranked last and relationship ranked first on the general and ID population. The question of whether an increased level of community integration is a positive thing seems to be implied in the subject title. This however is merely an assumption on the part of policy makers and service providers and it was not found to have any factual benefits.

Take an individual with ID living in a family environment. In a study of leisure time (Cummins & Lau 2003), it was found that there was no increased levels of friendships forged by individuals with ID living in the own community in a family based environment. Neither did the families see it as being particularly of importance to have this enhanced integration into the community at large. In fact the main qualities of life were based on friendships and the qualities of them. Therefore, there is clearly upper

limits that the physical environment can have on building quality of life issues such as friendships and integration. There was not seen to be any marked or significant increase in friendships outside someone else with disability, when living in a family structure.

On the flip side of the fact that there is a ceiling on benefits to physical integration, a study by (Cummins & Lau 2003) also looked at potential negatives to this community based model. The study discovered that there was significant levels of negative influence was found on members of families living with someone with ID. Stress was found at a level in seventeen of seventeen cases. On a similar basis, the school integration cannot be assumed to form a basis for an assured beneficial development community. Peers at school and teachers may not be able to cope or accept these added challenges.

The approach found to measure a successful integration at work falls short because it is merely measuring physical presence at work, as opposed to the more intangible integration aspects involved. The general community also prevents major changes for integration. People have high tendencies to prejudice people who are different for various reason, as is evident in everyday media. These prejudices can create self-esteem issues.

### 3.3.3 Measuring Integration

The most common practise for measuring integration is reliant on support workers to estimate the extend of activity experienced. The most widely used measurement is entitled the Community Integration Questionnaire (Willer et al. 1993). It records who in the household performs the most community based activities (such as shopping). It also measures how often these type of activities occur, and if that person is involved with employment or educational activities. There is an assumption that increased activity is a positive indicator. There have been numerous other studies aimed at measuring the integration levels of people with ID (Felce 2006). However, (Cummins & Lau 2003) concluded that the focus needs to be on whether an individual desired community integration, and also whether the community was a desirable or suitable environment for these individuals.

For community integration to be beneficial then this must be a dependable and supportive social structure. The measurement methods need to be subjective, not objectively physically counting community touch points with individuals. The general community is not a likely place to get this level of integration, rather it can be found easier within the same social structure. Lastly, new policies and literature needs to be developed to recognise community integration as meaning “ a sense of community” as opposed to generic references.

### ***3.4 Individualised Service Model***

In the Irish context the majority of ID service provision caters for groups of people, which are separate from the rest of the community. Ninety percent of day and residential services take place in a segregated and group setting (Department of Taoiseach, 2006) Many people who access a service receive what is described as a *Wrap Around* service from one service provider. This means that they receive a place to live, with daily support and a day service and a variety of health , personal or social services depending on their needs. The HSE funds the health service. This model of service does not look at the individual but rather at providing a service for groups of people. Therefore fostering little choice around the type of service that the individual would like to receive.

For many people using ID services their day is filled with paid staff and little choice about what happens on a daily basis. If attending a day service there will be a timetable of activities from nine to four with very little happening in the evenings or weekends. The provision of this type of service reinforces social exclusion and does not permit the person to exercise choice and control over their life. In this model the participant is a passive recipient of a predetermined service rather than an active participant in a service that is individually tailored to meet their needs and achieve their potential (Report of Disability Policy Review, 2011). The provision of an individualised way of working promotes choice and control and self-determination.

Individualisation promotes autonomy for the person and their families. The person receives support where and when they need it. They access generic services in the

community like other citizens. With the proper natural supports (family, friends and community) the individual is in the driving seat to lead a life of their choosing.

It is envisaged that Ireland will venture down the route of self-directed payments. It has already been introduced on a very small scale in larger agencies. However, it will present huge complexities for larger agencies in trying to debundle the funding, and also in creating safe guards for individuals who are vulnerable and have more complex needs. How an individual spends their money and what services they would like to access, and more so if they have the capacity to consent in these areas, will need to be considered.

This will be a huge change of practise for agencies as well as individuals with ID as they will now be able to spend their money on services that they want. There is a huge issue re capacity and consent. It will in effect be a more rights based approach. However at present the disability minister has allocated three percent of the budgets for ID service provision to be put towards individualised services. It is expected that this allocation will grow over the next few years to twenty percent.

Agencies can mask that person centeredness is happening. However this cannot happen if large groups are together, that is if all individuals with ID live together and work together.

#### 3.4.1 United Kingdom Model

Self-assessment is a key component of the United Kingdom (UK) model. It is not always easy for a person with ID to express their needs, so supported decision making mechanisms are required. The UK model measures individual needs rather than using a blunt instrument as the Irish do at present. In the UK once funding is approved it translates to a list of money. This essentially comes down to the cost per hour of a service. The cost of employing nurses, social care workers and so forth is expected to reduce. It is anticipated that individuals will pay minimum wage for these services, and with the perception of saving money in this aspect, individuals may choose to spend more of their budget on leisure activities

The UK model is the overall model but within it lies the Welsh model, that is generally the same but has some differences. Wales have a one hundred and fifty page standard to adhere to, whereas the UK do not have an official standard. Another key difference between the UK and Welsh model is in the Welsh model if you have the right to get the funding then you get the funding from the government.

There is a lot to learn from the UK model from an Irish perspective. While people may have access to direct funds, for some their natural supports (family, friends, neighbours) may not have been solidified in the planning process. This is an important safeguard so that the individual is not exposed to isolation and loneliness. In some instances crime has been directed at them. Or they too could be involved in crime.

### 3.4.2 Direct Payments

At present Ireland is currently learning from other countries who have over the years tried to develop a more person centred and individualised way of working. This is a challenge and continues to be a challenge for larger agencies that provide services for ID. However, countries like the US, the UK, Canada, New Zealand and many European countries have made some inroads by looking at self directed payments for individuals who use their service.

Direct payments enable individuals with ID to employ individuals and services to assist them with everyday tasks to facilitate their independent living. Individuals controlling the budget must be able to manage it themselves for direct payments to work most effectively. Direct payments give the person with ID the autonomy to assert control over their lives. Linked in with this are individualised budgets. These are paid directly to an individual to help meet the needs and goals identified by the individual. It uses different funding streams so it can offer flexibility in service delivery. The HSE document “Home Care Support Scheme for Carers” States:

*“Packages may consist of direct cash grants to enable the patients family to purchase a range of services or supports privately.... The package may consist of a combination of direct services and cash payments.” (Egan, 2008)*

Although it has its benefits direct payments can only be used with the consent of the person involved. Consent should be viewed as a protection for people who prefer to receive services organised by other methods. Even people who have a high level of need can indicate their preferences with regard to direct payments. However; they can only consent if they know what they want out of a direct payment. To know what they want they must be empowered to accept and manage the responsibility of a direct payment.

In Ireland, this is only at inception. The Final Report on the Disability Policy Review, 2011 published by the government, was convened to facilitate the policy review aspect of the Value for Money Review on Disability services. The central policy objective for people with disabilities is contained in "Towards 16", and advocates that people should be supported to lead:

*"full and independent life's, to participate in work and society and to maximise their potential".*

Individualisation is giving the person the chance to lead an ordinary life. It gives the individual the opportunity to choose how they would like to spend on staffing, where they would like to live, what services in the community that they would like to access (for instance work, college, a home of your own).

#### 3.4.3 Assessment Tools

The English use a self-assessment tool called In Control. This tool is used across all disabilities not just ID. The Irish NDA have reviewed two assessment tools, of which In Control was one, but have decided to go instead with the Support Intensity Scale (SIS).

#### 3.4.4 Reframing Disability Service Provision in Ireland

Funding disability services in Ireland is guided by the National Disability Databases. Currently, seventy five percent of disability funding is spent on residential and adult day services. Service arrangements with disability service provider's account for non-capital costs at present, which leads to an unstructured and inequitable approach to

resource allocation. A number of recent reports by the Comptroller and Auditor General, Office of Disability and Mental Health and the National Disability Authority (NDA) have argued for the implementation of a more equitable individualised system of resource allocation. We can learn from existing models internationally where individualised services are used. As the Expert Group on Resource Allocation and Financing in the Health Sector acknowledge, Ireland has ‘late mover advantage’ (that is we can learn from the mistakes and successes of others who have broached this before.)

#### 3.4.5 Smart Homes

With the change in style of service provision, the option of smart homes and the ability to monitor individuals with ID via technology instead of the traditional approach where individuals are physically monitored by staff is being investigated. (Ojasalo et al, 2010) carried out a study regarding smart home technology for individuals with ID. There emerged to be six main factors that should be considered in the design phase of smart homes for individuals with ID.

- ID individuals require a positive attitude towards using safety technology and services. This will assist in the engagement with these technologies and services.
- Safety and privacy are not mutually exclusive, and this is dependant on the right technology and services being chosen.
- There is a requirement for the right technology in traffic in particular where concentration levels are diminished.
- There is a need for technology and services to protect against abuse.
- There is a need for technologies and services to control pleasure giving activities, for example to monitor and control food consumption and Internet usage.
- There is a need for wristband technologies, for example if an individual gets lost.

### ***3.5 The Advocacy Movement Towards Individualised Services***

Advocacy places the individual at the centre and promotes autonomy and self determination, as can be viewed in the adage "Nothing About Me, Without Me". As service providers move away from the traditional model of service towards more mainstream and individualised supports it is critical that the person themselves is an active part of the process. The first step is consulting with the person in a meaningful way. This may require advocacy support in terms of being represented by a person who knows the individual well or an independent advocate (enabling a person who has difficulties speaking up for themselves but needs to be part of the decision making who is represented by an independent person so they can exercise their rights) to represent the individual wishes on their behalf. Currently staff working with individuals with ID act as a voice in representing the persons preferences and needs. However the need for an independent advocate becomes necessary when the person wants to "dream big" and live a more valued life beyond what the current service provision is.

With the best will in the world, services traditionally have come from the perspective of trying to care for people, fix them, make sure they are happy and in doing so are disabling them more. If people were having the services and type of life they desired, they would not need to advocate. For many ordinary citizens we take for granted the choices we make on a day to day basis. For people with ID and other marginalised groups in society, they have to fight for what is normal. If people are devalued in any way people are treated differently and therefore their rights are infringed.

(Gilmatin, 2009) reports that advocacy groups for individuals with ID offer support and a safe place to share experiences. Advocacy groups have grown in number for individuals with ID since the move towards individualised service. They advocate on the individuals behalf for accessible information to assist the individual in the decision making process.

There exists many levels of functioning with ID. With this many individuals need support in understanding what all these changes are about. Advocacy groups have sprung up all over to help support needs. Firstly to assist individuals in completing an assessment form. Secondly, to advocate on the persons behalf, when a person has



received funding. In essence, to assist them in finding the best service for the individual.

It is very important that the information is accessible as the jargon is complex. For those that have complex communication needs they will require supported decision making and have the right to choose someone who will advocate on their behalf so that they can have access to "a higher valued life".

Traditionally individuals with ID have had to fit into what the service can provide rather than the service fitting around the individuals needs. Large congregated settings like day services, residential housing are an example of this.

### ***3.6 Health Information and Quality Authority***

#### **3.6.1 About the Health Information and Quality Authority**

The Health Information and Quality Authority (HIQA) is an independent body founded in May 2007, under the Health Act 2007, to maintain improvement in Ireland's health and social care services. The Authority's role is to promote quality and safety in the provision of health and personal social services. The Authority is in charge of the registration and inspection of the residential services for children, older people and people with disability. The body reports directly to the Minister of Health and its mandate extends across the quality and safety of the public, private and voluntary sectors. HIQA has a set of values which comprise of five elements that are summed up in Figure 3.1.



Figure 3.1 HIQA Values (Source: <http://www.hiqa.ie/about-us>)

The Authority is organised into seven directorates. They encompass: (1) Social Services Inspectorate, (2) Health Quality and Safety, (3) Health Information, (4) Health Technology Assessment, (5) Corporate Services, (6) Communications and Stakeholder Engagement and (7) Policies and procedures.

### 3.6.2 The impact of HIQA on ID

HIQA intend to charge a fee of five hundred euros per house payable every three years. Each individual with ID attending a residential house will have to pay one hundred and ninety euros per year. This equates to a lot of money for individuals with ID who have a high rate of unemployment and little disposable income. Therefore, HIQA need to prove they are worthy of charging this amount and provide a service that is beneficial to the individuals in question.

The facet of social care is monitored by the Social Services Inspectorate (SSI) directorate. The SSI goal is to ensure that vulnerable people of all ages (including those with ID) living in a residential care setting have the appropriate quality and standard of service.

In two thousand and nine HIQA published the "National Quality Standards: Residential Services for People with Disabilities". These standards were set to make sure that those disabled living in residential services have a safe and good quality service, to help to improve the service provided to them and to protect their rights. The working group who wrote the standards included people with disability, parents of disabled, service providers, National Disability Authority, HIQA, the Department of Health and Children and those who work with the disabled. The document has been published in different versions and formats, such as; easy to read version and MP3 Audio version.

The standards are grouped into seven sections or dimensions of an individual centred quality service namely:

1. Quality of Life
2. Staffing
3. Protection
4. Health and Development
5. Rights
6. The Physical Environment
7. Governance and Management

### 3.6.3 HIQA and Accessible Information

ICT plays a key role in most of the seven dimensions, mentioned above. Its use is essential for information accessibility and in maintaining a good quality of service to the disabled.

Under the Quality of Life Dimension, ICT is part of the media tools used to allow the individual to access news and information. Similarly it is important for the Development and Health dimension, in providing access to the appropriate health information and education in all areas relevant to the individual's life.

As part of the Rights Dimension of the Standards, the individual is provided with information about his/her rights in a format that is appropriate to his/her information and communication needs. Section 10.3 specifies that:

*"The individual is provided with assistance and support to access information and communicate with others through a variety of information and communication media and to make contact with other services including advocacy and emergency services".*

ICT is also necessary for the Physical Environment Dimension, in achieving its goals in stimulating and providing opportunities for rest and recreation. Thus the premises are equipped with assistive technology, aids and appliances, including accessible information and communications technology. It is also necessary in ensuring that staff and individuals have active participation in health and safety education and training programmes.

Furthermore, ICT is used in the Staffing Dimension, in maintaining effective communication with the individuals, in making information accessible to them including advocacy services and in maintaining adequate records. ICT is also used by staff as a learning aid in their professional development.

There is a wide use of ICT in the Governance and Management Dimension. In this dimension there are systems for monitoring the quality of service as experienced by the individual in order to bring improvement. All information is made available in a format suited to the individual's communication need.

#### 3.6.4 Care Quality Commission - CQC

The Care Quality Commission (CQC) are the English version of HIQA. The CQC received very bad press following the BBC Panorama expose broadcast in May two thousand and eleven (Undercover Care, The Abuse Exposed).

### ***3.7 Capacity***

In the UK, the Mental Capacity Act (2005) declares that everyone has the right to be able to make decisions unless they do not have capacity to do so. It deems an individual has capacity if they can:

- "Understand the information about the decision
- Retain the information long enough to make a decision
- Use the information within the decision-making process
- Communicate the decision, for example, by indicating a consistent 'yes' and 'no' response ( Oldreive, 2011)".

An assessment pathway is displayed in Figure 3.2 below. There is an urgent need for reform with regard to Irish law. In Ireland, people continue to work from the eighteen hundred and seventy one Lunacy Regulations Act. Ireland was among the first countries to sign the Convention on the Rights of Persons with Disabilities in two thousand and seven. However it has not been ratified. Six years later Irish people with an ID, mental health problems and dementia continue to be referred to as lunatics under Irish law. At present a polling officer can decide on the day that the individual does not have the capacity to vote. This is on an individual basis and the polling officer has the power to do this as part of the Lunacy Act.

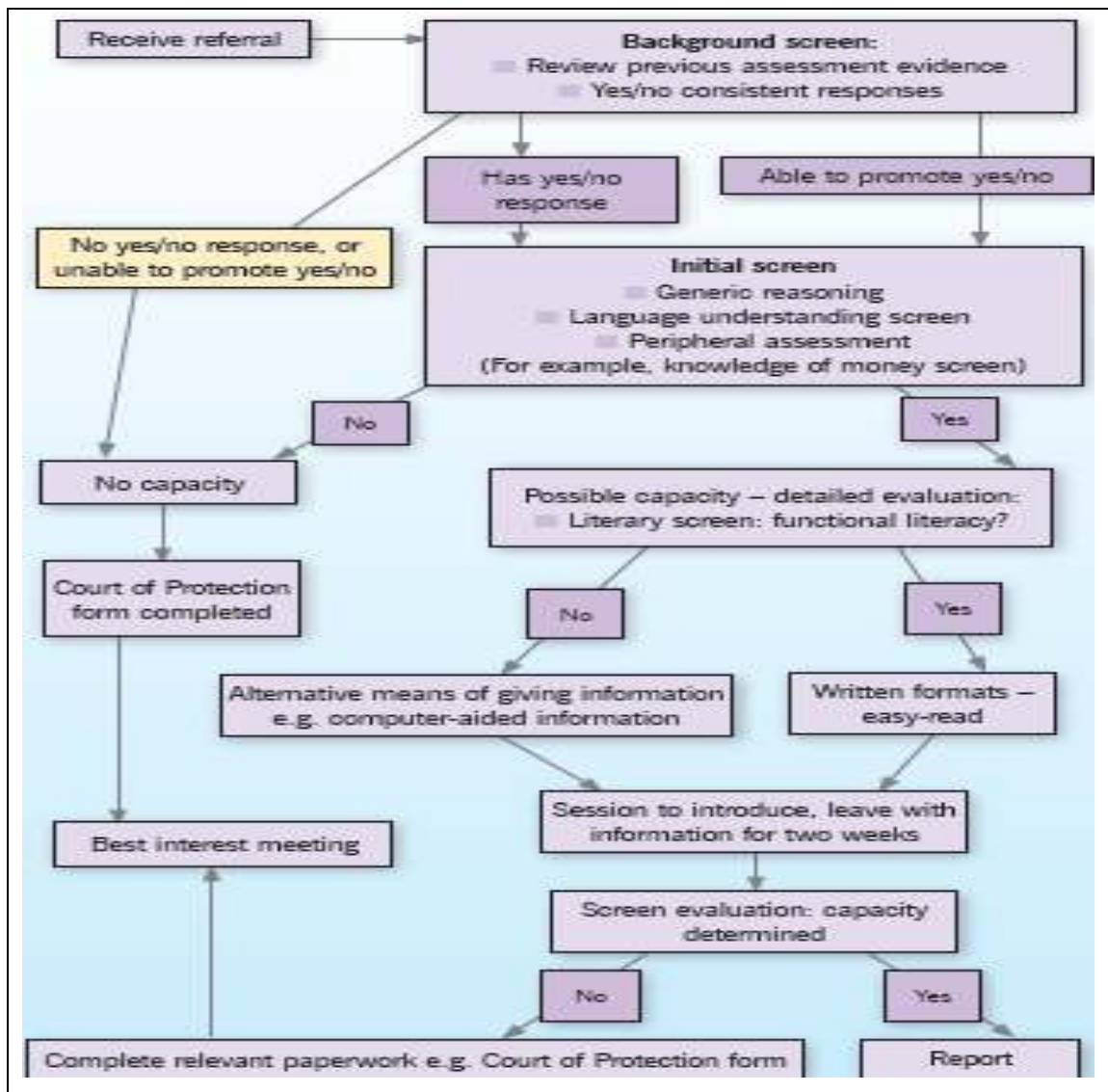


Figure 3.2 Assessment Pathway (Oldreive, 2011)

Another case in question in the Lunacy Act is Louise, a Down Syndrome woman, who was sexually assaulted. She followed all protocol, by contacting the guards and making the required statements. The case went as far as court. In court, the judge took one look at Louise and decided she did not have capacity and threw the case out.

However, in two thousand and eleven the programme for government introduced a "Mental Capacity Bill" that is inline with the Convention for Human Rights of People with Disability. This is going through government at the moment.

(Bailey et al, 2012) state that a decision can only be made if the individual has the capacity to weigh up the pros and cons of other outcomes. They found that individuals

with ID were able to make a decision but could not add more than one pro or con reason for making the decision they had. They suggest that executive functioning, as opposed to IQ, determines reasoning abilities in individuals with ID.

### ***3.8 Accessible Information in an ID context***

In an information society, the need to facilitate access for everybody to electronic information has become the new area of concern for social justice. It has become more important than ever that ICTs match the user's capabilities to design in order to ensure that people with ID do not become more marginalised. As discussed by (Lazar et al., 2003, p.331), ICTs that are not designed specifically for accessibility:

*“must be flexible enough to work with the various assistive technology devices that a person with a disability might use and to provide relevant content in an accessible modality”.*

For many individuals with ID, literacy difficulties dictate that they prefer to receive information via visual aids (videos, photos, icon sets). They enjoy the medium of story telling and information being depicted and played out through example scenarios.

#### **3.8.1 Symbol Sets**

There is no one icon set used for individuals with ID who have reading difficulties. For instance they may use six different images for one word, like telephone or money. For people who have higher functioning, they do not like using symbol sets, as due to the different usage of symbols for the same terms it causes confusion. A sample of this can be viewed in Figure 3.3 They prefer to use photos and visual aids that they have an association with. This can have an impact on accessible information as individuals may have only been exposed to one set of symbols.

Furthermore, for people who have more severe and complex needs tools such as Boardmaker (symbol set) and the Talking Mat (a mat facilitating yes or no answers using pictures when making a choice), with support, provide a very important and necessary mechanism when communicating.

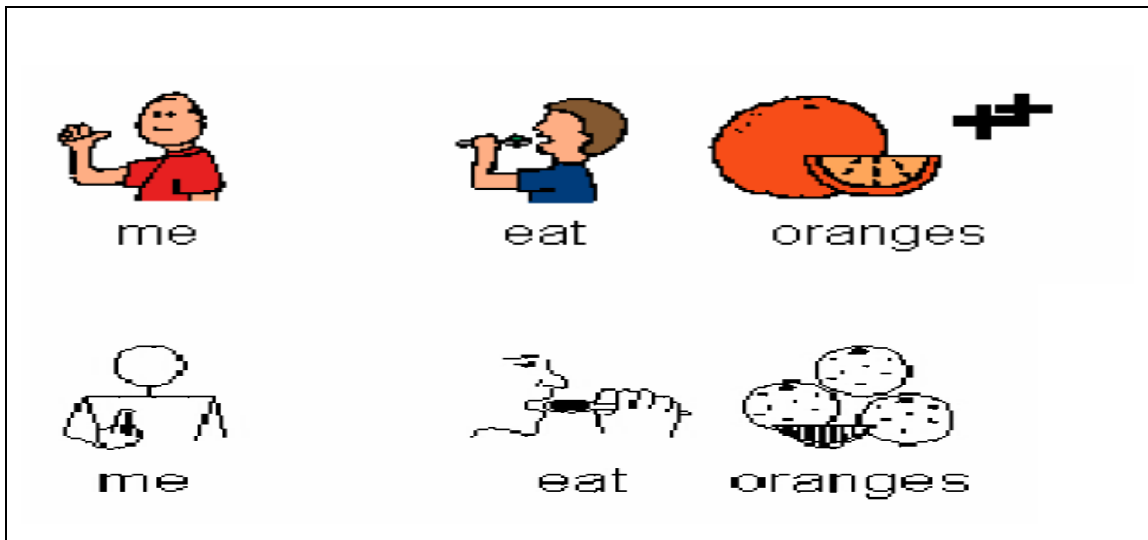


Figure 3.3 Example of different symbol sets Source:( Harrsion et al, 2008)

### 3.9 Conclusion

This chapter describes change in service provision models for individuals with ID. The last number of years have seen the progression from institution based dwelling to a model where individuals are encouraged to live within their community. The latest move involves the advent of personalised budgets and individualised service, where the individual has the choice to determine what services they wish to purchase through their direct payment.

Advocacy has been strongly linked to ID service provision. Furthermore, the move to individualised services has resulted in advocacy groups springing up. This is mainly for two reasons. Firstly to assist the user when filing our the required assessment form and secondly to advocate on their behalf to find services with the funding that has been allocated to them. Accessible information and its role to aid decision making in this process is also discussed. In the next chapter the role that cognitive disability places on design will be considered.



## 4 COGNITIVE DISABILITY AND ITS IMPACT ON DESIGN

### 4.1 Introduction

The chapter discusses the standards that have an impact on web accessibility, with attention paid particularly to the realm of cognitive impairment. Human Computer Interaction and user centered design are discussed and examples demonstrated. Universal design is discussed and the main principles that affect cognitive impairment are noted.

### 4.2 Standards

(Grguric, 2010) relates how new methods and technologies are being researched that will reduce the cost and development of accessible ICT solutions. A noted move in that direction is ACCESSIBLE (Accessibility Assessment Simulation Environment for New Applications Design and Development). This project enhances software accessibility by establishing accessibility methodologies within the design and development processes. A key challenge of ACCESSIBLE is to reduce the digital divide between individuals with and without disabilities in their use of technology. (WHO, 2011) report that standards for ICT accessibility are lagging far behind accessibility standards for building and transport.

#### 4.2.1 Web Content Accessibility Guidelines Version 1.0

The World Wide Web Consortium (W3C) operate as the standards body for World Wide Web-based technologies. A division of the W3C is the Web Accessibility Initiative (W3C-WAI). The mission of the W3C is to:

*"lead the World Wide Web to its full potential by developing protocols and guidelines that ensure long-term growth for the Web" (W3C, 1999).*

As a consequence of the formal recommendations of W3C, a set of guidelines titled the Web Content Accessibility Guidelines (WCAG) version 1.0 were first released in

nineteen hundred and ninety nine. These fourteen guidelines offer guiding principles on the authoring of web content with regard to reducing the difficulties some users with disabilities may have due to their use of assistive technology devices (ATDs). They aim to make web content accessible to individuals with disabilities. These guidelines are further broken down into an additional sixty compliance checkpoints. They have three priority levels:

- Priority one representing a minimum level of accessibility
- Priority two representing a moderate level
- Priority three representing complete accessibility

The Disability Rights Commission (DRC, 2004) in the UK completed a study of a hundred websites to review problems disabled users encounter most often. It found that eight checkpoint errors and warnings accounted for eighty two percent of the compliance breaches. The most reported problems included:

- Checkpoint 1.1: Provide a text equivalent for every non-text element
- Checkpoint 2.2: Ensure foreground and background colour combinations provide sufficient colour contrast, etc.
- Checkpoint 6.3: Ensure pages are usable when scripts, etcetera are turned off, or provide an alternative.
- Checkpoint 7.3: Until user agents allow users to freeze moving content, avoid movement in pages.
- Checkpoint 10.1: Until user agents allow users to turn off spawned windows, do not cause pop-ups without informing the user.
- Checkpoint 12.3: Divide large blocks of information into more manageable groups where natural and appropriate.
- Checkpoint 13.1: Clearly identify the target of each link.
- Checkpoint 14.1: Use the clearest and simplest language appropriate for a site's content.

WCAG 1.0 offered very poor guidelines with respect to cognitive disabilities. (Williams, 2006) reports that the accessibility guidelines support mainly individuals

with low vision, while references to individuals with cognitive impairments are almost absent.

#### 4.2.2 Web Content Accessibility Guidelines Version 2.0

WCAG 2.0 superseded the outdated WCAG 1.0 guidelines in December two thousand and eight. WCAG 2.0 introduced four principles; Perceivable, Operable, Understandable and Robust which are referred to as POUR. Under the principles are 12 guidelines, which provide criteria for making content more accessible to users with a varied range of disabilities. In order to meet the needs of different groups and different situations, three levels of conformance are defined: A (lowest), AA (medium), and AAA (highest). They provide parallel principles and guidelines for online accessibility from a ‘universal design’ standpoint aimed at a comprehensive approach to accessibility across populations (W3C, 2008). There is concern that the uptake of WCAG 2.0 will be hindered, as the guidelines may be considered too complex.

The main WCAG 2.0 recommendations for making information accessible to people with ID are as follows: timeout feature removed unless the user can control it (i.e. do you need more time to carry out the request), ability to control audio, clear structure and logical sequence with headings and consistent navigation to avoid confusion. Good contrasting colours for legibility. While the WCAG provides a guide to developers it is important that they don’t have a ‘band-aid’ approach to accessibility. As (Lazar & Wentz, 2011) note:

*“Regardless of intentions, separate is never truly equal.”*

Guidelines such as the WCAG 2.0 and those proposed here will help bridge the ‘digital divide’ that separates people with disabilities from opportunities for social and productive activities that otherwise might be beyond reach due to online accessibility barriers. These barriers may be with respect to information gathering, learning, informal social exchanges and volunteer activities. The guidelines are also key to access in the domain that is perhaps the single most important factor in retaining financial independence: paid employment.

In his study (Kuzma, 2010) reviewed the level of accessibility issues within one hundred and thirty websites of the UK houses of Parliament. The study used online accessibility tools to analyse the compliance levels within these websites. This was then applied to the standards set out in both UK disability law and Web Content Accessibility Guidelines. However, even with the combination of laws and standards, these sites were exposed as not being fully accessible.

(Kuzma, 2010) found similar results on most of the analysed sites to the (DRC, 2004) report mentioned in WCAG 1.0. This results in a discrepancy for accessibility for disabled users compared to non disabled counterparts. The first standards were breached. It recommended that there should be an understanding of these accessibility errors under current DDA law and WCAG guidelines when creating new sites. And that there can be a gradual implementation of these guidelines for current sites using these testing tools. As a motivation for designers, it should be noted that this design will increase the market for users of the relevant site, and prove a more beneficial experience for all users.

(Jin Li, 2010) reports that W3C guiding principles are more relevant to the technical rather than cognitive facets of accessibility. These conceptual aspects are more aligned to usability.

#### 4.2.3 Section 508

In US legislation, Section 508 falls under the Rehabilitation Act of 1973, which requires that federal agencies are legally obliged to eliminate barriers in information technology, open new opportunities for people with disabilities, and encourage development of technologies that will help achieve these goals (Hudson, 2002). The law applies to all Federal agencies when they develop, procure, maintain, or use electronic and information technology (Section508). The 1998 law specifically applies to create US government wide accessibility to anyone who uses the web or interacts with these departments using information technology as a medium.

In reference to cognitive impairments, it specifies that since cognitive disabilities are not as physically evident then there is a recommendation that certain provisions are

made. For example time constraints are taken into account, bulleted lists are used to mitigate difficulties with processing large volumes of text. Graphics are used, and information is well structured. Efforts are being taken to synchronise standards between WCAG 2.0 and Section 508 (Ashington, 2010).

#### 4.2.4 Digital Accessible Information SYstem

The Digital Accessible Information SYstem is recognised as DAISY. The DAISY consortium offer feature rich, accessible digital talking books to individuals with literacy difficulties. The consortium endorse that a DAISY format be produced in tandem with the original publication and at no greater cost. (WHO, 2011) note that in two thousand and five, *Harry Potter and the Half-Blood* was made available to visually impaired children on the date of original publication.

#### 4.2.5 Organisational Standards

Some sizeable organisations such as the British Broadcasting Corporation (BBC) provide accessible guidelines re the creation of its own web pages (Lee, 2010). In November 2010, the British Standards Institution (BSI) published the BS 8878 Web Accessibility Code of Practice. Its purpose is to assist web site owners by providing a comprehensive guide, which demonstrates how to make web products more accessible through organisational policies and processes (BSI Group, 2010).

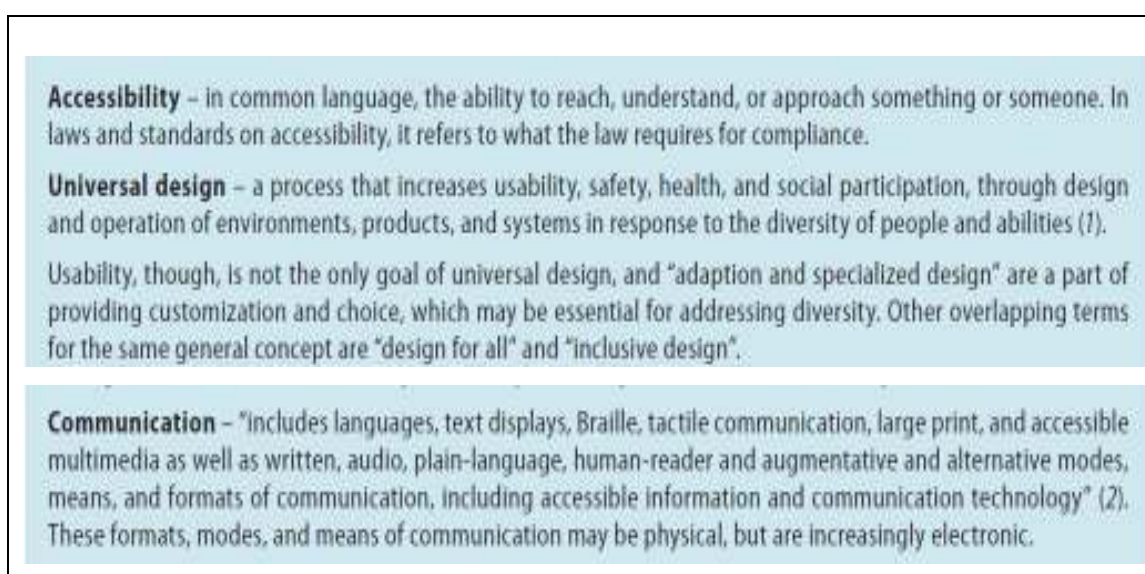


Figure 4.1 Definitions and Concepts of Accessibility, Universal Design and Communication (WHO, 2011)

### ***4.3 Human Computer Interaction***

Many researchers argue that computer technologies will increase independence for people with intellectual disabilities (ID). However, recent studies have illustrated that existing human-computer interfaces may not benefit all people with ID. (Li-Tsang et al, 2005) reported that people with a more severe level of ID are less likely to learn and use more advanced computer skills.

Human-computer interaction (HCI) involves the study of an individual's interactions in performing information processing tasks. (Jacko, Salvendy & Koubek 1995) discuss the HCI model, which they breakdown into three different stages stimulus identification, response selection and response execution. Stimulus identification is the ability of the user to identify the displayed information on a computer screen. Response selection refers to the motor responses for example use of keyboard etcetera to the stimuli on the computer screen. The design emphasis here is on matching the person with ID's cognitive and sensori-motor capabilities (for example visual searching) with the requirements of the computer tasks (for example finding a target icon). Response execution is the process by which a person selects appropriate responses to perform the different task functions. The individual decides the motor sequence to start the response for instance, clicking on the left mouse button.

Existing software and HCI designs have been targeted at the mainstream population. People with ID, are one of the minority groups who have been identified as encountering substantial problems in utilising these technologies (Li-Tsang et al., 2005, 2007; Wehmeyer, 1998,1999). To assist this group of users (Li-Tsang et al., 2005, 2007) proposed their study emphasise user-centred design to explore the specific task components that might restrict people with ID from using computer technology rather than investigating functional problems, which were the basis for previous studies. As their target group have varied cognitive and motor skills required for all computer tasks they measured the performance levels in relation to specific computer tasks.

The Internet Explorer (IE) program was selected to demonstrate the problems encountered by people with ID using an existing and commonly used human-

computer interface. By means of categorising tasks into general motor functions and using a customised bookmark, it was shown that different levels of mental abilities resulted in different success levels in operating the program. More importantly, successful performance during the computer tasks followed the processes of stimulus identification, response, and execution, which demands specific cognitive and sensori-motor abilities. It was shown that an enhanced design of the human–computer interface or a modification of existing design would facilitate usage by people with ID. Also, computer training programs should match the ability level of the user involved. A computer task-based screening test could be useful for serving this purpose (Wong et al, 2009).

The study recommended future research should investigate which sensori-motor and cognitive functions contribute to the competency of people with ID in using a human–computer interface, and how they do so. Ability profiles need to be developed in order to enhance the production of more user friendly programs for this user group.

The Human Computer Interaction community has recently focused more attention on the development of programs for individuals with Down’s Syndrome (DS). Children with DS are brought up surrounded by technology, and the purpose of this study is to understand the interactions with technology by this group. It must be noted that the uniqueness of this group is that all three channels of capabilities are affected. These are the cognitive, motor and perceptual channels. There is a further complication in that children with DS have different developmental growth between cognitive and analytical capabilities. Lastly, it is known that there are wide variances in capabilities from one person to another.

The methodology used was to complete a detailed survey with a base of approximately six hundred parents of children with DS. The reasoning to involve parents was because they could understand the questions and give proxy consent. The issue at hand is that these limitations and their implications on design need to be considered by the designer from the outset. For example, speech recognition software could be introduced for a user with physical difficulties, but in this case there may be cognitive limitations may render it ineffective. Therefore a major step forward is that designers

need to have at least an awareness of these traits. This is evidenced by the low level of research in this area (Feng, et al, 2010).

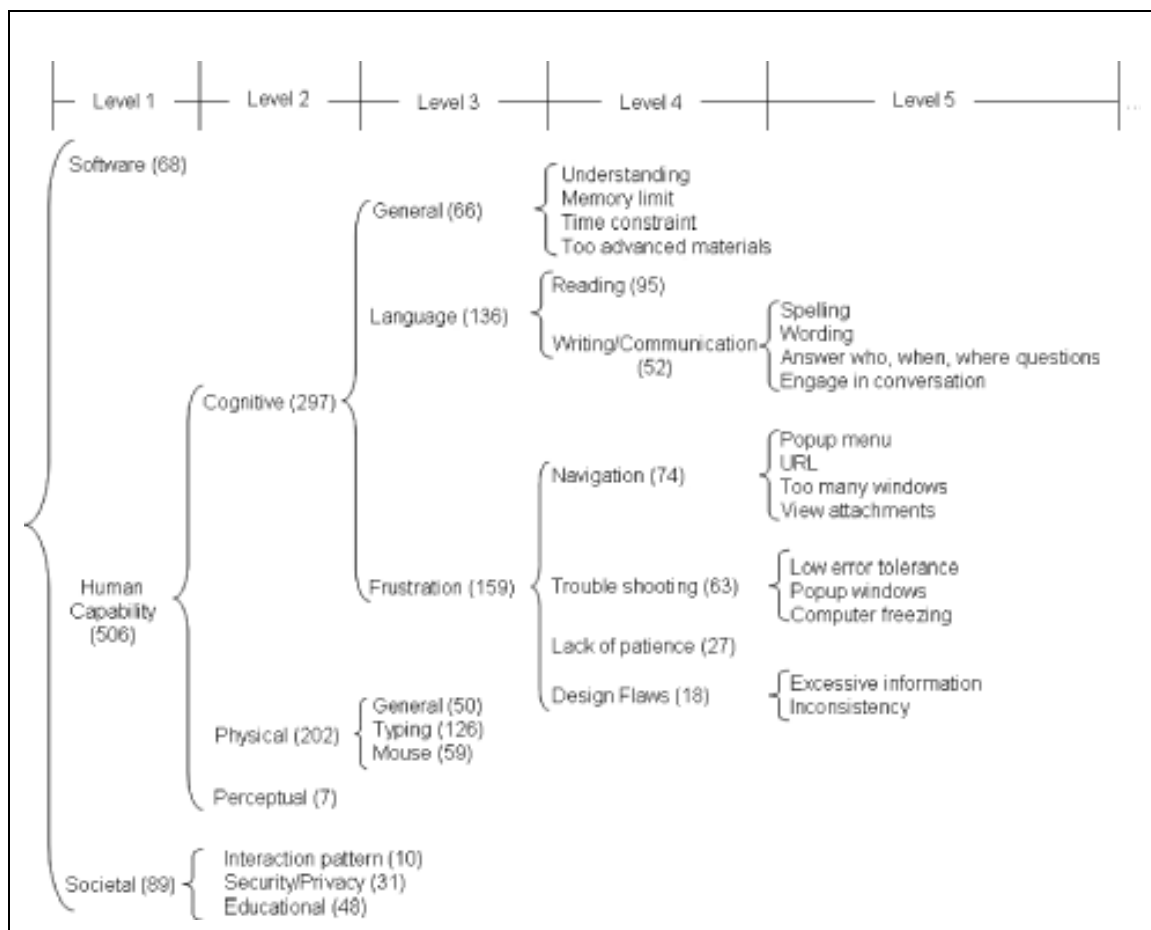


Figure 4.2 Summary of difficulties experienced by children with Down Syndrome (Feng et al, 2010).

The above graph illustrates the complicated and multi layered dimensions to an ID participant with more than one cognitive disability. The results were gained from a detailed survey of parents and answers were translated to the relevant subset. The conclusion arrived at is major study needs to be completed before a design concept takes place.

#### 4.3.1 User Centered Design

In their study (Keskinena et al, 2012) employed a user based approach in developing a communication method through pictures as a means of communicating via technology. It is designed to be flexible and applicable to varying degrees of cognitive disability, and evidences that a user based design approach has increased benefits for both users



and designers. These picture based methods are an interface multimodal picture-based communication platform called SymbolChat. A screenshot of the interface is viewable in Figure 4.3.



Figure 4.3 SymbolChat Interface (Source: Keskinen et al, 2012).

Since the design guidelines were user centered the starting point was to involve the users in the design process. In the case of cognitive disability, there was also the aspect to involve caregivers, as they are fundamental to the facilitation of this technology. Furthermore, extra consideration was given to guidelines on physical, mental and psychosocial areas. That meant that there was a focus on simplicity, and time independent inputs. Outputs were designed to be uncluttered, and potential consideration given to speech recognition software if circumstances allowed. The system was set up to be generalized to an appropriate degree, and once researchers considered the common design feature they were able to allow customizable features. The user centered design principle was in this case promoted beyond just user testing to include interviews and free usage of software on a freelance basis.

The success of this approach was evidenced by the results, as the participants were able to communicate and express themselves with a large-scale vocabulary with minimal training. Secondly, another element of success of this method is the engagement of users to see it as a fun and flexible system, since they had participation in the design to their liking.

#### ***4.4 G3ict***

The G3ict is part of the United Nations Global Alliance for ICT and Development. Part of the G3ict role is to assist policy makers worldwide to implement via a e-accessibility toolkit, the ICT accessibility dimension of the Convention on the Rights of Persons with Disabilities (CRPD).

#### ***4.5 Legislation***

In the US The 'Telecommunications Accessibility Enhancement Act' in nineteen hundred and eighty eight recognised that telecommunications services provided by federal and state governments had to be compatible with the ATDs used by individuals with hearing impairments. The Television Decoder Circuitry Act in 1990 recognised that all television sets with thirteen inch plus screen had to be capable of closed caption. Title IV of the Americans with Disabilities Act (ADA) in 1990 required that all phone service providers must supply relay systems for individuals with hearing and speech impairments. This service had to be offered free of charge. Section 508 the Rehabilitation Act, which was discussed earlier in this chapter, induces federal agencies to comply with accessibility guidelines. It appears with all US federal laws with respect to ICTs, there is a compliance opt out option, whereby compliance is not required if it causes undue burden (Jaeger, 2006).

In the UK, the Equality Act 2010, lays an obligation with the information providers to make sure that their web products are accessible (BSI Group, 2010).

#### ***4.6 Universal Design***

When choosing a design of a product or service, the fundamental concept should ideally be that the design is aimed at the needs of all people, and that this perspective

also means the design should be aimed at universally solving the requirement. This is called Universal Design, design for all, or barrier free design. The universal design process and the diversity of potential users needs to be considered. This consideration means that we need to review the principle of universal design:

*“Universal Design is the process of creating products (devices, environments, systems and processes) which are usable by people with the widest range of abilities, operating within the widest possible range of situations ( environments, conditions, and circumstances)”.*

In their research, (Wehmeyer et al, 2006) determined that people with ID benefit when devices are conceived with universal design. They note the following principles as being of particular importance to this population; Flexibility in use, Simple and Intuitive Use and Perceptible Information. In previous research (Weymeyer, 1998) noted that cognitive impairment was not carefully considered. An instance of this is not allowing enough time for an individual to consider what step they want to take next on a computer screen.

It is thought that the emergence of smart phones with universal design features aid cognitive access (Verstock et al, 2009). (Stock et al, 2008) reported that their research also showed benefits for those with ID when their mobiles were equipped with universal design features. They suggest many opportunities await for those with ID if these features, multimedia and simple user interfaces are applied to other electronic tools.

#### ***4.7 Web Accessibility Tools***

Tools are available that allow a person to check if a site is accessible according to the WCAG 2.0 guidelines, and to what compliance level. There tools are free. An example of one such tool is WAVE (available at <http://wave.webaim.org/>). This tool allows the user to enter a web address, upload a file or add some html code. This is then submitted and results returned re the sites, files, or html codes accessibility.

## ***4.8 Conclusion***

This chapter discussed the WCAG guidelines and Section 508. It also mentioned other standards such as DAISY. Universal Design was introduced. The impact of cognitive impairment on these design guidelines was reflected on. In the following chapter the design of the experiment will be discussed.

## **5 DESIGN PROCESS**

### ***5.1 Introduction***

The chapter will introduce the design concept from its initial conception to the final prototype product. It will discuss the evaluation methods used throughout the various iterations that led to the final development.

### ***5.2 Requirements Gathering***

This study involved discussions with two groups initially. Firstly, the Saint Michaels House EVOLVE team were looking at developing an online resource with respect to FETAC training and secondly the advocacy team were looking at an online advocacy resource. Even though what they are looking for may be somewhat different, both the EVOLVE and Advocacy teams wanted to use the same navigation tools to make it as user friendly as possible for the individuals. It was determined after this initial stage of discussions that future work would involve closer involvement with the advocacy group as they desire more peer to peer learning hence are very interested in videos and audio chat. This prototype will act as a template for these online resources as there will be direct liaising with the user group to determine images and navigation methods that they find most useful.

When designing for individuals with ID, understanding their user requirements is a key aspect of a successful design process. To determine what their preferences are open communication channels are required between the designer and the end users. The designer will require to be adaptable to meet the groups needs.

The foremost usability objective is that it must be easy for the individuals to learn to use. To best achieve this, an individuals expertise level at processing certain tasks should be agreed. Straightforward tasks may prove difficult for individuals with ID which needs to be considered during interface design. Consequently individuals with ID should be included in the interface design process. The goal here is to assist the

individuals with ID in learning something new or in a different way through the use of a new tool that the individual has not used before.

The prototype was tested using Internet Explorer (IE) as this is what is used throughout the organisation. Therefore the participants are familiar with IE if they access a computer in the any of the organisation services.

### ***5.3 Design Concept***

From the beginning this study sought to endorse meaningful use of ICT. It was not the development of an ICT system for the sake of it, but in a way that was helpful and fit in with existing organisational systems. It is also relevant in that it fits into one of the key things that are happening in the area now with regard to individualised services. Furthermore this piece of work is practical and sampling was completed in order to learn from people with ID in discovering what works best for them. Therefore the concept was to design a tool that can deliver information in an accessible format.

The concept design formed around an accessible VLE for people with ID, which would encourage and assist online communication and learning. As a large number of individuals with ID experience literacy difficulties it was envisaged that the prototype would facilitate picture-to-picture navigation. Minimal text was to be used throughout. After arriving at the desired topic the individual would have the option to learn about the information via audio, video or easy ready documents.

Working with advocacy groups that already exist and are part of the structure of the organisation, it was decided that advocacy news would be conveyed electronically, like an advocacy newsletter. The concept framed around an electronic version of the newsletter that is used at present in the organisation. For many individuals who attend SMH they require assistance, in the way of a staff member reading or assisting them with the language set on the newsletter. An example of the existing newsletter format can be viewed in Figure 5.1. The people involved decided on advocacy, as the template for the electronic newsletter. Therefore the participants were asked if this was a preferable way of viewing SMH news.



## Advocacy and Leadership course

As part of an organisation-wide strategy to empower and support service users to have a direct input into issues that affect their lives, a number of service users have just completed a training programme in advocacy and leadership in Dublin Institute of Technology, Mountjoy Square.

This was the second time the programme was run and covers areas such as understanding self advocacy, history of disability services, essential communications skills, voter education, how Ireland is governed, inclusion and awareness of service standards. The students also had to make a presentation on a personal, unit or service change they would like to see happen to successfully complete the course. Some of the students made a presentation on a change they are actually working on in their day unit or as an individual goal.

During the programme the students attended a variety of conferences on Advocacy and Leadership and participated in a national consultation process examining the future direction of service provision for people with an intellectual disability. The programme took place in the Dublin Institute of Technology Mountjoy Square. This setting enabled the students to sample student life and to socialise with other students attending the college.

The third year of the programme has just started and it is planned that this group of students will undertake some joint projects with other students in the college.

A formal conferring ceremony, which was attended by family and friends, was held in the college with each student receiving their Certificate from the Head of Department of Social Science, Mr Kevin Lawlor. Speaking on behalf of the students, Dermot Lowndes commented on how they all greatly enjoyed and benefited from the programme and thanked the tutors for all the support given to them.

We would like to congratulate the following students on completing the course and wish them every success in the future:

Audrey Seery, Francis Lally, James Burke, Yvette Goslin, Anne Marie Reid, Jacinta Halpin, Pauline Birkby, Tony Abbey, Helen Murphy and Dermot Lowndes.



3

Figure 5.1 Sample SMH Newsletter Winter 2011 (Source: <http://www.smh.ie/files/winter%20newsletter%20small1.pdf>)

The Moodle theme chosen had a clear backdrop and was bright and with a clean colour palette. The font style did not have serifs to aid legibility.

The design needed to address possible low computational resources, to support partly outdated technologies such as IE 6, and to allow for social and human matters. (Jin Li, 2010) asserts that:

*“The main aim in designing for accessibility is to reduce the so-called digital divide or e-gap phenomenon.”*

#### ***5.4 Design Principles***

(Bunning et al, 2009) highlights the benefits people with ID can retrieve from rich multimedia. It facilitates a move away from traditional linguistic exchange as those with ID form links between the images and connotations. Simple, jargon free language should be used; interfaces should be easy to navigate and based on images (Lennox et al, 2009). (McCoy, 1998) highlights the importance of being able to map datasets (either iconic or symbol sets) to word or phrase sets to improve ICT performance.

As the target audience is made up of individuals with ID, their learning styles, general characteristics and abilities should be taken into account for all design elements. The design should be easy to use, adaptive and offer affordance. Each web page remained uncluttered with a standard layout to help users become familiar with the site and easily move around it. Text was used minimally and instead the use of photos or symbols were used throughout. A description was added to the alt tags. The interface had to be user friendly and easy to navigate. For instance allowing the user within a few steps to navigate to the information they want in the modality of their preference.

The content should be relevant to the goals and desired outcomes of the individual. It was necessary that the content used was suited to the level of understanding of the user. There were instances where data was ambiguous. For instance for one section labelled News, one participant thought that this meant PrimeTime or RTE news. It needed to be more specific that this was Advocacy News that we were discussing. The group seemed very interested in learning new IT skills and were all keen to be involved in the making of the video and audio files.

Simplicity is best and where possible tasks should not place undue cognitive load. A key component of making this site accessible was keeping the language simple and understood by the participants. Limited text appears on the interface but where necessary short sentences were used. The text did not spill onto two lines. The use of commas, exclamations marks and abbreviations were avoided. The font type used was clearly readable and the font size was not below sixteen. On each page the user had the option to look for help or contact someone in a chosen format. The idea with the captivate files was when the user selected their chosen module the captivate would



start automatically for them. The user could then move through the lesson at their own pace – pausing, stopping or playing the lesson again from the beginning. It was desired that the process for each action was repetitive to reinforce the learning outcome for the user. It was agreed to display a maximum of six topic images on the screen at any one time. It was felt that any more than that would lose people.

The additional data accessibility constraints for people with ID were considered;

- ICT skills
- AT requirements
- Website accessibility
- Mapping (language set)
- Filtering
- Access control
- Cognitive capability

It is known that Internet users with ID are easily distracted and become unfocused. If the required target is not visually obvious and easily identifiable they will have difficulty maintaining attention on the main task (Li\_Tsang & Wong, 2009).

The UD principals that mostly impact this target group, that is Flexibility in use, Simple and Intuitive Use and Perceptible Information were borne in mind. The WCAG 2.0 guidelines were referenced, particularly those that have an impact on cognitive impairment. These include the timeout feature being removed unless the user can control it, ability to control audio, clear structure and logical sequence with headings and consistent navigation to avoid confusion, and finally good contrasting colours for legibility.

### ***5.5 Tool Selection***

The software package Moodle was chosen. Moodle is the acronym for 'Modular Object-Oriented Dynamic Learning Environment'. It is an open source Virtual Learning Environment (VLE) and Learner Management System (LMS) and has extensive functionality. Video and audio files were created via an iPhone. Big Blue

Button was chosen to test the audio and video conferencing aspect. It is an open source component that is compatible with Moodle. A trial version of Adobe Captivate and Adobe Photoshop was downloaded. The former to create captivates and the later was used to edit the PhotoSymbols images to attach the text heading to the relevant image.

#### 5.5.1 Why PhotoSymbols?

The icon set chosen for the prototype was PhotoSymbols 4. This package offers over four thousand images to choose from that have been specially developed for use in an ID community and feature many people from the ID community in the photos. BoardMaker Software Family from Mayer-Johnson is another product that is widely used in the Irish ID field and displays cartoon like images that are often used to help people with ID communicate. BoardMaker helps a user create symbols by offering a tool whereby when the user types in a word it offers a choice of symbols to choose from. However many individuals with ID find these cartoons babyish and prefer images that reflect real people and situations where possible. For that reason PhotoSymbols 4 was chosen for this prototype.

#### 5.5.2 Why Moodle?

Before deciding on Moodle, other open source LMS and VLE systems were identified. These were then reviewed under the headings cost, wide access, customisation, implementation, online support and documentation and finally quick response to extra requests or facilities. From this analysis Moodle was chosen as the most suitable option.

Some Moodle accessibility features include being prompted to add a description to an image if you leave that area blank on upload. A warning is given that some users may find it difficult. This can be viewed in Figure 5.2. During installation, if the screen reader setting is set to YES then a more accessible interface is displayed. This can be viewed in Figure 5.3

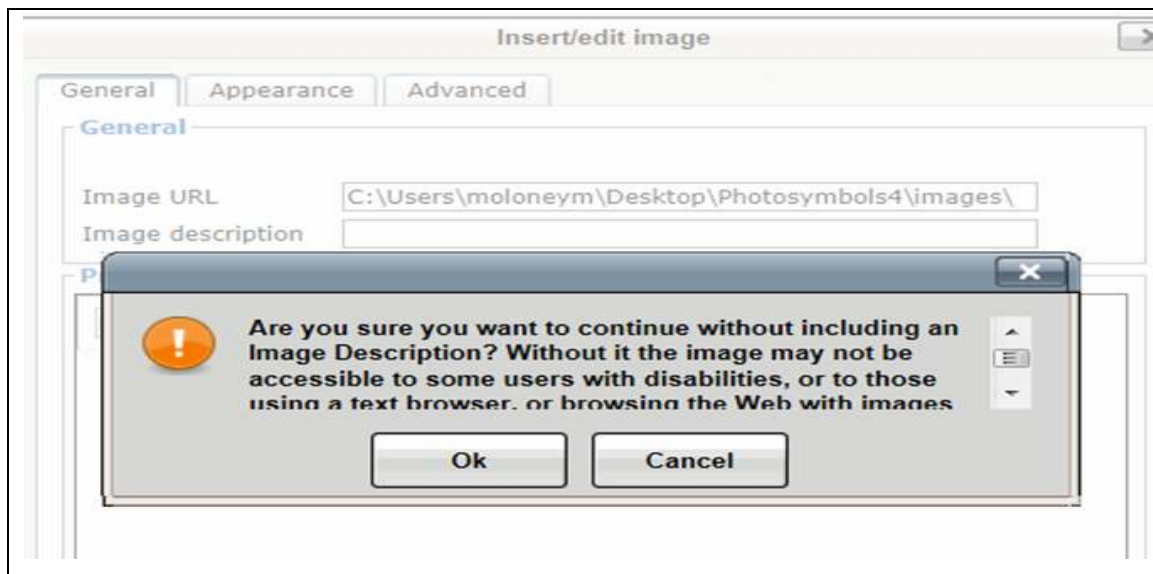


Figure 5.2 Moodle Prompt when trying to insert an image without a description



Figure 5.3 Moodle Prompt re Screen Reader during Installation

### 5.6 Online Learning Resource and ID

It is hard to depict what a typical learner using ICT is. The individual may have visual, physical or verbal disabilities (dysathria). For individuals with ID who can exhibit functional illiteracy and low levels of numerical literacy, this learner depends greatly on pictographic representations to interpret context. (Harrison et al, 2008) mentions the following issues impacted on the degree of success that individuals with ID experienced when trying to use Online Learning Resources;

- Accessibility: Physical and Intellectual disabilities resulted in impaired usage of the technology with conventional peripheral equipment for example mouse,

keyboard etc. The use of touch screens or switches are required in certain cases to allow the student to operate the computer.

- Adequacy: Conventional pedagogic software programmes do not meet the student's access requirements.
- Age- Appropriateness: a large amount of the available programmes were found not be age-appropriate for these students.

### ***5.7 Environment Content Selection***

The advocacy lead provided detailed information regarding the learning model for the domain. During discussion it evolved that while some individuals might already be aware of the advocacy information, for some it was a new topic. Therefore the content had to be presented in a format that individuals would be able to understand without any prior knowledge of the topic. Six key topics were chosen from the front page of the interface, which are extrapolated and expanded in Figure 5.4 below.

The main thing to keep in mind for designing an interface for individuals with ID is that it is kept clear and concise. The simpler the better is the rule of thumb in this instance.

Small studies have been carried out re teaching ICT skills to individuals with ID but at present there is no software that specifically deals with training or developing ICT skills to individuals with ID (Li\_Tsang, 2004).

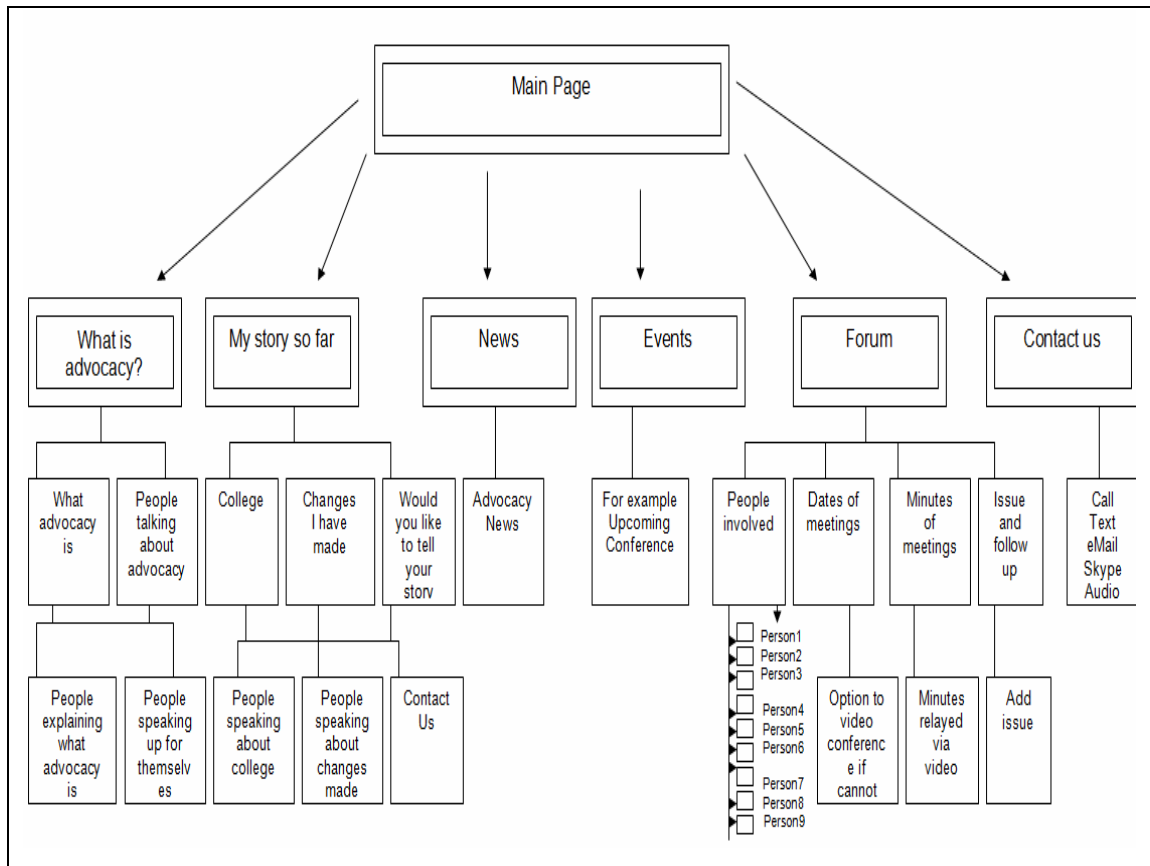


Figure 5.4 Site Map

### 5.8 Environment Content Development

It is suggested that the method and strategy adopted during content development should be guided by pedagogical expertise (Jin Li 2010). Accessibility considerations may impose guidelines on the presentation style chosen. In this case, restrictions were imposed on the handling of text. This decision was based on the perceived literacy levels of the target group. Offering data in different modalities presented the user with the choice of visual, audio or easy read content.

Initially the concept was to have the participants themselves taking part in the video clips. This was hindered due to the delay in receiving ethical approval. Video files were used to convey messages and stories to the participants. There was a clear message behind every video clip that was communicated. Each clip length did not exceed two minutes, to ensure the clip size was not huge and thus did not take long to open when selected. The clips were recorded in quiet environments to ensure there was no background noise. The videos were captured on an iPhone.

Content data was provided by the advocacy lead and a support worker for the purpose of converting into audio files. The clips were kept short to retain the participants interest. The audio data was recorded on an iPhone. All images used in the content were sourced from PhotoSymbols 4. As there can be many different images to indicate one item, the participants from Group A, were heavily involved in the deciding choice of image. On discussion with the expert user group and after showing them image samples, it was determined that the text should be placed at the top of each image as opposed to underneath the image. Adobe Photoshop was used for this process.

Any documentation that was on hand was offered in easy read format. Therefore simple language was used in conjunction with pictures an example of which can be viewed in Figure 5. 5

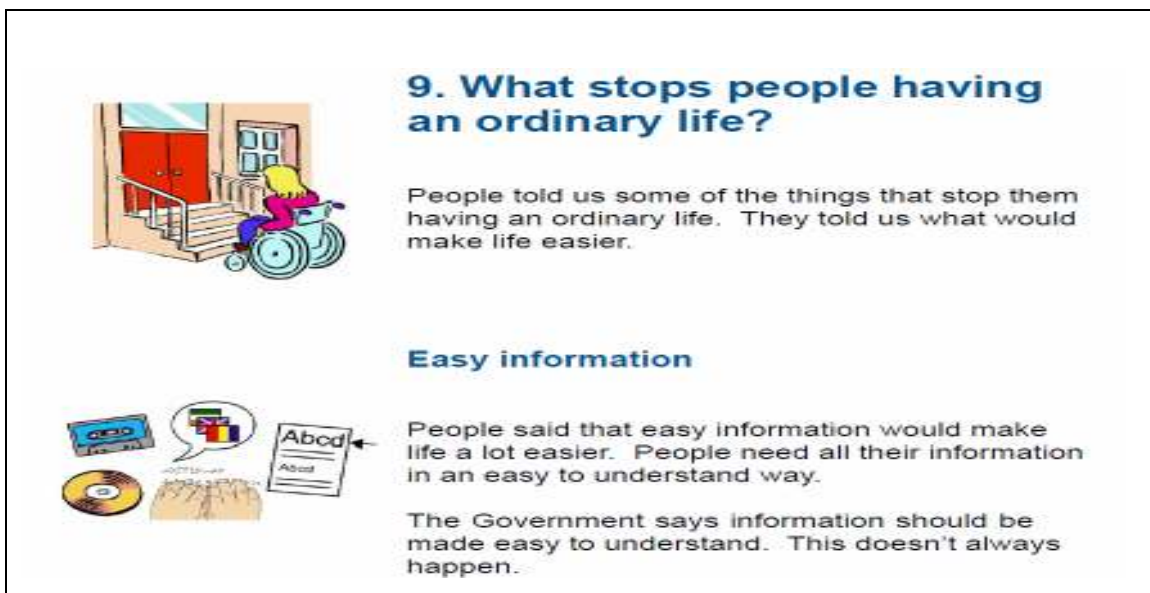


Figure 5.5 (Source: A life like any other? Human Rights and Adults with Learning Disabilities)

## **5.9 Design Evaluation**

### **5.9.1 Paper Prototype**

Following on from the agreed proposed design, paper prototypes were developed for the purpose of discussion with members of the intended target group. A sample of which is viewable in Figure 5.6. The pages were shown one at a time in a logical order

as if were stepping through the system. A facilitator was on hand to help explain terms when confusion arose. A lot of discussion took place regarding the images used, to determine if they accurately depicted the category. Any images that the participants were unsure of, alternative images were offered up and alternatives selected. The title of the image was placed above and below some images to see where the preference was for the title to be placed. They all preferred the writing on top. Any text used was discussed to see if it was understandable or if alternatives would be more suitable. This took the form of qualitative observation and the participants feedback was recorded to ensure the relevant modifications were addressed and reflected.

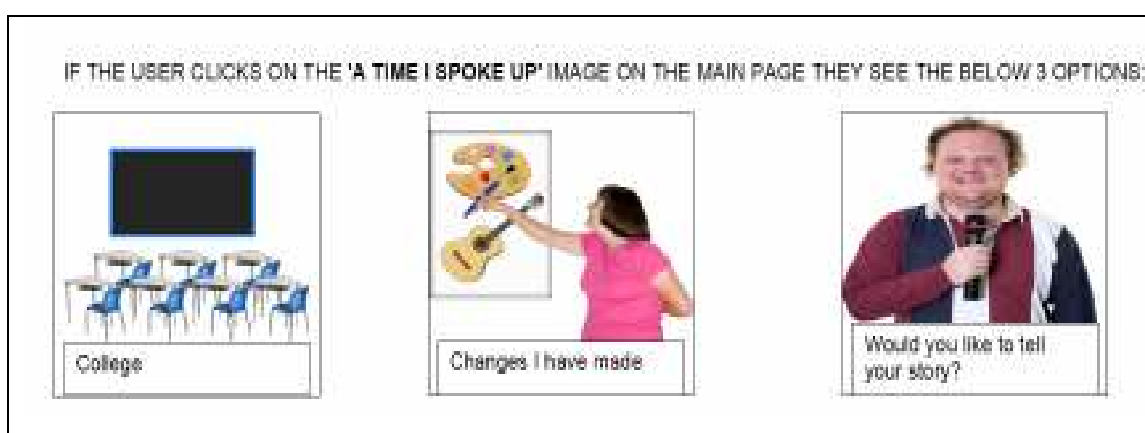


Figure 5.6 A paper prototype sample presented for evaluation.

### 5.9.2 Content Evaluation

Sample videos, audio clips and easy read documents were provided to form the content. The participants evaluated their preferred modality. One key thing that was evident is that the participants themselves would like to feature in the content. They wanted to partake in the audio clips, and nominated within their groups, participants who had good voices. They would all like to partake in the video section. Some of the participants like drama and to act things out whereas one participant mentioned that even though she would like to be involved in the video she did not know if she would like to see herself on screen. The participants were excited at the prospect of being so involved, in that it would be them on screen telling their story as opposed to someone else.

### 5.9.3 Interface Evaluation

Moodle has extensive inbuilt functionality. For instance options such as discussion forums, blogs, online chat, peer review, uploading and sharing of documents as well as the creation of online content by users is all available. For the purpose of this prototype much of the functionality was turned off to provide a simple interface and to hide the complexity for the user. This was to ensure where possible the participant focused their energies on understanding the content rather than using up all their energy trying to figure out how to use it.

The front page did not prompt for a log in. Guest access was used throughout so that the participant could access what they desired without logging in. This is not advisable from a security aspect, but was deemed appropriate for the prototype, when the time constraints were evaluated. The interface was viewed on Firefox and IE - albeit the organisation uses IE so that was the main focus for consistency.



Figure 5.7 Interface front page used to demo writing above and below images.



The type of user interface required can vary widely. However, through employing the expert group to evaluate the interface, modifications if deemed appropriate were made quickly to suit the users. A sample of the change requests made by the expert group to the user interface were:

- Change the picture of the lady used for the Contact section. Participant Five thought she looked too old.
- Replace the existing image for audio with a headphone image (Participant Fourteen). Samples of these changes can be viewed in Figures 5.8 and 5.9.
- Move the text at the bottom of an image to the top (Most participants).
- Make the writing bigger (Participant Twelve).
- For the My Story section have a picture of a man and a woman, not just a woman. The participant was male and would like to see a male up there (Participant 13).
- Change the heading News to Advocacy News as the term was confusing. Participant Fifteen expected to see PrimeTime and the RTE News when they clicked on it. Participant Seventeen expected to see something on Shootings in here. For that participant that is what they associated with the News.
- When playing the video or audio they would like to see the picture of the person who they will see or hear (Most participants).
- When given two options re the outcome of clicking on a video; (1) a video opening up within an allocated section of a page which meant the user did not have to leave the page or (2) a video opening up on a separate full screen page. Most participants in Group A (N=6) preferred the option of the full screen video, even if it brought them to a separate page. When asked they responded that they did not mind the additional step of closing the page.



Figure 5. 8 Initial images and layout for read, listen and watch



Figure 5.9 Revised images for listen, watch and read.

A point of interest was that the participants did not suggest at any stage to change any of the PhotoSymbols images for that of BoardMaker, which is a symbol set that they would be more familiar with.

The interface should not place undue cognitive load on the individual, and should provide benefit and augment the individuals understanding of the information presented. Further analysis of user interfaces with the expert group would perhaps allow the interface to be more tailored to the users abilities.

#### 5.9.4 Web Accessibility Considerations

From the outset it was evident that the language used had to be simple and concise. It was also evident that the site would be symbol heavy to aid communication.

Guideline	Method for Checking Compliance
A text equivalent should be provided for all non text items	Moodle prompts the user to provide a description of the image on insertion. However, manually checked that all images and non text items have a text equivalent..
Use HTML markup appropriately in the document structure	Manually check HTML, the header tags and page structure etcetera to ensure all is used correctly.
Use style sheets to control page layout and formatting styles	Picked a theme within Moodle- HTML is used for document structure and the THEME, that is the CSS chosen, is used for formatting
Avoid deprecated HTML features	Used a HTML validator, WAVE, to ensure page passes against the DTD that is claims to use.
Use clear and simple language	Manually examine the page contents

Table 5.1 Web Accessibility Considerations

### ***5.10 Accessible Documentation***

Accessible documentation was created to assist participants during the process. An expression of interest form was offered to those who might be interested in taking part in the study. An information sheet explaining what was going to happen, how long it would take and why it was happening was created. PhotoSymbols (an image database) and simple language were used throughout all documentation. Once the author had created the accessible information the advocacy lead and a support worker who works closely with the information transformer group, and thus is in tune to accessible information, evaluated it. Some changes were required, mainly to the phrasing of things. It was perceived the language used in certain instances was difficult and needed to be more basic.

### ***5.11 Moving Forward***

The target group, albeit engaged in the design and evaluation of the design throughout, should ideally have been involved in the development of the audio and visual media modalities presented. It would be preferable to use their voices to describe what is being played out in captive, video or audio clips. Similarly as the prototype is about individuals with ID, it should be individuals with ID where possible that we see talking about advocacy when a video clip is played. However, this was not possible for this prototype due to the delay in receiving ethical approval from the organisation. Creating audio files and video clips with individuals with ID, is not a quick process. Like anyone, individuals need to be advised beforehand so that they look their best on the day. Again like anyone on the proposed date the individual may not feel up to taking part. The recording (either audio or video) and the process involved may require much iteration.

### ***5.12 Conclusion***

This chapter discusses the design concept and explains the design principles used. The tool selection and the reasoning behind the selection are discussed. The environment content selection and development were outlined. The iteration that the design evaluation evolved through are depicted. The provision of accessible information is noted. Finally it concludes with points about moving the design forward. The following chapter will discuss the implementation of this prototype design.

## 6 IMPLEMENTATION

### *6.1 Introduction*

This chapter sets the scene and informs the reader of details regarding the service provider and the participants. The materials used during the process are outlined. As there are two sets of participants there are two set of procedures. These are noted here. The chapter ends with a discussion of other items for consideration.

### *6.2 About the Service Provider*

The organisation chosen provides a service to more than sixteen hundred individuals with ID, a breakdown of which can be viewed in Table 6.1. St Michaels House (SMH) has over one hundred and twenty units, providing day, residential and respite services to its users. Furthermore it provides community support for independent living and offers supported employment. It operates as a community based service provider. Over the past few years greater emphasis has been placed on providing computer access for these individuals, in many cases with staff advocating on their behalf. Previously to facilitate access to communication tools such as Skype, individuals and their families, purchased their own equipment, which remained stand-alone and off the network. A policy has now been drafted on Internet access for individuals with ID.

	<b>People with ID</b>
Not Verified	212
Borderline	11
Mild	302
Moderate	793
Severe	256
Profound	50
<b>All levels</b>	<b>1,624</b>

Table 6.1. Organisation Overview of ID Levels

### ***6.3 About the Participants***

All participants involved attend one of the seven training centres in SMH. All participants have mild to moderate levels of ID. Participants were nominated via the advocacy group to take part in the research. These participants consisted of members of the Work Options ACT group as well as members of The Advocacy and Leadership Group. The study involved two groups of participants, fifteen in one group and six in another. Each group performed a set of predefined tasks. One group was supported for each task they performed while the other group were supported in some tasks only. For a participant to partake in the study it was required that the individual possess the ability to express themselves verbally. If a person did not have this ability then this operated as exclusion criteria for the study. Ethical approval for the study was obtained from SMH Research Ethics Committee. All participants involved provided informed consent. The ratio of trainer to participant was kept low to ensure that the learning process was as effective as possible as individuals with ID traditionally possess a short attention span and a minimal ability for following instructions (Li-Tsang 2004).

### ***6.4 Materials***

Five SMH training laptops each with a mouse were used by the participants to evaluate the prototype. The laptops were running IE6 which is outdated and they did not come equipped with cameras. Webcams and additional non SMH laptops were used to test the video conferencing element. As Skype was used to test the video conferencing aspect, Vodafone dongles were used to connect to the Internet as the laptops were not configured to access the Internet on the organisation network. A local install of the Moodle software was installed on each laptop. An iPhone was used to record the participants answers to questions. Accessible documentation was developed for the participants.

### ***6.5 Procedures***

As mentioned previously there were two groups involved in this study. Individual sessions lasted between thirty and sixty minutes. Group A (N=6) undertook Procedure One and Two. Group B (N=15) undertook Procedure Three.

For each group this process occurred before evaluation commenced. After all the participants were seated they were informed why they were here. The advocacy facilitator talked through the information sheet first. Then she talked through the consent document with the participants. The participants ticked if they were happy to be involved in the various aspects of the study. The participants were asked if they had any questions through out and words that were perceived to be difficult such as voluntary were explained ( for example does everyone know what the word voluntary means? ). The participants were then asked if they needed help to write or sign their name so that we could help. The participants were furnished with an on screen demonstration of the prototype which was accompanied with verbal instruction throughout by the experimenter.

#### 6.5.1 Procedure One for Group A

Initially participants were given a demonstration of how the prototype works. At a preliminary stage participants were made familiar with the prototype each getting a chance to practice, interact and ask questions about it. The participants had the option to use the mouse, the mouse pad on the laptop or the keyboard for movement. The test session was comprised of four phases:

- Instruction. The experimenter highlighted the features of the prototype and how it was used.
- Modelling. The correct process was modelled for the participant before trial of specific aspects of the prototype.
- Guided practice. One-on-one instructional sessions were provided initially to ensure that the participant was comfortable using the prototype and to monitor how the participant proceeded.
- Independent practice. The experimenter promoted and encouraged independent employment of the strategies.

The testing procedure was conducted in the participants training centre, in a room that was free of distraction. The participants were asked to follow the steps below to complete Procedure One:

- Open the advocacy shortcut on the desktop
- Go to the what is advocacy section
- Select the video section
- Discuss the photo that is seen
- Play the video
- Close video
- Close web browser

Table 6.2 below demonstrates a breakdown of the one of the tasks required for completion of Procedure One.

---

<b>Task</b>	<b>Sub-tasks</b>	<b>Content</b>
Open Shortcut	1	Orient to target area
	2	Move and locate cursor onto target area
	3	Single click target area with left mouse button

---

Table 6.2 Task Breakdown of Open Shortcut.

### 6.5.2 Procedure Two for Group A

The participants in Group A performed a second task. They separated into smaller groups and tested using Skype to call each other. Each member was asked to perform the following in Procedure Two:

- Call a nominated person using Video Call
- The small screen on the bottom right hand side of the screen indicates what the person you have called can see. Move around until you are happy that you can be seen.
- Talk and listen.
- Close call.
- Accept a call from a nominated person.
- Close call.



- Call a nominated person using Call Phone.
- When you do this you cannot see the person. Look at the small screen at the bottom right hand side of the screen and you will see that it is greyed out.
- If the person calling you has used Video Call to answer they can still see you.
- Talk and listen.
- Allow the other caller to close the call.

### 6.5.3 Procedure Three for Group B

Group B consisted of fifteen randomly participants, allocated through convenience sampling. Group B carried out Procedure Three. The task was presented to the participant on a laptop computer. A max of five participants could partake at any time.

One by one the participants were asked to partake. The rest of the group watched while this happened. Each participant had a opportunity to go through the system one on one and become familiar with it. The experimenter asked the participants if had they used a mouse before and monitored how they used the mouse and if they could point at exactly what was needed. The advocacy prototype was open on screen when the participants started so they did not have to complete any steps to access it. The participants were asked to follow the steps below to complete Procedure Three:

- Go to the Forums section
- Go to the Minutes of Meeting section
- Select how you want to view the minutes - look, listen or read
- Open the video, audio or easy read document

Verbal and physical prompts were given where the participant was having difficulty completing a task. The task consisted of a series of choices between the type of modality that the information is presented in.

## ***6.6 Other Factors for Consideration***

The implementation of the experiment is only one aspect of this research. These other factors will also need to be taken into account:

- Usage policy: What will it be used for? What is the Intranet usage policy? Who controls access?
- User protocol: Who will use it? How will it be used – for instance access control levels?
- The legal viewpoint: Ethics, data protection, legislation and capacity need to be considered.
- Security – How will it be patrolled? What security practices are being used in similar agencies? Where will it be hosted?
- Monitoring – How much information can they add to it? Who determines what can and cannot be added?

View Figure 6.1 to see a pictorial view of these other considerations that factor into the implementation of the prototype.

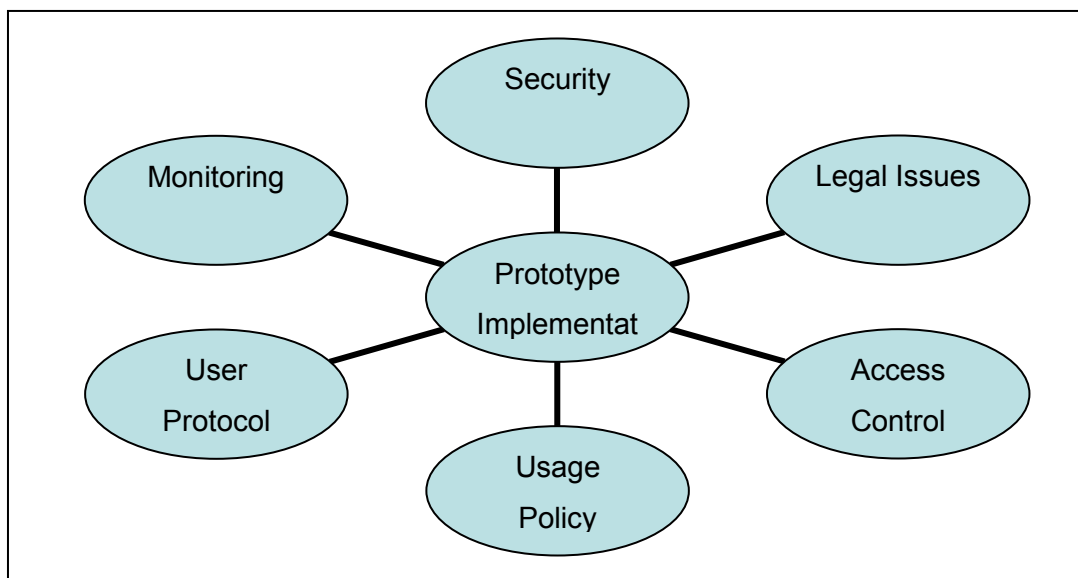


Figure 6.1 Other Implementation Consideration Factors

### **6.7 Conclusion**

This chapter discusses the service provider and the participants selected. The materials used during the implementation are depicted. As there are two participant groups carrying out different tasks two sets of procedures are outlined. The chapter ends discussing other factors that need to be considered during implementation. The

following chapter introduces the evaluation section and presents the results following on from the implementation.

## 7 EVALUATION

### 7.1 Introduction

This chapter outlines the demographic profile of the participants who took part in the study. The participants formed two distinct groups and carried out different procedures in the study. Due to the nature of the user group ethical considerations need to be applied during the consent process. The environment settings and assessment protocol are outlined. The methods of data collection are depicted and the results from the overall process are demonstrated and analysed.

### 7.2 Participant Demographics

In total twenty one participants were evaluated, of which thirteen were female and eight were male. The participants selected all had a mild or moderate level of ID. A further breakdown of this can be viewed in Figure 7.1 All participants were able to verbally communicate and express their opinions. The participants formed two distinct groups; Group A (N=6) and Group B (N=15). Seven of the overall group had mild ID whereas the remaining fourteen had moderate ID. The age range was from twenty three to forty one, with the mean age of the overall two groups being 32.69 years. Further analysis of this can be viewed in Table 7.1 and Figure 7.2

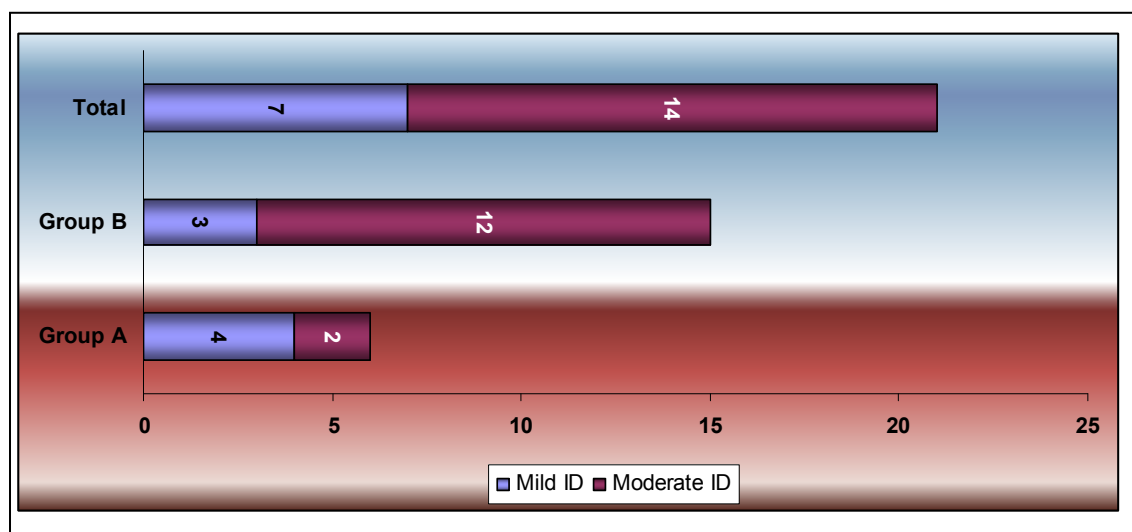


Figure 7.1 Number of participants with level of ID per group and overall

### 7.2.1 Group A

Group A consisted of six participants who were pre selected as they are considered information transformers and work as part of an accessible communication team. This group meet on a weekly basis at a set time for two hours. More time was allocated to this group with four evaluations taking place. There were three (50%) female and three male (50%) in Group A and the mean age is 38.13 years. The time commitment from these participants was over five hours spread over four separate meetings.

Female Groups	Mean Age (SD)	Male Groups	Mean Age (SD)
Females in Group A	38.58 (2.86)	Males in Group A	37.68 (5.19)
Females in Group B	31.01 (5.90)	Males in Group B	29.63 (3.74)

Table 7. 1 The mean age and SD by gender and group

### 7.2.2 Group B

Group B consisted of fifteen participants who were selected randomly through convenience sampling. Even though the participants selected in Group B were random, the majority appeared to have an interest in technology. All had used a computer before, albeit the level of expertise varied widely within the group. The group had no vision or hearing impairments.

At the training location the potential participants were informed of the prototype and anyone interested in taking part should advise staff. The names of those interested were then entered on a whiteboard and split into max groups of five. This also helped the participants as some were anxious to join in, but by looking at the board they could see when their time was scheduled for. Two participants were excluded from Group B as one was non verbal and another participant withdrew. For participants in Group B ten of them were female and five of them were male. The mean age was 30.51 years. The time commitment for these participants was about one hour fifteen minutes.

The average age of the female participants was lower than the male participants at 29.23, whereas the average age of the males was 31.87. Four of the twenty one

participants reside in a residential house with the remainder living at home. There was no sizeable disparity between the two groups with relation to gender composition, age and computer usage. Their demographic characteristics are summarised in Table 7.2.

Study	Number	Male	Female	Mean Age	Age Range (Maximum - Minimum)
Group A	6	3 (50%)	10 (66.6%)	38.13	23y 11m - 40y 4m
Group B	15	3 (50%)	5 (33.3%)	30.51	30y 8m - 41y 6m

Table 7.2 Summary of gender and age composition of participant groups

Written informed consent was acquired from all participants. The participants selected did not have visual or hearing impairments. It was not a requirement for any of them to need an assistive technology to access the computer. English was the native language of all participants. All participants had used a computer prior to this evaluation.

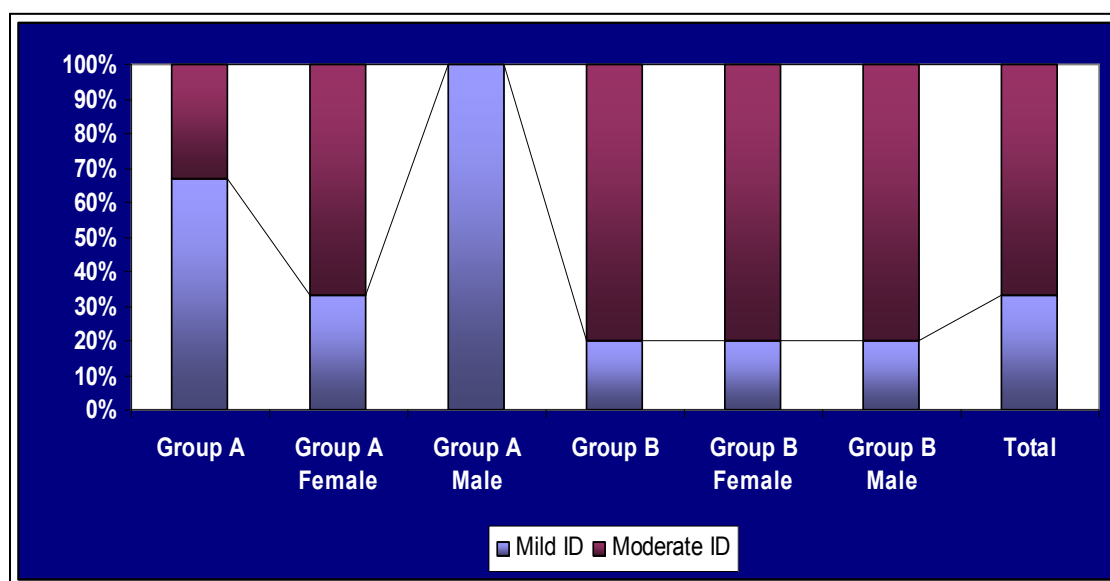


Figure 7.2 The percentage level of ID per group, by gender and overall

### 7.3 Ethical Considerations

SMH Research Ethics Committee approved the study. The ethical considerations are significant as the participants have cognitive impairments which impact how they comprehend information. At the start of the evaluation session the participants were handed an expression of interest form to sign if they were interested in partaking in

the study. This was communicated orally as well as through the provision of accessible information. Following that an information sheet was dispersed by the advocacy lead so that there was no undue influence on the authors side to agree to participate. It was highlighted to the participants that involvement was voluntary, so that the participant only took part if they if they would like to use the technology. When asked did they know what voluntary meant two participants in separate evaluation groups said 'Yes, that it was working for free'. This highlighted the requirement to have verbal input to facilitate understanding of the information.

The accessible information documentation was designed in easy to read format, with simple text and pictures. This documentation was accompanied with verbal information to ensure the participants understood the data presented to them. This outlined the purpose of the study and informed the participants of what it is expected that they do, all within an estimated timeframe. If participants decided to take part they were informed that how they interact with the technology will be recorded. They were advised of the interviews that take place afterwards and that the interviews would be taped with the participants agreement. Additional information re this information sheet can be viewed in Appendix A, B and C. Participants were encouraged to ask questions to ensure they understood what the study is for and what they will be expected to do. If they decided to go ahead then they would need to sign a consent form. Informed consent was achieved in this manner.

The participant will be informed orally as well as using accessible information that they can choose at any stage to no longer be involved. This means the participant can withdraw without reason at the evaluation stage even after having given consent.

#### ***7.4 Environment Settings***

The evaluations occurred in the training centres of the participants involved. The rooms chosen in each case were self contained and free from disruption. The size of the training group was contained where possible to a maximum of five participants. This group size was less depending on the level of intellectual functioning of the participants.

## ***7.5 Assessment Protocol***

The following assessment protocol was used:

- The laptops will be set up before the participants enter the room. Time is limited with the user group - forty five minute session at any one sitting is recommended. The participants can use the mouse or mouse pad.
- Thank the participants for deciding to partake in the study.
- The author explains briefly what they are going to do and talks to them about the Advocacy prototype. This tool is intended to provide information in different modalities for easy comprehension.
- Participants will look at the prototype to find certain information, and verbally give short responses. The author is interested in how the participant manages the picture to picture navigational style and if they can use it to find the information they are looking for. There is no wrong path for the participant. They should choose the path that makes sense to them to find what they are looking for. If the participants find it hard to locate the information that they are looking for, it means the author needs to change some aspects (for example an image does not clearly tell the participant what the topic is) to make it better.
- After the participants have performed the tasks they will be asked a few short questions about how they felt about the technology and using it. The participants will be advised that this will be recorded. This information is very important.
- The participants will be observed while using the prototype and will be encouraged to ask questions and express how they feel whilst using it.
- While the participants are executing their tasks the author will be taking observational notes and writing down any comments made.
- The tasks are presented to the participants and they are asked to begin.
- The participants are informed they can stop at any time.
- On completion of the session the participants are thanked for their time and for helping the author.



## **7.6 Data Collection**

Demographic data was collected from the participants of both studies regarding level of ID, participant ages, and participant gender. Naturalistic participant observation was undertaken on how the participants used and interacted with the prototype. The number of physical and verbal prompts required whilst using the mouse and navigating to a pre-selected end point on the system were observed and recorded manually. Any comments made whilst using the prototype were recorded.

Before asking any questions the participants were reminded that the answers to the questions will be recorded via audio to ensure the author does not miss any of their comments from the group discussion. The participants were informed about the author recording them at the consent stage, which had been explained before the participants started using the prototype. Therefore this operated as a reminder. In addition the group were asked three open ended questions at the end of the session, after having used the technology and in the same location.

The participants were asked the following scaled questions:

- (1) rate their preferred modality (read, listen , hear)
- (2) rate their computer usage (once a week, once a month, once a day)
- (3) could there friends or work colleagues use it . (yes, yes with help, no)

The author asked the following open questions and was facilitated by the advocacy lead;

- What they liked?
- What they did not like?
- Was it too easy?
- If they are looking for information how do they find it at present ?
- Do they log onto anything where it is required that they use a username and password at the moment? Can they remember the details?
- Have they seen the SMH newsletter and do they like it?
- If the newsletter information was presented like this would it be easier to understand?
- What makes it easy for you to understand something?

The questions were in this format to encourage discussion. This will help determine which aspects they preferred and found easier to use. The responses were recorded digitally with the participants agreement. Should the participant prefer not to have the responses taped their answers can be written down.

In evaluating the prototype for individuals with ID, observational data was noted, that is verbal and physical prompts were recorded during the study. The participants had a tendency to answer succinct yes or no responses regardless of the type of question. More dependable answers were obtained when the questions were semi-structured, and were logically ordered to ascertain the individuals experience with the prototype.

At the end of the process the participants were invited to ask any questions they may have and to add any additional comments they may have re using the technology. During the experiment, author contribution were restricted to repeating instructions and providing helpful feedback. The author demonstrated how to carry out specific tasks if the participant was not capable of completing it.

### ***7.7 Data Analysis Methods***

Participants were evaluated on how they carried out Tasks A, B and C. When the data collection stage was complete the quantitative data was analysed using Excel. If a participant requested assistance or needed help to correct an error during task completion, verbal or physical prompts were recorded. Data collection sheets were designed to assist the author record the observations. The open ended questions at the end of each sitting were analysed using content analysis. The procedure recommended by (Malterud, 2009) was followed. With this the first step was to transcribe the feedback received verbatim. In the next stage the notes were read though and short notes were taken of the key points. Subsequently relevant meaningful elements were established and coded. Finally the participants own words were used to express their participant view of the experience.

Applying formal usability testing to a user group comprising of people with ID is somewhat rare in the research. Two such examples were found. (Harrysson et al, 2004) carried out a study in which they monitored how seven individuals with ID

navigated between different web pages using a standard browser. The results demonstrated that the group could navigate proficiently, they encountered no issues with the back and forward buttons and were able to distinguish hyperlinks. However, those instances that called for text input, for instance entering in a URL or inputting search criterion, proved to be trying for the users. Project @pple also applied formal usability testing to an ID user group.

## 7.8 Results

### 7.8.1 Group A Results

Group A had the option of using a mouse or the mouse pad during their study time. All six chose to use the mouse pad. Three participants had no problem using a mouse pad and were able to move to the predetermined location with ease. Two participants needed verbal prompts to progress. Participant Sixteen kept indiscriminately hitting the mouse pad and was getting frustrated as it was not doing what they wanted. The participant found the mouse pad harder to use than what they would use normally.

Three participants said they used a computer more than three times a week. Two participants used a computer on a monthly basis and the remaining one used a computer on a weekly basis. This is demonstrated in Figure 7.3. Participant seventeen stated they had used a computer on a training course but had not really used one much since.

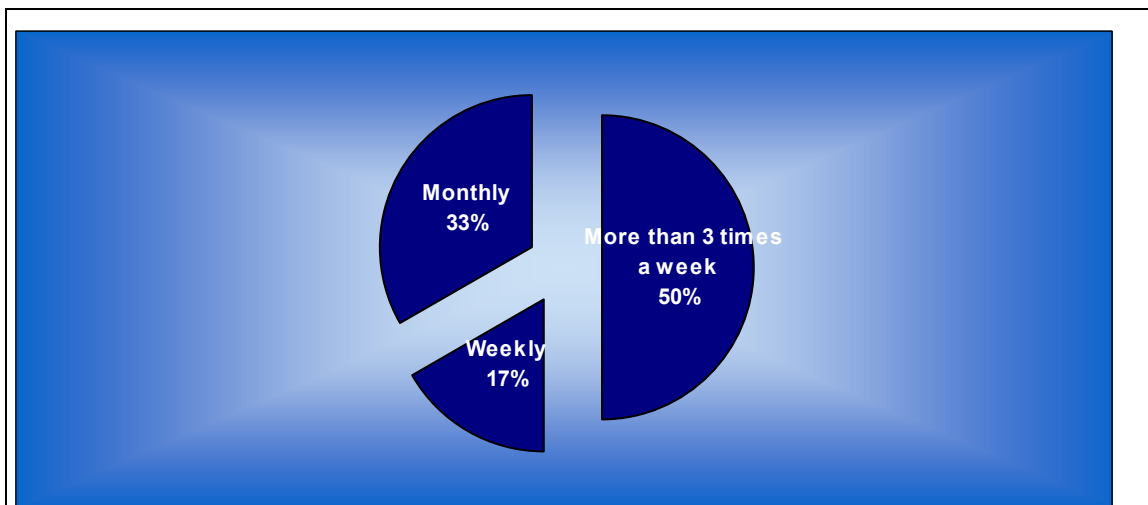


Figure 7.3 Computer Usage by Group A

When completing Procedure A three participants stepped through all the steps and were able to follow the instructions without requesting further verbal or physical prompts. The remaining three experienced difficulties in the following areas:

- Opening the shortcut - (one participant)
- Not sure where Advocacy was on the screen (one participant)
- Indiscriminately clicking the mouse pad when they were unsure why nothing was happening (one participant)
- When opening the video, confusion when it appeared and took up the entire screen (one participant).
- Explained how to resize window to a preferred viewing size (one participant)
- Difficulty closing the browser as found it hard to target the red x. Found it too small (one participant).

Essentially they were well able to perform the steps with minimal and at times no support required.

When completing Procedure B which was using Skype one of the participants was missing from the group on this day so there were only five available to test. Of the group, four participants loved it, whilst one did not care for it. This participant has a speech impediment and therefore this was not her preferred medium. The remaining four made comments such as:

*"My mother uses Skype to call my brother. I must get her to let me use it"* (Participant seventeen)

*"My brother uses it a lot. I will ask me to show me. I really enjoyed that."* (Participant twenty one).

All five preferred the video call to the audio call. They enjoyed being able to see the other person. They were very excited by the technology and found it easy to use. The only difficulty they had was in closing the call. They did not think that this was very

clear. Participant sixteen expressed this is something they would like to see in SMH so that they could contact people and see what they were up to.

For all the participants they preferred when they could see a picture of the contact that was calling. Some asked why the others were shaded out and did not have a picture. There was much discussion about why people would not add a photo. The participants said it would be easier to know who to call if they saw a photo. View Figure 7.4 for an example of a Skype contact with a picture included.

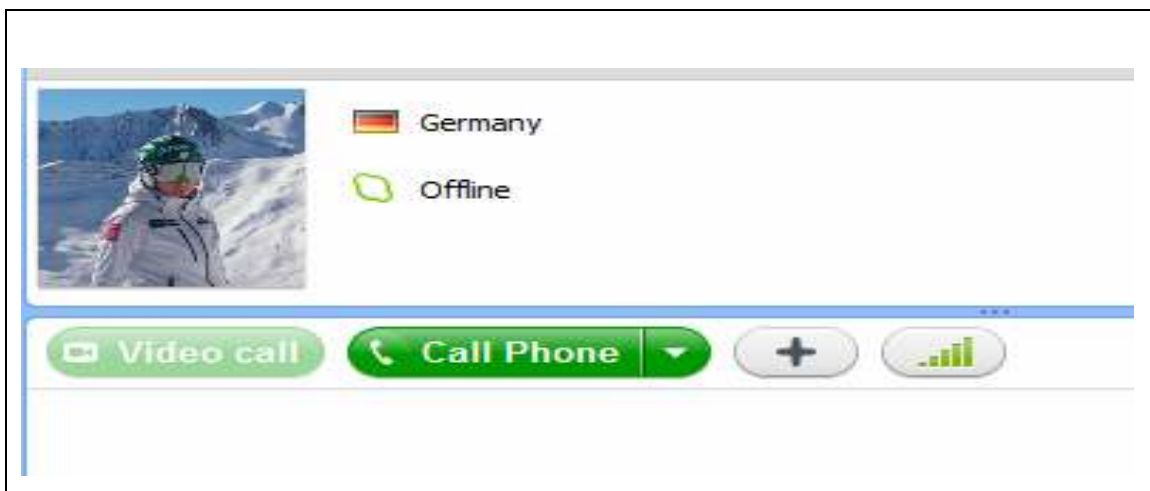


Figure 7.4 Sample of Skype Interface

Group A were also asked about their mobile phone use. Again there were only five participants available on the day. All owned a phone, with one participant having access to the Internet. All participants preferred to receive calls. All participants except participant twenty prefer to call instead of sending a text. Three of the five use it purely for calls and do not use the texting facility. Participant twenty one said that they would like to learn how to text.

### 7.8.2 Group B Results

The experimenter asked the participants if they has used a mouse before and monitored how they used the mouse and if they could point at exactly what was needed. The advocacy prototype was open on screen when the participants started so they did not have to complete any steps to access it. The participants were asked to follow the steps below to complete Procedure Three:

- Go to the Forums section
- Go to the Minutes of Meeting section
- Select how you want to view the minutes - look, listen or read
- Open the video, audio or easy read document

Verbal and physical prompts were given where the participant was having difficulty completing a task. The task consisted of a series of choices between the type of modality that the information was presented in.

Group B had a nearly fifty-fifty split re who had access to a computer. Seven participants had access to a computer either at home or in their service. Eight did not have access. This can be seen in Figure 7.5 What is interesting here though is that all of the participants had used a computer and a mouse before. Even though most would not have regular access they adapted quickly to using a mouse and navigating through the site.

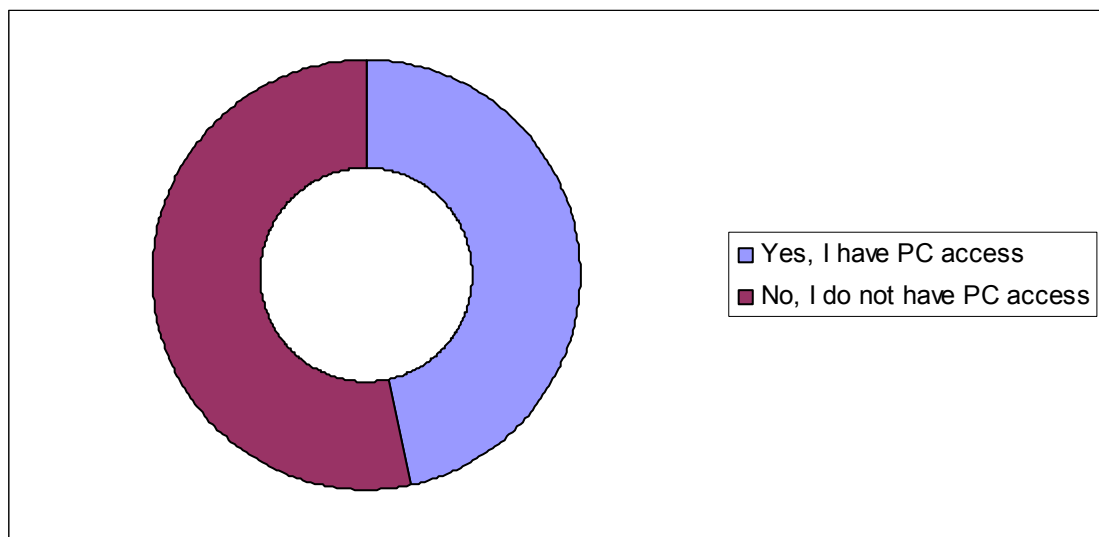


Figure 7.5 Computer access for Group B

For those that did use a computer, the participants used it to:

- Play games - nominated by three participants (bowling online being a favourite)

- Look up information - nominated by two participants (a participant interested in wrestling used it for finding out what was happening)
- Facebook - nominated by two participants
- Internet - nominated by two participants
- Skype - nominated by one participant (contacting family)

When asked what they would like to use a computer for, the responses were:

- Use it like a TV to watch the soaps - one participant
- Play games - one participant
- Listen to music - nominated by two participants (the latest version of NOW was mentioned)
- Typing - one participant
- Record himself playing the guitar - one participant
- Skype - one participant (making contact or keeping in touch with people online).

The participants had varying degrees of proficiency at using a mouse - some had problems pointing to the exact area on the screen, others had problems clicking on the mouse. Nearly four fifths of the group had no problem using it to navigate, point, double click and hit the relevant target. The remaining four had difficulty pointing the mouse at the suggested image and were unsure what double click meant. A visual breakdown of this can be viewed in Figure 7.6

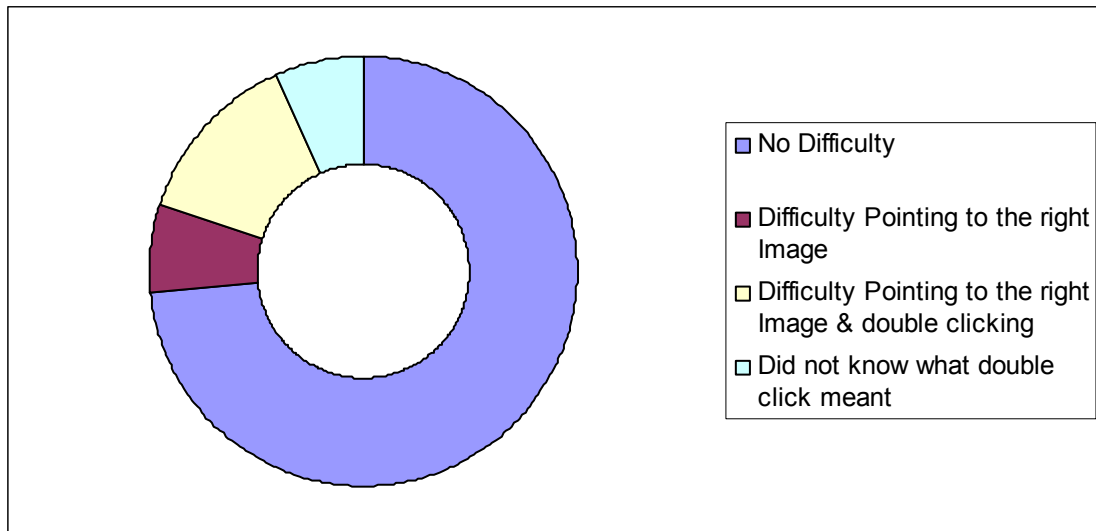


Figure 7.6 Mouse Usage Analysis of Group B

When following the procedure five participants required physical prompts whereas the remaining two thirds could follow the steps just with verbal prompts. The physical prompts required were mostly for the use of the mouse but also in some cases explaining what some of the pictures meant so that the participants would navigate in the way determined by the procedure.

On being asked what could make this system better the responses were:

- Keeping in touch with a named friend who is in SMH, can the system be used to do that?
- Would like the names of the people added to the audio and video
- Large in and out like you can do on the phone
- If they could make their own film

When asked if the system was ok for them to use or was it too easy, four fifths of the group thought it was ok whereas the remaining fifth thought it was too easy. The analysis of this can be viewed in Figure 7.7.



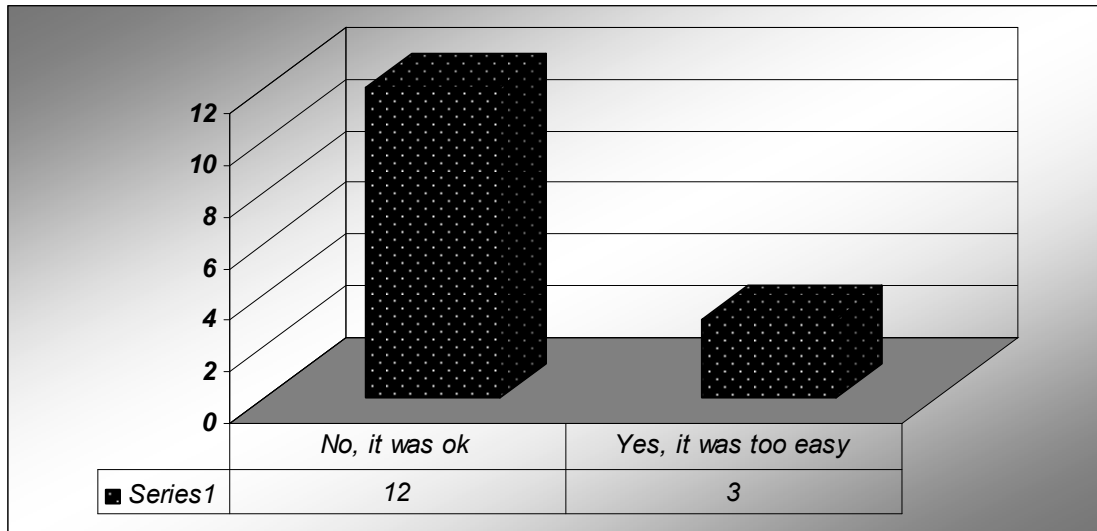


Figure 7.7 Group B analysis if too easy or not

When asked if they thought that their friends or work colleagues would be able to use the system, fourteen said yes, and one said yes but with some supports.

### 7.8.3 Results Applicable to Both Groups

Some analysis was the same for both groups. An example of such is that all participants were individually asked to rank their preferred modality for receiving information. The author had depicted the options as Look (the individuals watched a video clip), Listen (the individuals listened to an audio clip) and Read (the individuals opened an easy read document). It is clear from Figure 7.8 below that there is an overwhelming favouritism for video as their first preference.

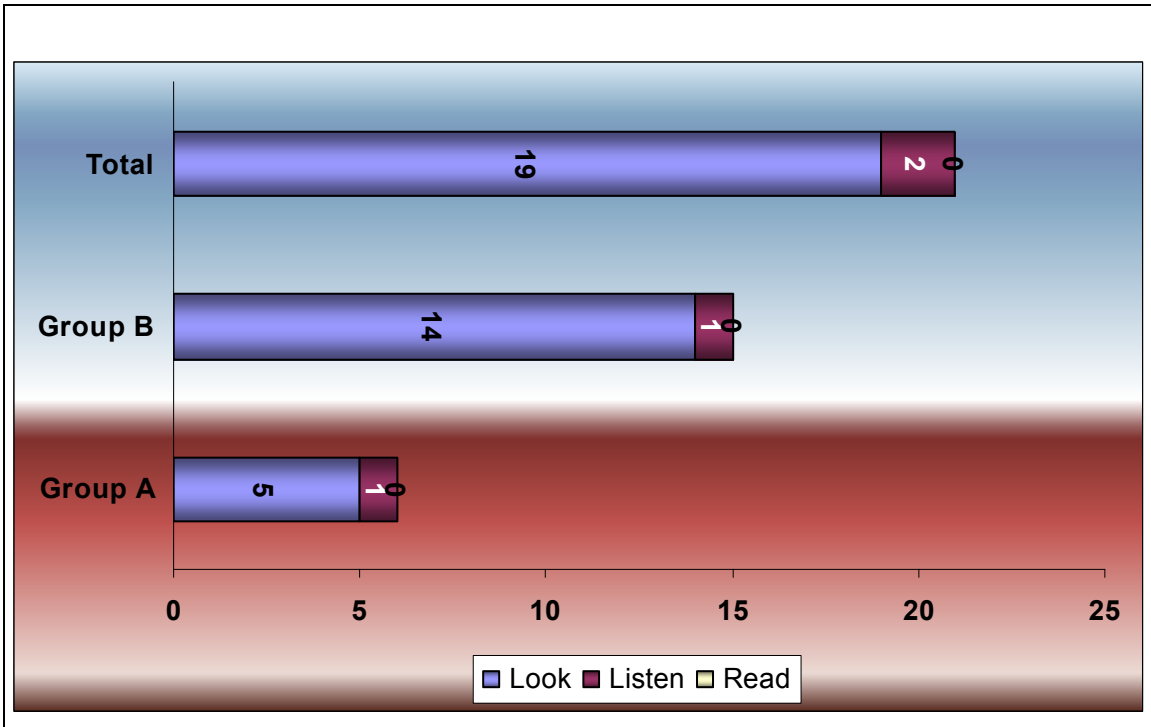


Figure 7.8 Analysis of First Preference Modalities Chosen by Groups and Overall

Their second preference overall is to listen to audio. However, there is a slight difference in the groups here. Group A, slightly prefer reading as their second option. Whereas Group B clearly demonstrated a strong preference for audio as their second modality preference. This can be viewed in Figure 7.9.

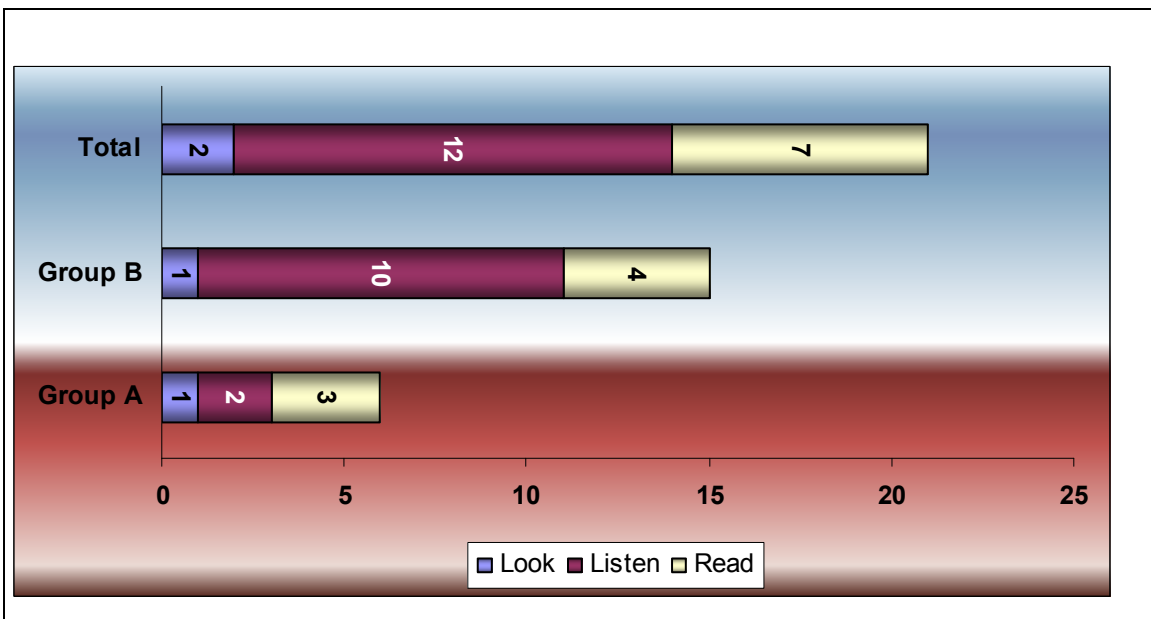


Figure 7.9 Analysis of Second Preference Modalities Chosen by Groups and Overall

Finally the third preference came down to just listening and reading. Group A split this evenly with half choosing reading and the other half choosing listening to audio as their last alternative. Again in Group B, there was a greater difference with nearly two thirds options for reading as their last choice, and the remaining third choosing audio. This can be viewed in Figure 7.10.

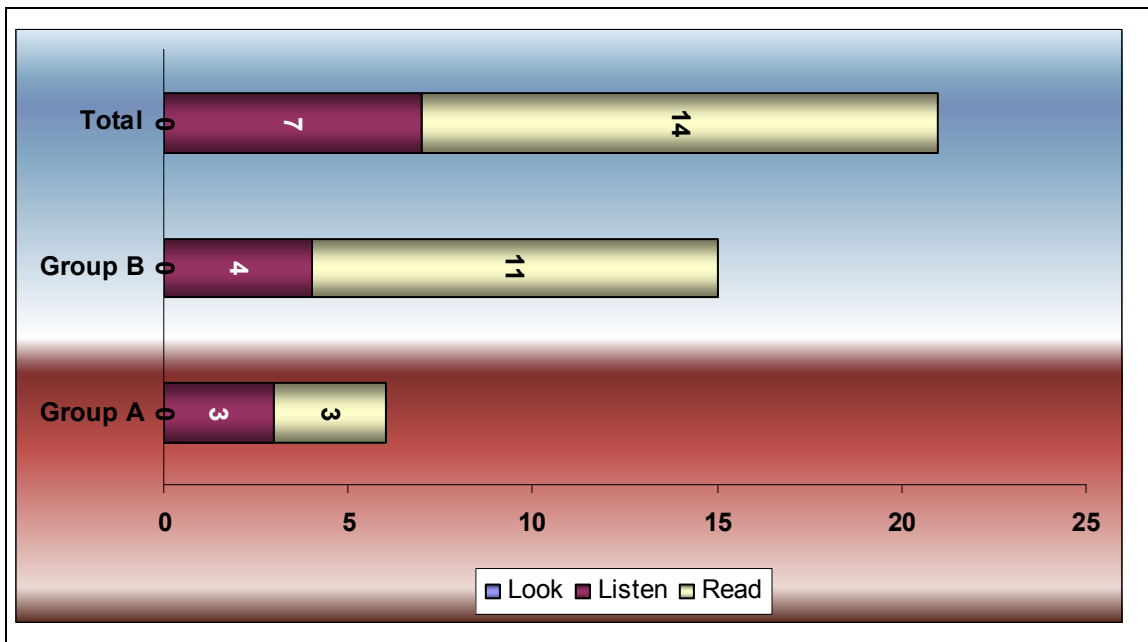


Figure 7. 10 Analysis of Third Preference Modalities Chosen by Groups and Overall

When asked did it matter if it was someone they did not know appearing on the video, all participants said no, it did not matter. When the participants were asked did they want their stories to be told by themselves or have someone else tell them, all participants wanted to tell their own story. One surprising element that came out of this is that all participants wanted to be involved in the video and audio section. This got them all excited at the prospect. The participants in Group A were nominating members amongst themselves saying participant seventeen had a great voice and that participant twenty loved drama and to act out scenes so would be great for video. Only participant fifteen raised a doubt. Although they would love to do the audio they were unsure they would like to hear the sound of their own voice. All participants thought this a preferable way to deliver news about advocacy than via the traditional newsletter format used by the organisation.

## ***7.9 Limitations***

Prior to meeting the participants there was no indication of their ICT experience or even whether the individuals required ATDs to interact with the technology. No pre-test was carried out to assess the ICT skill level of the individual prior to their completion of the tasks. It would have been preferable to do this, but it was not feasible with the time restrictions placed. This is due both to the delay in receiving ethical approval as well as the suggested time frame of constraining each session with the participants to about an hour, with a suggested forty five minute period preferential.

The number of participants involved was small, and included only relatively able participants. SMH has a mix of nationalities attending the service, however the user group selected were all Irish where English was their first language. The literacy levels of the participants were unclear with respect to reading and writing. Digital literacy has been discussed above.

## ***7.10 Conclusion***

This chapter discussed the results that Groups A and B had following the evaluations when they carried out their procedures. The ethical consideration as well as the environment where the evaluations took place are described. The data collection methods are depicted and the analysis and subsequent results are demonstrated. The next chapter concludes proceedings and will document reflections and future work.

## 8 CONCLUSION

### *8.1 Introduction*

This chapter will provide an overview of the research undertaken. The experiment and its limitations will be briefly discussed. Future work and research as well as contributions to knowledge are addressed. Final reflections concludes proceedings.

### *8.2 Research Overview*

ID in all its glory was introduced to the reader. What it means, its prevalence in a national and global context, as well as employment opportunities (or lack there of) were all explored. The terminology surrounding the word itself is interesting. When AAMR decided to remove mental retardation from their name in two thousand and one, it took them six years to think of what to change it to. Indecisive? Yes, no doubt. Nonetheless, ID is labelled many different things in different countries. What is important to note here, is that merely changing the term to learning disability or ID or intellectual impairment, will not tackle the negative mind-set focused on individuals with ID (Wolfensberger, 2002).

Language barriers, accessibility and operational difficulty were considered the major barriers. (Parson et al, 2006) considers time and training to be major constraints with respect to ICT uptake in an ID environment.

The change of service provision from institutional, to community based living to individualised services is depicted. The Panorama example mentioned in the first chapter is worth a view just to highlight that this move is not necessarily without its issues. HIQA and the role it will play are analysed, with particular reference paid to any of its references on accessible information. We are hopefully soon bidding adieu to the Lunacy Act. Again this name, Lunacy, in its day of eighteen hundred and seventy one, perhaps did not hold such a negative stereotype.

The standards that impact on web design from a cognitive impairment standpoint were discussed. The aspect that were relevant to cognitive impairment were incorporated in the design stage of this experiment.

### ***8.3 Experimentation, Evaluation and Limitation***

The experiment tested if the participants could navigate through the prototype via image to image thus reducing the cognitive load for those that have literacy issues. Then when it came to the stage that they would need to access the information they wanted it would be available to them in different modalities (audio, video and easy read) so they could access what was their preferred method of receiving information. The experiment also evaluated if audio chats and video conferencing communication tools are accessible for the participants.

It became clear that many of the participants with a little support could manage the navigation quite easily. Some would need work with developing their mouse skills. This prototype did not require them to use the keyboard so those skills were not assessed. The preferred choice of modality for viewing information was by far the video. Audio and Easy Read documents lagged very far behind. They really enjoyed using Skype and all but one were visibly excited and happy to use the technology. Their preference was to video call instead of audio call as they wanted to see the person. They also wanted peoples pictures on their contact list. They did however find it difficult to close calls.

What really came out of this is that the target group really wanted to be the person up on the screen that we were looking at. They wanted to be involved in making the video and audio clips. This was initially the concept, but due to the delay in receiving ethical approval it was not feasible in the time scale to have the participants provide some of the audio and video content.

A major limitation was the time factor. Again due to ethical approval, the time was pushed out for when the evaluations could actually take place. Then Group A could only meet on a Tuesday at two. If they had another item on their agenda, then either the meeting would be scheduled for the following week or the meeting/evaluation

would take place before or after their agenda item and therefore the time spent with the participants would be reduced.

Another serious limitation is that it was unknown what level of ICT skills the participants had. If a potential participant turned up would they be able to use the laptop as was or would they need AT to use it. Ideally the system should be adapted to different layers and levels of users. To do that, an audit will need to be carried out to evaluate what the individual can do and more importantly wants to do.

The author was trying to establish if a learning and communication tool is a viable resource for individuals with ID. With the right supports, sufficient training, reinforcement and accessible documentation, this can be viable.

#### ***8.4 Contributions to the Body of Knowledge***

The key contributions to the body of knowledge are:

- The design and evaluation of a custom built VLE for people with ID. This was based on image to image navigation and featured limited text and a choice of modality for perceiving information. Video and audio chat were also evaluated within this.
- This system was then implemented. The user group were part of the design team and had a strong input.
- Having individuals with ID as part of a formal usability testing group.
- The development of accessible information using PhotoSymbols, an icon set developed for and featuring individuals with ID.
- Discovering through the evaluations that the participants want to feature in the information themselves. They want to be up on screen and listening to themselves or their friends via audio.
- Individuals with ID can learn to use ICT independently or with some supports.

### ***8.5 Future Work and Research***

Based on the research carried out in this dissertation project and subsequent results from the experiments, the following recommendations on future work and research in the field are proposed:

- NIDD will have to completely overhaul their database in order to be able to deal with the concept of individualised services where all services are costed. At present it operates as a blunt instrument. Also on the NIDD there is no requirement to record the language (verbal functioning) or understanding (level of instruction the individual can follow) level of the individual. The literacy level of the individual is also not captured; this should not only include reading, writing and maths but also digital literacy. The preferred modality for an individual to receive information is not retained anywhere. Furthermore, nor are any ICT skills or ATD requirements captured. If this data was required as part of the national dataset for the NIDD it would ensure that organisations focus a little more attention on carrying out this skill audit. With the provision of this data the style of information an individual prefers to communicate with can be identified.
- ICT SKILL AUDIT: Discovering the skill set of a individual with ID with regard to ICT. Can they log onto the Internet? Can they bookmark a page? Can they target the mouse and close a window? (Aspinall, 2001) identified that there are three main stakeholders in the effective introduction and accessibility to technology. Firstly, there is of course the end user who is using the ICT. Secondly, there is the support worker, who facilitates the usage of this technology. Finally, there are the line managers and fund distributors who make the decision around providing the access to the technology. Therefore the point of the audit was to align the goals of the actual ICT usage and needs to the perceptions of what management levels consider should be made available as effective ICT tools. This in theory allows the organisation to plan for further introduction of innovative technology within the organisation.



- **ICT ACCESS AUDIT:** Within SMH only between five to ten percent of units have access to the Internet. If the only time an individual gets a chance to use ICT is in SMH then this is a huge issue. SMH and other organisations may offer computer training courses to individuals with ID, but if there is no where to practice after the course, those skills will be lost. Reinforcement is required.
- **ICT HARDWARE AND SOFTWARE AUDIT:** If only two computers are allocated to individuals with ID in a training centre that may have forty or fifty individuals how does this operate? So succinctly, verify if a individual has access to a computer at home or within SMH. The next step is them determining if they get an opportunity to use the computer.
- **ATD AUDIT:** At present SMH have no concept of what Assistive Technology Devices (ATD) are being used, who is using them and on what computers? SMH have no idea who requires ATDs or who has abandoned them and for what reasons.
- **IMAGE DATASET FOR ACCESSIBLE INFORMATION:** At present within the ID community, many icon sets are used. Therefore when an individual with ID is presented with accessible information, although for instance it is in easy read format, the document may be using a icon set that they are unfamiliar with. This causes great confusion. No one dataset works for all, so perhaps the option when an individual with ID logs on to a site that they can choose their preferred icon style and the information will be displayed to them in that manner.
- **SELF TRAINING:** This prototype was set up with an advocacy theme. However it could be used more as the learning resource that Moodle is intended to operate as. For instance the prototype could be used for self development and teach individuals how to use a computer, a mouse and how to log onto the Internet and search for information. A review of compatible open source software could add other training elements for this user group

- **PARTICIPANT INVOLVEMENT IN CREATING VIDEO AND AUDIO FILES:** One of the key things that came out of the experiments is how keen the individuals are to be involved in the process itself. Tools such as Audacity, is not only free, but the interface can be scaled back so that individuals with ID could potentially use it themselves and learn the process first hand. It is used to edit audio files. EasyTube is a simplified way of downloading YouTube Clips. Accessible information could step the individuals through creating a video.
- **MOBILE PHONE:** Traditionally individuals with ID do not own bill pay phones. Therefore they need to purchase credit. For many putting the credit onto the phone is difficult. Adding a friend, sending a text and understanding some of the settings can be a chore. As a high percentage of individuals with ID possess a phone, time needs to be allocated in training them on the basics. Accessible information would greatly assist here. (Urturi Breton et al, 2012) claim that nearly seventy four percent of individuals with ID, who are aged between fifteen and sixty four, own or use a mobile phone. Perhaps a more interesting statistic is how many can use them?
- **AUTHENTICATION STYLE:** To create learner profiles, one needs to have a way of identifying the person. The idea of choosing pictures as a password has been introduced for individuals with ID. It would be beneficial to test this and see how it operates.
- **STAFF INVOLVEMENT, AVAILABILITY AND TRAINING:** (Lotan et al, 2011) describe a scenario whereby through using a video capture VR system, caregivers help participants with ID simulate games such as soccer, to encourage exercise. Participation in leisure activities for this category of participant is at the extreme end of being unsupported. The general leisure characteristics tend to be watching television or arts and crafts type work. Despite certain technical problems, the care giving staff were able to help the residents with ID participate and enjoy physically challenging activities. Therefore, this technology widens the choice of available activities with severe levels of ID. Furthermore, implementing VR technology at a local level such as

residential units was found to be feasible and beneficial to caregivers and participants. It would be very interesting to attempt this approach in units to determine how staff and individuals alike felt about the experience.

- SKYPE: Accessible communication could be developed to encourage the use of Skype. The participants were very excited when using this technology and could not believe how clear everyone looked on screen. Many expressed interest in using it again.
- POODLE: This option allows a user to export a version of Moodle onto an external device, which allows the user to view the information at a later stage. It facilitates access to information offline meaning individuals without access to the Internet can still view the information.
- VIDEO BLOG: As the preferred modality for viewing information was clearly via video, sharing of information through a video blog should be investigated.
- TOUCHSCREEN: For those that had difficulty using a mouse, alternative input devices such as a touch screen need to be considered.
- Hopefully we can wave goodbye to the working of the Lunacy Act shortly, and welcome in legislation that adequately addresses capacity.

## ***8.6 Final Reflections***

While the government has said it has a strong commitment to mainstreaming (the Disability Act 2005) and ensuring all its citizens have access to the same supports and services as the general population, this is not the experience of people with disabilities. When the National Rehabilitation Board disbanded, people with disabilities had to access employment through set ups such as FAS. This was unsuccessful and very challenging for individuals who wanted to work but required individualised supports. Many had to return to disability services.

One of the most important pieces of work that needs to happen in supporting people with disabilities is assisting people to feel connected in their neighbourhoods and communities. However in order for this to happen community capacity building is critical; prejudice, exclusion and a poor image of people with disabilities is alive and well in communities. One only needs to refer to (Yuker, 1988) who established that living next-door to someone who has ID was ranked the twenty second worst scenario out of a possible twenty four outcomes. Only through community engagement can cultural change happen.

With regard to education, in particular 'Life Long Learning' for adults with disability, there are huge gaps in community practice. As a result the service provider has to facilitate because supports in the community do not currently exist. Often adults with ID have had poor and negative educational experiences. Regularly the class they may be accessing in their local community also has participants who have had difficult experiences. Sometimes class members become concerned that the class will move at a slower pace and also have fears around 'minding' the person with disability. The teacher may also feel overwhelmed and recognise that more supports are needed but is not aware where the person can access them.

With individualised service waiting to pounce in the wing, people are worried about their jobs. But perhaps they should only be worried if they are not prepared to think differently. The reality is that for a lot of families, they may not welcome the bureaucracy of dealing with paying staff on a weekly or monthly basis. Therefore there will remain a place for ID agencies and therefore the service provider may be in a position to be flexible in those arrangements.

(Who, 2011) state that two of the biggest barriers to living an ordinary life are the lack of accessible information and being able to advocate. In order for the individual to lead an ordinary life the individual needs to be exposed to making decisions and choices. For many of the individuals who have ID making a choice can be a complex one. This is because the individual learns in many different ways.

A large percentage of individuals with ID are unable to read and write. This may be due to their cognitive abilities or in the past having missed educational opportunities,

or a right to an education. For this reason in order for the person to make an informed choice the person needs to have good information presented in a way that they can understand. They may need to see tangible visual aids (video, role play, film, photographs). It may need to be demonstrated to them a number of times. They may need to experience it to fully understand the choices that they are making. If the person has more complex ID, having an advocate who knows them well and shares their best interests can help support them to make the decision to lead a full life. This assists a person in making choices and decisions so that they can actively participate not just in their own lives but in the community. Otherwise the person cannot make the decision, and other people are making it for them.

A person cannot be an active citizen if they cannot access the information or understand the way it is presented. This is the case for voting, banking, decisions about wills, money and so forth. It effects every part of your life. For people who find it difficult to communicate they use an advocate. It will never be completely accessible as people learn in different ways, but we should at least be doing a better job. We need to be consulting with individuals with ID on how to do it better.

It is imperative going forward that individuals with ID, their families, and advocates are consulted and listened to. They are the "experts" in what is needed and how best to get there. It is also their right to be part of that process in order to become an active Irish citizen not just a person with disabilities living in Ireland. Essentially the person needs to be in the driving seat of their life and not waiting for life to happen to them.

## REFERENCES

Abbott, C., (1991). Word processing for all. *British Journal of Special Education*. 18(1):8.

Adams, R., (2009). Cognitive Science meets Computing Science: The Future of Cognitive Systems and Cognitive Engineering. *Proceedings of the ITI 2009 31st Int. Conf. on Information Technology Interfaces*, June 22-25, 2009, Cavtat, Croatia.

Ashington N. Accessible Information and Communication Technologies: benefits to business and society. *OneVoice for Accessible ICT*, 2010 ([www.onevoiceict.org](http://www.onevoiceict.org), accessed 30/06/2012).

Asonall, A., Hegarty, J.R., (2001). ICT for adults with learning disabilities: an organisation-wide audit. *British Journal of Educational technology*. 32(3): 365-372.

Baker, P.M.A., Bricout, J.C., Moon, N.W., Coughlan, B., Pater, J., (2012). Communities of participation: A comparison of disability and aging identified groups on Facebook and LinkedIn. *Telematics and Informatics*. <http://dx.doi.org/10.1016/j.tele.2012.03.004>

Bailey, R., Willner, P., Dymond, S., (2011). A visual aid to decision-making for people with intellectual disabilities. *Research in Developmental Disabilities* 32: 37-46.

Brandao, A., Trevisan, D.G., Brandao, L., Moreira, B., Nascimento, G., Vasconcelos, C.N., Clus, E., Mourao, P.T., (2010). Semiotic Inspection of a game for children with Down Syndrome. *2010 Brazilian Symposium and Digital Entertainment*.

Bray, N.W., Flethcher, K.L, Turner, L.A., (1997). Cognitive competencies and strategy use in individuals with mental retardation. In W.J. Maclean Jr., et al. (Ed.) *Ellis' handbook of mental deficiency, psychological theory and research*. 3rd ed. (pp. 197-217)

BSI Group, (2010). Digital Inclusion: First British Standard to Promote Web Accessibility Globally. Press Release 30 November 2010. Available from:<http://www.bsigroup.com/en/about-bsi/News-Room/BSI-News-Content/Sectors/ICT--Telecommunications/digital-inclusion-first-british-standard-to-promote-web-accessibility-globally>. Accessed 6/6/2012

Chang, Y.-J., Hsu, H.Y., Chang, W.C., Peng, S.M., Chen, Y.R., (2009). Context-aware Task Prompting: Sustaining of Supported Employment for People with Severe Mental Illness. 2009 International Conference on Communication and Mobile Computing.

Chen, M.C., Chu, C.N., Wu, T.F., Yeh, C.C, (2006). Computerized Assessment Approach for Evaluating Computer Interaction Performance. Lecture Notes in Computer Science, 4061, pp 450-456.

Child Protection Agency, 2012. BBC Panorama Programme CQC And Vulnerable Adults. Available at: [<http://www.childprotectioncompany.com/news/general/bbc-panorama-programme-cqc-and-vulnerable-adults>]. Accessed 05/07/2012.

Community Counselling Services. Intellectual Disabilities. Available at: [[http://www.hsccs.org/poc/view\\_doc.php?type=doc&id=10356&cn=208](http://www.hsccs.org/poc/view_doc.php?type=doc&id=10356&cn=208)]. Accessed 08/06/2012.

Cummins, R.A., Lau, A.L.D., (2003). Community Integration or Community Exposure? A Review and Discussion in Relation to People with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*. 16; 145-157.

Davidson, C.M., Santorelli, M.J., (2009). The Impact of Broadband on People with Disabilities. Washington, United States Chamber of Commerce.

Davies, D.K., Stock, S.E., Wehmeyer, M.L., (2004). Computer-Mediated, Self-Directed Computer Training and Skill Assessment for Individuals with Mental Retardation. *Journal of Developmental and Physical Disabilities*. 16(1), 95-105.

Department of Taoiseach (2006). Towards 2016: A Ten Year Framework Towards Social Partnership.

de Urturi Breton, Z.S., Hernandez, F.J., Mendez Zorilla, A., Garcia Sapirain, B., (2012). Mobile communication for intellectually challenged people: a proposed set of requirements for interface design on touch screen devices. *Communications in Mobile Computing*. 1(1): 1-4

Donnelly, M., Hillman, A., Stancliffe, R.J., Knox, M., Whitaker, L., Parmenter, T.R., (2010). The role of informal networks in providing effective work opportunities for people with an intellectual disability. *IEEE*.

Feng, J., Lazar, J., Kumin, L. and Ozok, A, (2010). Computer Usage by Children with Down Syndrome: Challenges and Future research. *ACM Transactions on Accessible Computing*. 2(3): 13-44

Ford, C., Rabe., K, (2011). Using the iPhone for Assistive Technology; A CASE STUDY. *EP Magazine/www.eparent.com*. July 2011. pp 20-23.

Franklin, K.S., (1991). Assistive Technology: Where Are We? Where Are We Going? *Journal of Vocational Rehabilitation*. 1(12): 6-7.

Gilmartin, A., Slevin, E., (2009). Being a member of a self-advocacy group: experiences of intellectually disabled people. *British Journal of Learning Disabilities*. 38:152-159.

Golledge, R.G., Richardson, D., Rayner, J.N., Parnicky, J.J., (1983). Procedures for defining and analysing cognitive maps of the mildly and moderately mentally retarded. In H.L. Pick & A.P. Acredolo (Eds.), *Spatial orientation: Theory, research and application*. New York: Plenum Press.

Gottliebson, D., Layton, N., Wilson, E., (2010). Comparative effectiveness report: online survey tools. *Disability and Rehabilitation: Assistive Technology*. 5(6):401-410



Guardian, (2011). Panorama Care Home Investigation. Available at: [<http://www.guardian.co.uk/society/2011/jun/01/panorama-care-home-investigation-inspectors>]. Accessed 05/07/2012.

Grguric, A., Benc, I., Desic, S., Mosmondor., M., Krizanic, J., Lazarevski, P., (2010). Designing user interfaces for the elderly: A case study in applicability of thin vs. fat clients. IEEE.

Harrysson, B., Svenck, A., Johansson, G.I., (2004). How people with developmental difficulties navigate the Internet. *British Journal of Special Education*. 31(3): 137-142

Hayes, B.K., Conway, R.N., (2000). concept acquisition in children with mild intellectual disability: Factors affecting the abstraction of prototypical information. *Journal of Intellectual & Developmental Disability*. 25(3):217-234.

HIQA. Draft National Quality Standards: Residential Services for People with Disabilities. pg 7. Available at: [[http://www.hiqa.ie/system/files/Draft\\_Standards\\_People\\_With\\_Disabilities.pdf](http://www.hiqa.ie/system/files/Draft_Standards_People_With_Disabilities.pdf)]. Accessed on 03/07/2012.

Hudson, H., (2002). A New Age of Accessibility. *Net Connect*. 127(1): 19-22.

Jaeger, P.T., (2006). Telecommunications policy and individuals with disabilities: Issues of accessibility and social inclusion in the policy and research agenda. *Telecommunications Policy*. 30:112-124.

Jin, L., (2010). Developing Accessible E-learning Content. IEEE.

Joseph, L.M., Konrad, M. , 2009. 'Teaching students with intellectual or developmental disabilities to write: A review of the literature. *Research in Developmental Disabilities* 30: 1-19.

Keskinena, T., Heimonena, T., Turunena, M., Rajaniemia, J., Kaupponenb, S., (2012). SymbolChat: A Flexible Picture-based Communication Platformfor Users with

Intellectual Disabilities. Interacting with Computers. In Press. Available online 4 July 2012

Kuzma, J.M., (2010). Accessibility design issues with UK e-government sites. *Government Information Quarterly*. 27(2): 141-146

Lancioni, G.E., Van den Hof, E., Furniss, F., O'Reilly, F., Cunha, B., (1999). Evaluation of a computer-aided system providing pictorial task instructions and prompts to people with severe intellectual disability.

Lazar, J., Beere, P., Greenridge, K., Nagappa, Y., (2003). Web accessibility in the mid-Atlantic United States: A study of 50 homepages. *Universal Access in the Information Society*. 2: 331-341.

Lazar, J., and Wentz, B. (2011). Separate but Unequal: Web Interfaces for People with Disabilities. *User Experience Magazine*. 10(3): 12-13.

Lee, E., (2010). BBC Future Media Standards and Guidelines. Accessibility Guidelines v1.9. Available at <http://www.bbc.co.uk/guidelines/futuremedia/accessibility/>. Accessed on 16/05/2012.

Li-Tsang, C.W.P., Chan, C.C.H., Chow, S.L., (2004). Evaluations of an Information and Communication (ICT) Training Program for Persons with Intellectual Disabilities. *ICCHP. Lecture Notes in Computer Science*, 3118, pp 1032-1038

Li-Tsang, C.W.P., Wong, J.K.K., (2009). Enhancing visual search abilities of people with intellectual disabilities. *Research in Developmental Disabilities*. 30: 124-135.

Lotan, M., Yalon-Chamovitz, S., Weiss, P.L., (2011). Training Caregivers to Provide Virtual Reality Intervention for Adults With Severe Intellectual and Developmental Disability. *Journal of Physical Therapy Education*. 25(1): 15-19.

Martinez, R., Lopez de Ipina, K., Irigoyen, E., Asla, N., (2010). Automatic Evaluation of Emotion Elicitation oriented to people with intellectual disabilities.

Mengue-Topio, H., Courbois, Y., Farran, E.K., Sockeel, P., (2011). Route learning and shortcut performance in adults with intellectual disability: A study with virtual environments. *Research in Developmental Disabilities*. 32: 345-352

Oldreive, W., Waight, M., (2011). Assessment of capacity: reflections from practice. *Learning Disability Practice*. 14(7): 31-36.

Ojasalo, J., Seppala, H., Suomalainen, N., Moonen, R., (2010). Better Technologies and Services for Smart Homes of Disabled People: Empirical Findings from an Explorative Study among Intellectually Disabled. 2nd International Conference on Software Technology and Engineering (ICSTE).

Panek, P.E., Smith, J.L., (2005). Assessment of terms to describe mental retardation. *Research in Developmental Disabilities*. 26:565-576.

Pushchak, T.A., 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

Reyer, H.S., Sturmey, P., (2009). Effects of systematically depriving access to computer-based stimuli on choice responding with individuals with intellectual disabilities. *Research in Developmental Disabilities*. 30:1177-1187.

Section 508. Section 508.Gov. Opening Doors to IT. <http://www.section508.gov/index.cfm> (Accessed on 01/01/2012),

Shpigelman, C-N., Weiss, P.L., Reiter, S., (2009). e-Empowerment of young adults with special needs. Behind the computer screen I am not disabled. *CyberPsychology & Behavior*. 11(2): 196-200.

Stewart, C., Ward, T., (2007). Human Rights and Intellectual Disability. *Journal of Developmental and Physical Disabilities*. 20(3): 297-311

Strum, J., (2000). Supporting writing development in adolescents with developmental disabilities. *Topics in Language Disorders*. 20;73-92.

Taber-Doughty, Shurr., J., Brewer, J., Kubik, S., (2010). Standard care and telecare services: comparing the effectiveness of two service systems with consumers with intellectual disabilities. *Journal of Intellectual Disability Research*. 54(9): 843-859.

Undercover Care, The Abuse Exposed : Panorama 2011, television programme, British Broadcasting Corporation One, London, 31 May.

Van der Molen, M.J., Van Luit, J.E.H., Van der Molen, M.W., Klugkist, I., Jongmans, M.J., (2010). Effectiveness of a computerised working memory training in adolescents with mild to borderline intellectual disabilities. *Journal of Intellectual Disability Research*. 54(5): 433-447.

Wennberg, B., Kjellberg, A., (2010). Participation When Using Cognitive Assistive Devices - from the Perspective of People with Intellectual Disabilities. *Occupational Therapy International*. 17: 168-176

Williams, P., (2006). Developing methods to evaluate web usability with people with learning difficulties. *British Journal of Special Education*. 33 (4): 173-179.

Wolfensberger, W., (2002). Needed or at least wanted: sanity in the language wars. *Mental Retardation*, 40:75-80.

Wong, A.W.K., Chan, C.C.H., Li-Tsang, C.W.P., Lam, C.S., (2009). Competence of people with intellectual disabilities on using human-computer interface. *Research in Developmental Disabilities*. 30(1): 07-123

World Health Organization, (2011). World Report on Disability. Available from: <[http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf)>.

Yuker, H.E., (1988). Perceptions of severely and multiply disabled persons. *Journal of the Multihandicapped Person*. 1:5-16.

**APPENDIX A - EXPRESSION OF INTEREST FORM**

**EXPRESSION OF INTEREST FORM**



**PLEASE SIGN AND RETURN**



**Yes, I would like to be in the focus group.**







**No, I don't want to be in the focus group.**

**Signed: \_\_\_\_\_**

**Date: \_\_\_\_\_**

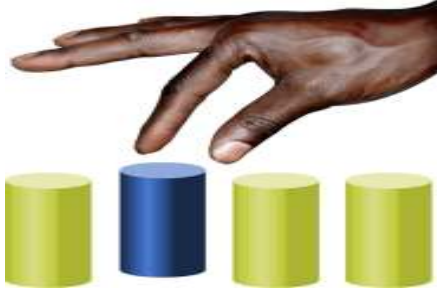
APPENDIX B - INFORMATION SHEET

INFORMATION SHEET

	<p>You are being invited to take part in a research study.</p>
	<p>This study is part of a college course that Michelle Moloney is doing.</p>
	<p>It will help Michelle.</p>
	<p>You will have to use a computer. How you use the computer will be recorded.</p>



You have been asked as you are interested in using the computer to access information.



Deciding to take part is voluntary and your choice. You only have to take part if you want to.



If you decide to take part you will have to sign a consent form.



This is about finding out what you like and do not like about an advocacy website.



You will use the computer for a maximum of 45 minutes. Michelle will go to your unit at a pre-arranged time.



You can stop at any time.



You can talk about using the website.



What you say will be recorded.



Michelle will write your feedback from the evaluation in a report.

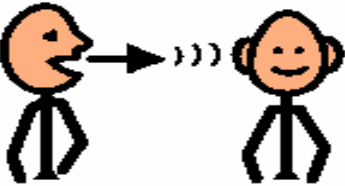






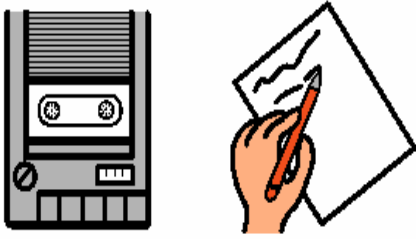
APPENDIX C - CONSENT FORM

**CONSENT FORM**

**Research Title: Finding out what you like and do not like about how information is presented to you on the computer.**

Please tick

	The team has talked to me about the focus group.	
	I was able to ask questions about the focus group.	
	I understand what the focus group is about	

	<p>I understand that I can say yes or no.</p>	
	<p>I understand how I use the computer will be recorded</p>	
	<p>I understand that what I say will be recorded</p>	

# APPENDIX D - RESEARCH ETHICS APPLICATION FORM



**St. Michael's House**

For Official Use Only

**Date Received**

\_\_\_\_\_

## RESEARCH ETHICS APPLICATION FORM

### TITLE OF RESEARCH:

Evaluating the viability of web based learning and communication tools for clients with ID

### NAME & TITLE OF APPLICANT:

Michelle Moloney \_\_\_\_\_

CURRENT ADDRESS: \_\_\_\_\_

TELEPHONE NO: \_\_\_\_\_ MOBILE No: \_\_\_\_\_

E-MAIL ADDRESS: \_\_\_\_\_

### STAFF:

NAME OF UNIT: \_\_\_\_\_ REGION: Shared Services

### ORGANISATION / INSTITUTION TO WHICH AFFILIATED:

N/A \_\_\_\_\_

### PLEASE STATE ANY RESEARCH FUNDING SOURCES:

N/A \_\_\_\_\_

### NAMES & TITLES OF OTHER RESEARCHERS INVOLVED:

1. \_\_\_\_\_ Tel: \_\_\_\_\_

2. \_\_\_\_\_ Tel: \_\_\_\_\_

3. \_\_\_\_\_ Tel: \_\_\_\_\_

• **Signature of Applicant:**

\_\_\_\_\_

• **Signature of Internal Sponsor**  
(if applicable – see Appendix I of the R.E.C. Policy)

\_\_\_\_\_

• **Signature of Line Manager / Head of Unit** (if applicable)

\_\_\_\_\_

• **Signature of Academic Supervisor**  
(if applicable)

\_\_\_\_\_

**Position:**

\_\_\_\_\_

**Stamp of  
Institution:**

**1.1.1.1.1** Date Submitted to Research Ethics Committee:

\_\_\_\_\_

**NOTE:**

Research Ethics Applications must be with the St. Michael's House Research Ethics Committee at least 4 weeks in advance of the next meeting - (Contact Elaine Burns at 8840208 for date of next meeting)

**INFORMATION REQUIRED BY THE RESEARCH ETHICS COMMITTEE**

In order for the Committee to respond to your research ethics application, the following details are required:

**1) Please give a summary outline (in plain English) of your research, e.g. aim, methodology, proposed analysis.**

I hope to determine the viability of using a web based tool as a learning and communication resource for people with ID. I will develop an online tool that will reference the Web Content Accessibility Guidelines (WCAG) that need to be followed when making online data accessible to people with ID. Analysis will take the form of a

usability study, whereby the participants interactions with the system will be logged V and evaluated.

**2) What is the aim or purpose of your research? What are you trying to find out / establish / evaluate?**

I am trying to establish if a learning and communication tool is a viable resource for clients. I want to determine if clients can independently or with some support, navigate through a web tool via image to image to the information they desire. The participants will choose from 6 images initially which will drill down giving them a choice of further images they can choose from. For example they could choose the topic **Forums** from the home page and then choose **Minutes** from the sub category in the next page. They will then have the option to view the minutes in pdf format (better than word for accessibility), audio format or video format. I want to determine how easy it is for the participants to navigate through the site and evaluate how easy it is for the participants to navigate through the site and evaluate what formats they prefer to view information. I want to evaluate how the web tool is used and to determine if audio chats and video conferencing communication tools are accessible for the participants.

**3) Who will benefit from this research, and how will they benefit?**

This work will involve discussion with both the EVOLVE team who are looking at developing an online resource with respect to FETAC as well as the advocacy team who are looking at an online resource. Even though what they are looking for may be somewhat different EVOLVE and Advocacy want to use the same navigation tools to make it as user friendly as possible for the clients. What I am developing may act as a template for these online resources as I will be liaising with the clients to determine images and navigation methods that they find useful.

**4) Is this study part of a recognised qualification or course? (give details)**

This section will take the form of an experiment that will be documented in a dissertation that will be go towards the qualification of an MSc in Computing (Assistive Technology).

**5) METHODOLOGY:**

**a. What research methodology are you using:**

The research methodology used will be a mixture of quantitative and qualitative. The quantitative aspect will refer to the measurement of key strokes required to access the various aspects of the technology. The qualitative aspect will involve 3 open ended questions to the group after they have used the technology as I want to understand and describe the participants interactions with the technology. This will involve adopting a participatory approach to the research.

**b. Please outline details of your sampling method.**

Participants will meet the following inclusion criteria – (1) an adult with intellectual Disability (18 years of age or above) (2) verbal communication skills sufficient to provide information about their thoughts and experience of using the technology.

**c. From whom will you collect data?**

I will invite clients who will be nominated to me via the advocacy group to take part in the research. These clients will consist of members of the Work Options ACT group as well as members of The Advocacy and Leadership Group.

**d. What data are you collecting?**

I will be monitoring how the participant interacts with the web tool. I want to collect how accessible the data is for them and determine if delivering learning tools or communicating in this format is a useful tool for the participants. This will involve counting key strokes when they are using the tool. This is collected automatically by the computer through a program that is installed. The max size of each group will be 5 participants. In addition 3 open ended questions will be asked to the group after they have finished using the prototype. They will be asked (1) What they liked? (2) What they didn't like? and (3) Was it too easy? The questions are in this format to encourage discussion. This will help me determine which aspects they preferred and found easier to use. The responses will be audio taped with the participants agreement. Should the participant prefer not to have the responses taped their answers can be written down.

**e. How will you collect your data?**

*(from interviews, files, postal questionnaires, etc.- you must include copies of any questionnaires / instruments / interview protocols)*

I will log the participants interactions with the web tool and see what they found easy or difficult to navigate. To do this a software program will be installed on the computer that will record the number of times the participant touches the keys. The open ended questions to the group will take place after the participants have used the technology and in the same location. I will be asking the questions, but will be facilitated by Sabrina Barrett. Before asking the questions the participants will be reminded that the answers to the questions will be recorded via audio to ensure I do not miss any of their comments from the group discussion. They will already have been informed that I will be recording them through the consent document and information sheet which will be gone through before the participants start using the prototype.

**f. Time commitment from research participants?**

It is estimated that a period of 1 hour may be required. A max period of 45 minutes will be used at any sitting. It has been suggested that a time slot of 11-1 would be the best time for the participants to interact with the tool.

**g. Please give an outline of the proposed analysis (e.g. statistical tests, qualitative data analysis, etc.)**

I will have a set of scenarios that I wish the participants to fulfil. I will be determining how long it takes to get from task a to task b, as well as recording who can or cannot complete the nominated tasks. Key stroke data will be analysed using descriptive Statistics and open ended questions will be analysed using content analysis.

**6) CONSENT:**

**a. How will you acquire full, free and informed consent from participants?**

I will liaise with a member of the advocacy team, Sabrina Barrett, during this process. A presentation will take place explaining what I propose to do and what is expected of the clients who participate. I will meet the potential participants face to face alongside Sabrina who will help facilitate the information session. Participants will be encouraged to ask questions to ensure they understand what the study is for and what they will be expected to do. Information sheets in accessible format will also be provided.

**b.** How will you inform participants of the purpose of your research and of the information you are seeking from them?

Information sheets explaining why the study is being undertaken and outlining what is expected of the participants if they take part will be provided in accessible format. It will be highlighted that any involvement is of a voluntary means. If participants decide to take part they will be informed that how they interact with the technology will be Recorded. They will also be advised of the interviews that take place afterwards. The interviews will be taped with the participants agreement.

**c.** How will you ensure they understand this information? (If the person can't communicate, who will communicate for them?)

N/A – it is envisaged that the participants selected will have the ability to communicate. However all documentation will be presented in accessible language Using visual prompts where needed.

**d.** If the participant has difficulty communicating, how will you determine if consent has been given?

N/A – it is envisaged that the participants selected will have the ability to communicate.

**e.** How will you support the participant to decide freely? (e.g. giving time to consider, friend/family member to discuss it with)

It is important that the participants understand what the study is for and what they will be asked to do. An accessible information sheet explaining what the study will entail will be provided. The clients will be given time to consider if this is something they wish to be involved in. They will be encouraged to read the provided information sheets and to ask questions.

**f.** How will you ensure that the participant is under no pressure to agree to participate?

This is voluntary so the participant only has to take part if they would like to use the technology. The participant will be given an expression of interest form and following that a consent form by Sabrina Barrett (Advocacy representative) so that there is no undue influence on my side. This will be communicated orally as well as through using accessible information.

**g.** How will you let the participant know they are free to withdraw at any stage?

The participant will be informed orally as well as using accessible information that they can choose at any stage to no longer be involved. This means the participant



can withdraw without reason at the interview stage or after having giving consent.

**\* You must include all participant information sheets and consent forms**

**7) Risks associated with this research, for the respondents or for St. Michael's House and how you propose to manage this?**

**a.** In your opinion what are the risks associated with this research for the respondents?

The risks are minimal as essentially the web tool will be offered as an internal learning & communication resource, where access & interactions will be monitored by the researcher. If the participants feel tired at any time during this session, they can opt out entirely or take a breather for a while and then continue at their own pace.

**b.** What are the risks associated with this research for St. Michael's House?

I see minimal risk as the research aims to establish accessible data in a web format to clients. Once determined the approach can be used elsewhere in the organisation.

**c.** How do you propose to manage any risks identified above?

Data will be held internally on a secure server. Access to the data will be through a secure URL that only nominated staff and clients can use.

**8) DATA PROTECTION:**

**a.** How will you protect the confidentiality of the individual participants?

Minimal data relating to the personal details of the participant will be retained throughout the study. A Unique ID will be used as a client identifier. The data will only be accessible to nominated staff and client members. Audio responses from the open ended group questions will be transcribed. They will be stored on an encrypted computer and only supervisors will have access to the data. Individuals will not be identified.

**b.** How will the data be stored?

The data will be stored on an internal server on the SMH network which will have the necessary firewall protection.

**c.** At what stage will the data gathered be destroyed or archived?

Any participant data that is collected which will not be used going forward in the organisation will be destroyed. If the educational tools developed prove useful they shall be retained for further use. Development work that upon testing is not viable or suitable for the clients to use will be destroyed.

**9) DISSEMINATION:**

**a.** How will you communicate your findings with participants?

The communication may not involve myself directly, but could involve members of the FETAC and Advocacy team communicating with the participants involved.

**b.** Do you intend to publish your findings?

The findings will be published as part of a dissertation.

**c.** Will St. Michael's House be identified?

SMH will be identified in the experiment section of the dissertation.

## Application Form Checklist

<b>1)</b>	A fully completed application form including all required signatures	<input type="checkbox"/>
<b>2)</b>	I confirm that I have read the St. Michael's House Research Ethics Policy	<input type="checkbox"/>
<b>3)</b>	Attached all appropriate, consent forms, standardised measures and other supportive documentation	<input type="checkbox"/>