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Comparing understanding of Health related knowledge following Easy Read alone or Easy Read with additional support in adults with intellectual disabilities.

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Contents

Abstract

Individuals with intellectual disabilities (ID) have poorer health and are affected by health inequality. In this research, Easy Read, a form of accessible information, is being explored as a means to improve this. The research evidence into Easy Read, its format, efficacy and use are often conflicting. This research aimed to compare the health related knowledge, understanding and gain of adults with ID following reading an Easy Read booklet alone, or reading Easy Read with additional support. Participants were given a baseline questionnaire of health followed by two phases in a randomised order. Phase one, reading an Easy Read booklet alone followed by a questionnaire and phase two, reading an Easy Read booklet with the support followed by a questionnaire. Results from Wilcoxon Signed Ranks Tests ($z. = -1.60$, $p < .10$) indicated that participants (n=6) showed no significant difference in understanding following Easy Read with or without support. All participants responded differently to support based on needs. Results are discussed in light of the existing literature and suggest the need for future research to explore individualised support packages to assist individuals with an ID. This will help to gain knowledge and understanding of new health related subjects. Future research should also focus on improving methodology in this area.

The term intellectual disability (ID) is used to describe individuals who are permanently affected by weaknesses/impaired intelligence that affects adaptive functioning (American Psychiatric Association, 2013; Mencap, 2015; World Health Organisation, 2015a.). An ID is life-long (Foundation for people with learning disabilities, n.d.; World Health Organisation, 2015a) and to be diagnosed with an ID, symptoms must begin during the developmental period in life (American Psychiatric Association, 2013; Mefford, Batshaw & Hoffman, 2012). However, having an ID does not necessarily mean your life goals should be any different to anyone else, such as career and relationship aspirations.

The primary focus of this thesis is the type of support an individual needs to understand new health information. As this introduction progresses it will address; the definition of an ID and debate models around ID; the current literacy and health research around ID; the health inequalities that face a person with an ID and the impact of accessible information; and finally, assessing the current literature on a newer concept called Easy Read.

Intellectual Disability

As discussed above an ID is defined by am impairment in adaptive and intellectual functioning. When assessing someone with a potential intellectual disability, it is important to focus on strengths, peers, culture, language as well as weaknesses (American Association of on Intellectual and Developmental Disabilities, 2013; Schalock et al., 2007). In this way an individualised support plans can be put into place. To measure impaired intelligence, an IQ test is usually conducted (American Association of on Intellectual and Developmental Disabilities, 2013). If the results indicate that the individual has an IQ of 75 or below, they are recognised as having an impairment or weakness in intellect.   Adaptive functioning consists of three domains, which are conceptual, social and practical. The conceptual domain includes skills such as knowledge, reasoning and writing (American Association of on Intellectual and Developmental Disabilities, 2013; American Psychiatric Association, 2013).

The social domain refers to social skills, for example, the ability to make and retain friendships, social judgment and empathy and the practical domain focuses on self-management such as money management, personal care and recreation. A person with an ID may have poor reading and writing skills (conceptual), may find it difficult to make friends (social) and may have poor money management skills (practical). Intellectual disabilities can vary between person to person and the level of support varies based on individual needs (Mencap, 2015). An individual with a severe ID may need full time care and an individuals with a mild ID may be able to live independently with very little support.

There are many frameworks, ideas and models that have devised to improve the quality of life of a person with an ID. Many have been widely debated over years however, the Medical Model and the Social Model are two that have been debated and compared the most. The Medical Model states that you are disabled because of your impairment (Barnes 2012; Emerson & Hatton, 2014; Scope, n.d.). This model looks at fixing the impairment medically or by use of other treatments such as rehabilitation or care. The impairment does not have to be causing illness or pain to be fixed, for example the use of genetic screening programmes of certain conditions that would cause disability (Emerson & Hatton, 2014). The social model states that there is a difference between the impairment and disability (Barnes 2012; Emerson & Hatton, 2014; Scope, n.d.). The impairment being the person having an ID and the disability being the barrier that stops the person from completing the task they wish to fulfil. Under this model having an ID is not what causes barriers but societal exclusion and oppression (Emerson & Hatton, 2014). Scope (n.d.) discussed an example of how both models would have impacted a person with an ID. A person with an ID would like to live independently however, does not know how to pay rent. Using the medical model the person may be expected to live in a communal home where he or she would be cared for and not

have to worry about rent. Under the social model the person would be supported to pay rent, this would enable he or she to live in there own home.

Both models have been subject to debate. Many argue that the Medical Model only focuses on what is wrong with the person and not us as a society and as a result it further separates people with a disability from the general population (Barnes 2012; Emerson & Hatton, 2014; Scope, n.d.). A further argument is that the Medical Model will give the individual low expectations of themselves and it does not encourage independence, choice, social justice and control of there own lives like in the Social Model (Scope, n.d.). Without encouraging self care and independents the Medical Model created generations of institutionalised and costly care facilities for people with an ID (Barnes, 2012). Although many say that the political change encouraged by the social model is a good thing, it is not a fully explained theory (Barnes, 2012; Shakespeare & Watson, 2002). There are also debates as to the model not always looking at the reality of the persons health and well being (Emerson & Hatton, 2014).

People who have an ID are also more likely to have a dual-diagnosis of another mental health illnesses (Chaplin, 2004; Mencap, 2015). Emerson (2003) conducted a secondary analysis of statistics released from the Office for National Statistics. It was specifically data from a survey of the Mental Health of 10,438 children and adolescents (aged 5 to 15) that lived in England, Wales and Scotland. The results suggested that children and adolescent with an ID are at an increased risk of attaining certain psychiatric disorders. Individuals with specific conditions can also have an ID, for example an individual with Down's syndrome (DS) or Autism Spectrum Disorder (ASD: autism west midlands, 2014; Mencap, 2015; Sherman, Allen, Bean, & Freeman, 2007;). ASD and ID are often confused; both are separate conditions (autism west midlands, 2014; The National Autistic Society, 2015). ASD is a neurological disorder that is more common in boys than girls (American

Psychological Association, 2013; Croen et al., 2015; The National Autistic Society, 2015). There is no official ratio as research varies. This research will follow the DSM IV definition of ASD. ASD is seen as a specific disorder present from childhood that causes impairments and limitation in daily function. The disorder is categorised into two domains; social and behaviour (American Psychological Association, 2013 Croen et al., 2015; Frazier et al., 2011; The National Autistic Society, 2015). The social category affecting social communication and interaction, for example finding it difficult to make eye contact. The behaviour category looks at restrictive and repetitive patterns of behaviour, activities and interests for example a strong interest in a TV series such as "Dr Who". Each domain is graded on level of support from one to three, with three indicating the most support needed. Similar to a person with an ID, a person who has ASD, the needs and the severity of these needs will vary from person to person (Autism West Midlands, 2014; The National Autistic Society, 2015). Individuals with ASD also have been recognised as individuals who have a high chance of a dual diagnosis of mental ill-health (autism west midlands, 2014; Russell et al., 2016; The National Autistic Society, 2015). Russell et al., (2016) did a retrospective case review on 859 adults referred for an ASD assessment. The adults who were diagnosed with ASD had a higher prevalence of anxiety disorders and obsessive compulsive disorder than the adults without an ASD diagnosis.

Down's syndrome (DS) is a genetic condition, an individual with DS has 47 chromosomes as they have an extra copy of chromosome 21 whilst an individual born without DS has 46 chromosomes (Down's Syndrome Association, 2015; Down Syndrome: Parents sharing, 2015; National Down Syndrome Society, 2012b; NHS Choices, 2015a). It is estimated that there are 1000 babies in the UK born each year with DS (Down's Syndrome Association, 2015). There are three forms of DS, they are Trisomy 21, Translocation, and Mosaicism (Down Syndrome: Parents sharing, 2015; National Down Syndrome Society,

2012b; NHS Choices, 2015a). There are very little differences between these three types of DS but Trisomy 21 is the most common form of DS (National Down Syndrome Society, 2012b; NHS Choice, 2015a). Trisomy 21 causes the individual to have extra copies of chromosome 21 in each cell in the body. Individuals with Translocation only have 46 chromosomes in each cell but one cell has extra material from chromosome 21 attached to it. The cell usually affected is cell 14. Only one precent of individuals born with DS are diagnosed with Mosaicism. Individuals with this form of DS have two types of cells; some cells have the 47 chromosomes and some have 46. Individuals with DS are often identified through their ID, health problems like issues with hearing or thyroid or physical features like the eyes slanting upwards and outwards or broad hands but short fingers (Eunice Kennedy Shriver National Institute of Child Health and Human Development, 2014; NHS Choices, 2015b).

This research focuses on the reading of individuals with an ID and there subsequent gain of knowledge. This person may also have a dual-diagnosis of Down's syndrome or a Mental Health Condition. However, the focus here is to follow the social model and remove the disability, in this case the lack of health related knowledge. However, before understanding health we must first understand what being literate is and what that means for an individual with an ID.

Literacy

There are many different definitions of literacy, all definitions include the ability to read and sometimes include the additional skills of reading, writing, speaking and listening (Cambridge Assessment, 2013; Keefe & Copeland, 2011). According to the National Reading Panel (2000), there are five components needed for reading instruction. These are phonemic awareness, phonics, oral reading fluency, vocabulary and comprehension. Phonemic awareness is the ability to recognise the different small units of sound and being

able to use the units of sound in different ways, for example, when using "ch" at the start of a word it is not always pronounced in the same way, for example "ch" would sound different in the following words, cheese, chef and choir (National Reading Panel, 2000; Phonemic Chart, n.d.). Phonics is the ability to put sounds together to make words **(**McCracken & McCracken, 1996; National Reading Panel 2000, PhonicsPlay, 2015). Oral reading fluency is the ability to quickly and accurately, understand the words connected in text with expression (National Reading Panel, 2000; Rasplica & Cummings, 2013). Vocabulary is the overall understanding of words that are in text and then linking them to the oral vocabulary (National Reading Panel, 2000; Open Learn Works, n.d.). Vocabulary tends to expand with age (Open Learn Works, n.d.). Comprehension is the understanding and consequent interpretation of what is read in text or is listened to (National Reading Panel 2000; Miller, n.d.). In this research, literacy is defined as the ability to read, comprehend and understand what is read.

Literacy is regarded as an important skill and there are various strategies to improve literacy in individuals of all abilities (Morgan, Cuskelly & Moni, 2011; Katims, 2001). In research that concerns individuals with an ID, strategies such as the use of a teacher dictating to the student (Morgan et al., 2011), specialist computer instructed reading programmes such as Headsprout® Early Reading (Blaine, 2015; Tyler, 2013**)** or a phonological reading skills programme (Conners, Rosenquist, Sligh, Atwell & Kiser, 2006) have successfully been used for children with an ID. However, although these studies have shown an increase in reading for children with an ID they have not been used in adults with ID. Although a recent pilot study of the use of Headsprout Early reading in an adult LD forensic setting offers some promising data further research is still needed (O'Sullivan, Grindle, & Hughes, in press).

The reading comprehension of an adult with an ID is lower than that of someone from the general population (Jones, Long & Finlay, 2006), it is a difficult skill for children who

have an ID to acquire (Conners et al., 2006). According to the National Pupil Database in 2009, only 2.2 % of children who attended special needs schools met the required levels of literacy at age seven (level two) and only 7.5 % reached level one (Tyler, 2014). The skills an individual with an ID has in literacy are extremely varied however, there is a correlation between the level of severity of the ID and the individual's literacy level (Ratz & Lenhard, 2013). People with an ID find it difficult to comprehend what they have read, as they have difficulty decoding written materials (Jones et al., 2006; Van Den Bos, Nakken, Nicolay & Van Houten, 2007). Historically, it has been assumed that individuals with an ID do not have the required skills set to be literate (Browder, Gibbs, Ahlgrim-Delzell, Courtade, Mraz, & Flowers, 2008; Forts & Luckasson, 2011). As a consequence, individuals were only taught what was necessary to survive on a day by day basis such a understanding safety signs or knowing their home address. The first recorded education act for individuals with an ID was in 1886 when the Idiots Act was put in place (Rescare n.d.; The Open University, n.d.). This was the first legislation addressing the educational needs of individuals with an ID. It was the first time a distinction was made between a clear distinction between 'lunatics', 'idiots' and 'imbeciles'. However, the Lunacy Act in 1890 dissolved the distinction clarified in the Idiots Act. This Idiots Act greatly differed from the Education Act for mainstream children in 1870 (16 years before the Idiots Act), which allowed the building and management of schools (Parliament, n.d.).

Nevertheless, recent research has demonstrated that individuals with an ID can learn to read and write with the appropriate instruction (Katims, 2001; Tyler, 2013). Van Den Bos et al. (2007) conducted research with adults with mild ID. Thirty-eight participants had 15 weekly lessons that lasted an hour each over a 3 month period, lessons included various strategies such as summarizing and questioning. Van de Bose et al. (2007) reported that although after the intervention, the participants still had poor reading skills, there was an

improvement from baseline suggesting that the intervention could be a basis for improving the reading ability in adults with a mild ID. There is very little known about the literacy skills of adults with ID, especially those who leave school, who are literate and how those skills are used every day (Morgan et al., 2011). Recent research conducted by Morgan, Moni and Cuskelly (2013) followed three young adults who had left school, two individuals had DS and one had an ID. All participants had reading ages ranging from eight to ten years old. They discovered that all three used literacy in their daily lives based on school or context based strategies, such as looking at a picture or using prior knowledge to understand something. The research discusses such strategies in different scenarios such as when the participant looks at a DVD cover and in this case the strategy is an ineffective strategy and lead to a misunderstanding of the general subject.

Esbensen, Bishop, Seltzer, Greenberg and Taylor (2010) looked at differences in independence between 70 adults with ASD and ID and 70 adults with DS. Adults with DS appeared to score higher in independence in comparison to those with both ASD and ID. They also found that adults with DS scored higher for literacy skills than adults with both ASD and ID. Various research papers have concluded that individuals with DS can show strong reading skills (e.g., Fletcher & Buckley, 2002; Kennedy & Flynn, 2003; Martin, Klusek, Estigarribia & Roberts, 2009). Martin et al. (2009) suggest that individuals with DS are able to develop literacy with the right amount of support. They discuss how individuals with DS have strength and weaknesses in literacy, such as primary strengths in whole-word recognition and weaknesses being in phonological awareness. Various studies have provided further evidence to support this such as, Roch and Jarrold (2008) who selected individuals with DS between 15 to 26 years old who were asked to have a reading skills at a level above the ability to recognise letters. The results of this study provided further support that suggests that individual with DS have difficulties in phonological awareness tasks, especially non

word reading. Similar findings were also evident with individuals with ASD who appeared to struggle with reading comprehension but have good word recognition skills (Nation, Clark & White, 2006; Chiang & Lin, 2007). Individuals with ASD have the ability to learn to read when given an effective learning environment (Mirenda, 2003; Nation, Clark, White & Williams, 2006). However, research discusses that there is a wide variation of linguistic abilities in individuals with ASD (Nation et al., 2006). Individuals with ASD appear to struggle with reading comprehension but have good word recognition skills (Chiang & Lin, 2007; Nation et al., 2006). This is called Hyperlexia. This is a condition where an individual has stronger decoding skills than comprehension skills (Chiang & Lin, 2007; Mirenda, 2003; Nation et al., 2006; O' Connor & Klein, 2004).

There are many benefits to gaining adequate literacy skills such as improved health outcomes; individuals who are literate have better health (Gottfredson & Deary, 2004; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman & Rudd, 2005). The next section explores health and its overall impact on those with an ID.

Health

Individuals with an ID have poorer health, increased risk of death and shorter life expectancy than those from the general population (Emerson & Baines, 2010). The shorter life expectancy and increased risk of early death compared to an individual from the general population is known as health inequality (Ouellette-Kuntz, 2005; Tyrer, Smith & McGrother, 2007). However, this is a preventable and unjust difference in health and is experienced not only by individuals with an ID but also individuals from different social classes or individuals of different gender (National Institute for health and care excellence, 2012; World Health Organisation, 2015b). The Marmot Review estimated that in England alone that between 1.3 and 2.5 million extra years of life could be gained by reducing health inequality (Marmot et al., 2007). Nevertheless, recent research indicates that life expectancy is

increasing for individuals with an ID. Yet, there is still a gap between an individual with an

ID and an individual from the general population (Emerson & Baines, 2010; Ouellette-Kuntz,

2005; Tyrer et al., 2007). For example, Emerson and Baines (2010) suggested that

respiratory disease is a lead cause of death for people with an ID, with mortality rates of 46 to

52 percent, in comparison to individuals from the general population who have a mortality

rate of 15 to 17 percent. Emerson and Hatton (2014) claimed that there are several conditions

that are factors in relation to the impact of the health inequalities faced by people with ID,

these are socio-economic, cultural and environmental factors; living and working; social and

community; individual lifestyle and finally, constitutional factors. Socio-economic, cultural

and environmental factors are essentially our social class indicators, which impact upon the

material, psychological and social parts of our lives (Emerson & Hatton, 2014; Graham,

2005; Marmot et al., 2007). This could affect anything in our lives from the quality of the

food, quality of healthcare and/or the quality of education that can be accessed. The Marmot

Report maintains that the higher the social economic status, the better the quality of health of

individuals therefore, statistically, an individual from a lower social class will die before an

individual from a higher class (Marmot et al., 2007).

Nevertheless, Emerson and Hatton (2014) maintain that the living and working

conditions of an individual are defined by the exposure the individual has to social and

environmental difficulties, their access to quality healthcare and other services. Individuals

with an ID are more likely than those from the general population to be exposed to social and

environmental difficulties that affect their health, for example, poor housing conditions or

unemployment. The Foundation for People with Learning Disabilities (2011) reported that

only 6.6 % of adults with an ID are in paid employment and the majority of those who were

in paid employment worked part-time. However, it is estimated that 65 % of people with an

ID want a paid job.

There is evidence to suggest that individuals in the general population, who have good social and community networks, have better health than those with poor social and community networks (Emerson & Hatton, 2014; Heany & Israel, 2008; Stansfeld, 2006). Lippold and Burns (2009) asked participants with an ID to self-report on the social support they received and compared the results with those who have physical disabilities. The results suggested that individuals with an ID have a more restricted social support and social networks than others in society, including those with physical disabilities. The research also stated that people with an ID scored significantly lower for social relationships than individuals with physical disability.

Emerson and Hatton (2014) further maintain that an individual's lifestyle is a condition that can affect health quality, for example, diet, exercise, body weight, substance use and sexual health. An individual with an ID has an increased chance of being obese or underweight compared to an individual from the general population (Emerson, 2005; Hove, 2004; Rimmer & Yamaki, 2006). Emerson (2005) conducted research with 1517 participants (824 men, 693 women) ages 16 plus (M=49.3, SD=15.5) and found that only eight percent of his sample qualified as physically active. The results also showed that participants with an ID were less active than those without an ID. Emerson measured physical activity by using The Physical Activity Scale was the one used by Health Survey England (use from 1993 to 1998). Over a four week period it was used to record the number of times physical activity (moderate to vigorous) was engaged in. Inactivity was defined 12 hours or less of moderate to vigorous physical activity in the recording time of four weeks.   The health impact of individuals being physically inactive presents a higher risk of morbidity and mortality, such as the development of conditions such as Type 2 Diabetes (Emerson, 2005; Emerson & Baines, 2010; Rimmer & Yamaki, 2006).

Finally, constitutional conditions are the inherited characteristics (Emerson & Hatton,

2015; Farlex Partner Medical Dictionary, 2012). This when an individual has inherited a condition through family genes (for example, sickle cell anaemia) or has inherited a condition because of a genetic condition (for example DS). This has an overall affect on their health. For example, it is common for an individual with DS to have congenital heart disease (Emerson and Hatton, 2014; National Down Syndrome Society, 2012a; NHS Choices, 2015c).

Emerson and Hatton (2014) maintain that individuals with a mild ID may lack information and understanding on certain health related subjects. For example, research shows that individuals with an ID who live in a care setting are more likely to have had an eye test in the past two years, compared to those who live with family or who live independently (Emerson & Baines, 2010). It could be claimed that health related support and information may not be meeting the needs of the general population and the needs of those individuals with an ID. Despite guidelines being available which recommend how to make patient information leaflets for the general population more accessible and readable. Research has shown that current information leaflets contain high levels of unreadability in relation to complex information (Albert & Chadwick, 1992; Gal & Prigat, 2005). Gal and Prigat (2005) examined possible causes for high levels of unreadability and complex information being reported in patient information leaflets. Gal and Prigat interviewed professionals who developed leaflets in large health organizations and the research findings suggested that readability is an important concern for developers, but that organizational complications cause interference when creating leaflets, such as organizational politics. This is not beneficial for patients from the general population or individuals with an ID, as research has shown that being able to recognise letters and decode may not be sufficient for understanding written information (niace, 2009). The lack of confidence in the skills needed to understand complex information can create a barrier for those who want to understand this

information, such as individuals with an ID. The next subheading explores accessible

information and how this should support not only individuals with an ID but person from the

general population and with other disabilities.

Accessible Information

Accessible information comes in many different forms, and depends on what is

accessible to that individual and whether it reaches the individuals specific need (Collis,

2012). Accessible information gives the information the individual wants without over

complicating or over simplifying. There are several ways to change and provide information

dependent on needs. One example of this is if you are blind or partially sighted you can have

information in an audio file, braille, large print or tactile diagrams (RNIB, nd.). A second

example is if you have a specific learning difficulty like dyslexia there are guidelines

available on how to make text accessible and easier to understand, such as changing the font

or the page's background colour (Dyslexia Association Ireland, n.d.). Information is not just

made accessible for individuals with disabilities or difficulties, it has also been made

accessible for the general population. The Plain English Campaign was started in 1979 by

Chrissie Maher OBE with the purpose of making complicated documents as clear as possible

for the general population (Plain English Campaign, 2015). The Crystal Mark was developed

by the Plain English Campaign to indicate that a document has clarity. This is currently being

used by over 1600 organisations. Everyday writing was designed for members of the general

public (Collis, 2012); this form of writing incorporates words that are used in everyday

language. Research by the Basic Skills Agency and National Institute of Adult Continuing

Education (known as NIACE) resulted in guidelines being produced that advise professionals

how to make information suitable and readable for the general public. Therefore, importance

must be placed on the design and readability levels because this determines how easy a

document is to read (NIACE, 2009).   However, this research primarily focuses on

individuals with an ID because research has shown that although a document may have a Crystal Mark, it can still be deemed as too difficult to understand for certain individuals with an ID (Collis, 2012).

There have been several key developments in removing barriers for people in relation to the readability of significant information. The Welsh Government values the opinions of people who use their public services and use this in any reform they make (Collis, 2012). The Welsh Government have attempted to conduct all consultations with the public involve accessible information. In the NHS in England there is the Accessible Information Standard, meaning that everybody should be able to receive health information in a format that is easier for them to read (NHS England, 2016). It is a legal requirement ensuring that patients should now be able to communicate effectively with health and social care services how they want. There are now several laws, legislations and acts that protect a person's right to accessible information. The Disability Discrimination Act states disabled people must be treated fairly (Real Roles, 2010). This law states that public places and public organisations must make adjustments for people with disabilities so that they will be treated as fairly as others. This includes making accessible information so that a person with a disability understands information to the same level as someone without a disability.   The Mental Capacity Act (Department of Health, 2005) states that a person is not to be treated as unable to make decisions until attempts have been made to help the individual to understand the information (Disability Wales, 2013; Collis, 2012). This gave people with an ID the power to make decisions for themselves with information they understand. During 2010 the Equality Act was introduced, which asks organisations to make reasonable adjustments and to think ahead for the needs of individuals with a disability (Collis, 2012). An example of this would be providing information to clientele that suits all needs. The Human Rights Act (1998) was introduced so everyone would be treated in a good and a fair way (Disability Wales, 2013).

Everyone within this act is equal and should be treated fairly. For example an individual with a disability should get the same standard healthcare as anyone else. If this means an individual with a disability should get adjustments to understand the healthcare then that should be accounted for. Within the Human Rights Act or the Equality Act the United Nations Convention on the Rights of Persons with Disabilities was released to make the law stronger (Collis, 2012; Disability Wales, 2013). There are several articles within the act that make reference to accessibility. For example, the right to work and have extra support or special equipment if you need it, such as a keyboard with larger keys if you have issues with your vision or a form of accessible information called Easy Read.

Easy Read

Easy Read is another form of accessible information that is different to both everyday writing and Plain English and is targeted at individuals who have an ID. Easy Read is the use of easy words, short sentences and pictures (Collis, 2012). An Easy Read document should tell you what you need to know and should be easy to understand. Easy Read is widely used to improve the lives of those with an ID in the UK, for example, accessible information, including Easy Read has been part of developing changes in the way people with an ID access services and how involved they are in important decisions such as policy making (Walmsley, 2010). Tuffrey-Wijne et al. (2013) identified Easy Read information as a frequent used reasonable adjustment for patients with an ID within NHS Hospitals.

Easy Read is produced by Easy Read guidelines and research suggests that in order for a piece of Easy Read information to be effective there needs to be planning, user consultation and testing of materials (for example Strydom, Forster, Wilkie, Edwards, & Hall, 2001). Ward and Townsley (2005) stated that information producers need to work in partnership with the individuals from their target audience from the very beginning of producing. Although there is a cost to this such as transport and support costs for using

individuals with an ID there is also benefits such as the individual with an ID learning new skills and gaining confidence. In Collis (2012) guidelines Clear and Easy she discusses how information needs to be checked by both the person producing the information and a panel of individuals who the information is targeted at. Having a panel checks for misunderstandings that the producer may have overlooked, helps to ensures that the final draft avoids these misunderstanding. It is suggested work should go in front of the panel several times before it is finally published. The involvement of individuals with an ID in sourcing and development Easy Read is being used by organisations such as United Response is "Easy News" (United response, n.d.). This is news produced by people with an ID for people with ID, claims to be the first of its kind and has won awards.

There are several different courses and guidelines available on Easy Read, for example Clear and Easy by Collis (2012). There are several different organisations that produce Easy Read information such as Learning Disability Wales (n.d.) and other companies that produce Easy Read photos such a PhotoSymbols Cloud (Le Grys & Seymour, 2015). There are also companies and websites where you can buy or download booklets of Easy Read information, for example Easy Read Health Wales (Learning Disability Wales, 2013). Health Rights Information Scotland (as cited in Walmsley, 2013) discovered that although Scottish Health Boards where producing alternative format leaflets there was little demand or effort put into distributing them. This research is ten years old, it is not known if there is any follow up research assessing this in 2015.

Unlike the Crystal Mark, there is no official symbol or body who monitor the production and quality of Easy Read. This means there are currently many organisations and individuals producing Easy Read in different ways and of different quality. Effectively anybody could read or attend a course and start producing Easy Read. This is affecting the availability and the quality of the information that is being produced using the Easy Read

format (Walmsley, 2010).

Research by Mander (2015) focused on the experience, knowledge and attitudes of individuals towards accessible information, which included Easy Read. The research was qualitative in the form of either semi structure interviews or semi structured focus groups. There were a total of 18 participants from four different groups. These were adults with an ID (n=4), specialised ID service staff (n=7), staff from mainstream public services (n=4) and speech and language therapists (n=3). There were three different discussion outcomes, the ideology of accessible information, accessible information practice and the deliver of accessible information and consequent outcomes. There were several different outcomes, such as accessible information was not just being viewed as a resource but also as supporting the individuals understanding and comprehension needs. There was also a fast difference in practices seen which does not comply with national policy and guidance that is currently available. For example, professionals and speech and language therapists who understood the needs of individuals who need accessible information wanted to produce accessible information and saw it as part of their role. While others who were less experienced tended to blame their lack of practice in accessible information on uncontrollable factors. Buell (2015a) produced a commentary on Mander's (2015) research. Buell discusses three reasons why there is no consistency between the ideal way accessible information should be produced and the way it is currently delivered. Buell stated that there is no way of making this closer in this current climate. The first argument from Buell is making a good design is not an easy task. Buell discussed how there needs to be a good analysis of the audience the information is targeted to, for example their current baseline understanding of the subject by the target audience. Not knowing what the audience needs could result in a document that has too much information for the individual to process, for example the over use of colour and pictures. The product then needs to be tested on the target audience and that revisions (if needed)

should be made. Buell discussed how this can be time consuming and expensive and therefore is not achievable due to the way our current systems work. The second argument is the need for understanding of information and the ideas that are given. Time and effort should be taken to ensure that information results in cognitive gain and understanding for individuals it is intended for. Some individuals will require more information for understanding and cognitive gain than others. The Third argument is the differences in the audience the information is intended for. Information should be personalised to make it easier for the individual to understand as groups can be so different in abilities.

In relation to Easy Read, it could be claimed that there is conflicting research evidence about the effectiveness and benefits of Easy Read for individuals with an ID. Karreman, Van Der Geest and Buursink (2006) asked participants with an ID to read two websites, one website used 'easy-to-read' (author word use) and the other was a non-adapted website. The results suggested that participants had a better comprehension of Easy Read text than non-adapted text. However, other research suggests that some people with an ID may be temporarily confused by Easy Read leaflets. Strydom et al. (2001) detailed the process of developing and drafting an information leaflet for individuals with an ID about a specific psychiatric medication. The researchers enlisted the help of service users who gave their opinions on aspects of the information leaflet, for example, participants preferred pictures to symbols. This allowed the researchers to focus on the need of the user and produce what they believed to be a better information leaflet. Following on from this research, Strydom and Hall (2001) gave participants either medication information verbally by a nurse or psychiatrist (control group) or medication information verbally with the Easy Read information leaflet about their medication (leaflet group). Results from this research indicated that neither group benefitted from the information given. Participants in the leaflet group did not show any significant improvement on knowledge about their medication.

Individuals in the leaflet group scored significantly less than participants in the control group, however when tested again a month later, there was no significant difference between the groups. When the scores of individuals with a mild ID were analysed separately to those individuals with a moderate ID the leaflet group scored significantly less than individuals with a mild ID in the control group. Strydom and Hall suggested that the Easy Read leaflets were confusing for participants with a mild ID and perhaps less confusing for participants with a moderate ID because of their lower reading ability. Buell, Bunning, Langdon, and Pounds (2014) research investigated the different between multiple Easy Read samples and its matching "mainstream" versions for the UK Department of Health. They did multiple quantitative and qualitative linguistic analysis of the text of samples and found that Easy Read samples where more restrictive, directive and generally less inclusive. They concluded that there needed to be a change in the way Easy Read is made.

It is stated in guidelines that Easy Read text should be accompanied by images, however, there is conflicting in their recommendations on this subject, with some studies debating the question: What is more suitable, pictures or symbols? Whilst Strydom et al. (2001) suggests that symbols may not be as effective as pictures; Jones, Long, and Finlay's (2007) research results suggest that participants had higher comprehension when given passages with symbols for adults with mild or borderline ID. Poncelas and Murphy (2007) explored symbol-based documents where participants were given simplified manifestos, one text based and one symbol-based with text. The participants were then assessed on their understanding of the document; the results suggested that understanding was not improved by adding symbols to simplified text. They concluded that perhaps participants needed to be familiar and understand the meaning of the symbols in order to have a full understanding of the text. Other research debates whether there is a need for pictures or symbols at all and that simplifying text is sufficient in increasing the understanding of the passage for individuals

with ID. Fajardo, Ávila, Ferrer, Tavares, Gómez, and Hermández (2012) asked participants

with mild ID to read "easy-to-read" (author defined) text from news articles from a Spanish

news website. The results indicated that participants were able to comprehend most of the

easy-to-read text. Dye, Hare and Hendy's (2006) research results showed that providing

additional images and reducing demand on memory made no difference to participants with

ID's understanding of text. When evaluating different types of questionnaires, Cardone

(1999) suggested that supplementing a questionnaire with pictures did not help participants

with lower language abilities. He suggested that research needed to be done into the type of

questions asked and not the effect of pictures. However a major criticism of this research is

that it does not address Easy Read and the guidelines that we use now. Hurtado, Jones and

Burniston (2014) presented participants with two sections of an Easy Read document. One

section had Easy Read text and pictures and another section had pictures. All the participants

were supported to read the pictures with text section and the text from the pictures only

section was verbalised to participants. Participants' knowledge was tested before during and

after each section. Results from the research suggested that perhaps placing pictures

alongside text is not the most effective way of presenting information. Hurtado et al. further

suggested that perhaps using pictures and auditory cues only allowed a greater processing

capacity than if the participant was to receive text, picture and auditory information together

as this seemed to be a form of sensory overload for the participants.

It appears that Easy Read is having an impact on web design as a number of websites

are providing information written in Easy Read style for example Learning Disability Wales

(2013). Williams and Henning's (2015) study wanted to determine the best web design for

people with an ID. Participants looked at eight different interface configurations and were

asked to carry out tasks and answer questions on the eight different interfaces. As a result, the

study has a series of recommendations, for example, juxtaposing (placing side by side)

images and text and using phrases not sentences. Buell (2015b) has been working with an advocacy group in Norfolk called "Opening Doors" on "The Easy Read Project". From discussions with various advocacy groups, Buell discovered that there was no correct or specific way to develop Easy Read information. Participants discussed how it took a long time to make Easy Read of a good standard and how difficult it could be to agree on how to present certain information. They also all discussed how expensive professional organisations were. There was a mixture in feedback in regards to the use of symbols, photographs, photographs drawn for them, photographs they drew themselves or no photos at all. Buell discovered that many individuals asked for additional help to read and they needed help to understand it. The biggest finding from "The Easy Read Project" is that adapting the Easy Read and explaining information simply is not enough for adequate understanding. This could lead to the conclusion that every individual should have a plan around how is best to support them to understand new information. Easy Read is not the only way to provide information to those with an ID. Ferguson and Murphy (2014) examined the affects of three training sessions had on the ability of adults (n=28) with an ID to consent to taking medication. They found that after three training sessions participants had an increased knowledge of their medication and as a result had an increased ability to consent to taking their medication. They argued that information may need to be presented to some individuals in training sessions as they would be more effective than leaflets.

Oldreive and Waight (2013) discussed how accessible information needs to be personalized and adapted for the individual. Easy Read does not cater to those who cannot read or have very basic literacy skills, for example, those who cannot read more than a few words or struggle with spelling or recognising their own name. Walmsley's (2013) commentary on Oldreive and Waight (2013) discussed her opinions on accessible information for individuals. Walmsley agrees with them and discussed how information

needs to be tailored to the individual and during her time trying to design courses for individuals with an ID at the Open University she first started to support that Easy Read being used as a tool for understanding but that we should not be reliant on it as the only form of communication. The author discusses four criticisms on Easy Read (Walmsley, 2013, 2010) .The first is that the use of images in Easy Read can be a hindrance to individuals with an ID, for example the use of too many images. The second is that Easy Read can be converted in a way that does not describe the information correctly, for example making the information too simple. The third is that some Easy Read is oversimplified because individuals make assumptions as to the levels of literacy an individual with an ID can achieve. The fourth is that individuals need to be informed about the information available to them. There is no use in producing Easy Read if the audience it was attended for do not know about it.

The process of finding Easy Read research papers and information for this research was not an easy process and Easy Read is a fairly new and under-researched concept. All papers that were made publically available are from 1999 onwards, some do not specifically address Easy Read, have small sample sizes or address opinions from personal experience and not research. There is currently not enough literature to explain why Easy Read is such a popular form of accessible information and whether it is fit for purpose.

Research Question

Due to the lack of literature on Easy Read and the conflicting findings, the current study focused on individuals with a mild ID who are most likely to come into contact with Easy Read. Given the research of Tuffrey-Wijne, Giatras, Goulding, Abraham, Fenwick, Edwards and Hollin (2013) identifying Easy Read as a frequently used adjustment within the NHS and the popularity of websites where you can access Easy Read information on health related subjects, this study rationalized that it would be a suitable reasonable adjustment to

use when introducing new health information to persons with an ID. The study also further

decided to focused on the topic of health related literature and ID as people with an ID have

greater health needs than the general population (Emerson & Baines, 2010). It was hoped

that by introducing Easy Read as a suitable reasonable adjustment it would provide better

health outcomes for an individual with an ID and help reduce health inequality. The purpose

of this study was to assess whether an individual with an ID can read a sample Easy Read

leaflet independently or if the individual needs support to read the sample in order to ensure

understanding and cognitive gain (remembering the appropriate information). Knowledge

and understanding of content was measured before and after the intervention. This research

provides further evidence into the effectiveness of Easy read, and focuses on whether or not a

level of support is required in order to comprehend the information appropriately.

Method

Participants

The research consisted of six participants (female n=3 and male n=3) aged 25-55

(M=34.5 years). Relevant participant and respondent demographic data was collated into a table

(Appendix A for Table 1). Table 1 is a summary of participant gender, age, corrected vision (for

example glasses), type of disability, chosen language, nominated individual and residential

setting. All participants self identified as having an ID, and aetiology was known for three

participants who had DS. Two other participants also identified as having ASD.

The inclusion criteria consisted of a diagnosis of an ID, aged between 18 and 60

years, and could read with or without glasses. All participants who volunteered to take part in

the research and completed the research had passed the functional assessment of capacity in

accordance with the Mental Capacity Act (Department of Health, 2005: see procedure

section). Due to the inclusion criteria four participants who expressed interest in the research

were not used in the final analysis due to not completing the intervention to the methodology.

Measures

Three measures were used in this study:

Baseline Health Questionnaire:

This non-validated questionnaire (Appendix B) was designed to gather the participants' basic knowledge of health. The questionnaire had 15 questions based on health to assess participants' current knowledge of health. Two of these questions were closed questions and 13 were open questions. Eight of the 15 questions were from the two questionnaires mentioned below (4:4 ratio). These four questions were then at a ratio of three open and one closed questions.

Questionnaire "Having an Eye Test":

This non-validated questionnaire (Appendix C) had ten questions, four of which were in the Baseline Health Questionnaire. The purpose of repeating the questions again was to assess the knowledge gained by participants before and after exposure to the Easy Read sample. There were eight open and two closed questions in this questionnaire. After the participants finished reading the Easy Read sample, they were then asked the questions. Questions were not in chronological order to minimise order effects.

Questionnaire about "All about Health Checks":

This non-validated questionnaire (Appendix D) had ten questions, four of which were in the Baseline Health Questionnaire. The purpose of repeating the questions again was to assess the knowledge gained by participants before and after exposure to the Easy Read sample. There were eight open and two closed questions in this questionnaire. After the participants finished reading the Easy Read sample, they were then asked the questions. Questions were not in chronological order to minimise order effect.

Materials

All materials given to the companies and participants were available in both Welsh and English. These were translated by a specific Easy Read Welsh language translator. Although Easy Read is an established tool to support individuals with ID to comprehend information it was difficult to find samples that were consistent with Collis (2012) booklet "Clear and Easy". The materials were found using online resource easyreadhealthwales.org.uk. Due to time constraints it was not possible to involve individuals with ID in the sourcing and development of the materials. As discussed in the introduction a good piece of Easy Read should involve people with an ID in the development and sourcing of Easy Read materials. It is unknown if this occurred for the two pieces of Easy Read involved in this study. Due to the nature of the research, it was important that the topics being used would not cause issues for participants ethically, or a topic that could be deemed traumatic.

Having an eye test Part A:

This Easy Read booklet was produced by The Clear Communication People Ltd on behalf of SeeAbility (Appendix E). The booklet was divided into two sections, Section A and Section B. Section A was 353 words long and had a SMOG index of 13.8. Only Section A was used in this research as its length and SMOG test results were similar to the booklet discussed below. Permission was given by Stephen Kill, the National Manager for eye care and vision to use this booklet in this research. The booklet contained Easy Read text and Photosymbols (Le Grys & Seymour, 2015) imagery and "real life imagery".

"All about Health Checks"

This Easy Read booklet was produced by Learning Disability Wales on behalf of Aneurin Bevan Health University Board (Appendix F). Permission was given by Aneurin Bevan University Health Board to use this booklet in the research. The booklet contained Easy Read text and photosymbols (Le Grys & Seymour, 2015) and "real life imagery". The

whole booklet was used in this research as its total word count was 344, and had a SMOG index of 13.2.

The SMOG index otherwise known as the Simple Measure of Gobbledegook is a calculation of the readability level of a piece of text (niace, 2009). Having a SMOG index between 13 and 14 means that the two Easy Read samples have a reading age below that of level two at the National Adult Literacy Standard. To put this into context, level 14 is the reading standard of the newspaper "The Sun". At entry level two adults are expected to be able to read and understand short documents about familiar subjects (The Basic Skills Agency, 2000). Although the SMOG index did not specify that participant would be reaching this level it was decided to choose these samples as at level two individuals are expected to use illustrations and captions to understand information, such as seen on Easy Read.

Apparatus

A Dictaphone and video recorder were used in Session Two of the research to capture each participant's response to the questions. This allowed the researcher to focus on the research at the time and to mark the participant's answers afterwards. It also ensured that the researcher was able to complete fair marking by listening and watching the results. The Dictaphone used was the DM-670 model manufactured by Olympus. The video recorder was lent by Bangor University School of Psychology and was the Legria FS200 model manufactured by Canon.

Training

The researcher had experience of working with individuals with an ID and had previously completed Easy Read training and has had previous experience in producing easy read for individuals with ID.

The researcher had previously received training sessions on the Functional Assessment of Capacity in line with the Mental Capacity Act (Department of Health, 2005) during her undergraduate degree.

Nominated Individuals

A nominated individual (NI) accompanied the researcher during Session Two. The NI acted as the independent support for the participant. In this research support was defined as a nominated individual who would support the participant to read through the sample with the participant. The NI was responsible for conducting Phase One and Phase Two of the research in Session Two: the NI could identify particular key terms and explain them. Participants were allowed to ask questions about the meaning of words or sentences during reading. The NIs were two individuals identified from the sponsor company, both NIs had a background in providing support and information to individuals with an ID. Nominated individual one was male and an English only speaker who supported four of the participants. Nominated individual two was female, a fluent Welsh speaker and supported two of the participants.

Ethical Consideration

The researcher was required to complete and have a satisfactory Disclosure and Barring Service (DBS) check. This confirmed that the researcher was suitable to be working with vulnerable adults. On arrival and departure, the researcher was required to phone a responsible individual, who was aware of the location.

Many ethical considerations were taken into account during this research. No participants received payment for taking part in the study. This was to limit participants taking part for external reasons and to try to ensure participants were taking part in the research because of a genuine interest and a capacity to understand what it meant. Potential participants were not put under pressure to take part in the research at any point. All

participants were informed that is was OK for them to decline to take part and that they did

not have to give a reason why they were withdrawing. Sessions one to three were designed

so that participants had more time to think about participating. If participants did not have

capacity to take part it was explained to them why they would not be able to take part in the

research this time. Participants were offered breaks regularly and were continually reminded

they could stop at any time. This was to prevent tiredness and fatigue. If a participant became

distressed at all during the research they would be able to stop the research immediately. If

the researcher observed a participant becoming distressed a break was issued and could be

reconvened when it was appropriate. Support was offered in terms of providing the phone

number for the Wales Learning Disability Helpline. The researcher would also ask if the

participant would like someone to be contacted. Participants were made fully aware of who to

contact if they wanted to complain or if they do not feel like taking part in the research

anymore. This study submitted a full ethical application to both Bangor University and NHS

Research Ethics Committee. The Application for Ethical Approval was granted by Bangor

University on the 23/07/2015 and granted by the NHS Research Ethic Committee on the

21/08/15 by reference number 15/WA/0301.

Design

Quantitative methods were used for data analysis. The intervention used a single case

within subject design; investigating the effects of the use of Easy Read with and without

support. The independent variable (IV) was the Easy Read with or without support. The

dependent variable (DV) was the score on the pre- and post-questions. Constant variables in

the study were that all participants were given the same two pieces of Easy Read, however

whether or not they were given support varied (as discussed in the procedure).

Procedure

The research consisted of three sessions. All sessions occurred within three to ten

days of each other. Once ethical approval was granted via the school of psychology ethics committee and NHS Research Ethics Committee approved the research, the researcher emailed organisations/groups and asked for permission to attend and give a brief talk about the research. An agreement in principle was arranged with, four organisations in the North Wales area. Three were advocacy service and one was a social enterprise. After data collection began a further four organisations consisting of two day services, a supported living provider and a sports club for individuals with an ID.

After contacting various groups the researcher sent the poster information sheet (Appendix G) to the identified groups and organisations to advertise to their members who could read it if they wished, before the researcher attended session one.

Session One - Recruitment

The attended nine pre-arranged meetings at groups as a guest. During the meeting the researcher gave a short presentation (Appendix H) regarding the research. In the presentation, it was explained to participants what would take place during the research, what Easy Read was, a description of the exclusion and inclusion criteria and that consent would need to be obtained for the use of a Dictaphone and video camera in Session Two. Any potential participants were encouraged to ask any questions they had during the session. If the participant wanted to take part, they were informed to tell the researcher at the meeting and provided their contact details. The researcher also gave out information packs containing an information sheet, contact sheet, postal form and freepost envelope (Appendicies I, J & K). The contact form and postal form was so participants could contact the researcher at another time to express an interest. Once an individual expressed an interest, the researcher arranged a date between three to ten days after session one to complete session two.

Session Two - Testing

During testing, the participant met with the NI and the researcher at an agreed time and location. During Session Two, participants were asked to re-read the information sheet (Appendix I). Participants were then assessed for capacity using the protocol for assessing capacity (Appendix L). The researcher and the participant worked through the form and the researcher marked if the participant understood what was being discussed, for example, who the researcher was and why the researcher was there. If a participant had capacity to consent they were then asked to provide informed consent for participation in the research (Appendix M). Participants who did not have capacity were not included in the study. Participants who did not have capacity were thanked for their time and letting us visit them that day. They were told that they were not suitable to take part in the research this time.

The two Easy Read booklets were used during Session Two (Appendices E & F). In order to control order effect, participants were randomly selected to take part in one of two different phases. The two phases were; Read "About health checks" with support (Phase One) and read "You need to have your eyes checked" without support (Phase Two) or read "About health checks" without support (Phase Two) and read "You need to have your eyes checked" with support (Phase One).

Participants were given the option for a break between both phases. Participants were tested on baseline knowledge of health by using the Baseline health Questionnaire prior to Phases One and Two (Appendix B). Each individual was monitored and allowed extra breaks if needed.

Phase One

Participants were given a randomly selected booklet of Easy Read from the two samples without support (Appendices E or F). Participants were given one hour to read the Easy Read sample. Participants were then asked to read this Easy Read sample independently. Participants were informed that they were not allowed to ask questions about

the meaning of words or sentences during reading. They were told that they could not ask questions as we were trying to mimic what would happen if they were reading this alone. If they did ask questions during the reading they would be reminded that they were not allowed to ask questions. After participants finished reading the sample, they were questioned about their understanding using the related questionnaire (Appendices C or D).

Phase Two

Participants were given a randomly selected booklet of "Easy Read" from the two samples with support from the NI (Appendices E or F). Participants were given one hour to read the Easy Read sample with the support from the NI. After participants finished reading the sample, they were questioned about their understanding using the related questionnaire (Appendices C or D)

At the end of Session Two participants were given a debrief form explaining the purpose of the research (Appendix N). The researcher went through the debrief form with the participant. A phone call was then arranged with the participants for Session Three. Session Three was scheduled between three to ten days after Session Two.

Session Three – Close

The researcher phoned the participants and thanked them for taking part and that this was the end of the research.

Analysis

Data was entered into Excel and analysed.

Capacity and Consent

During the second meeting, participants were asked to re-read the information sheet (Appendix I). Participants were then assessed for capacity using the process as discussed in the procedure and as stated in (Appendix L). If participants passed the functional assessment of capacity and were considered eligible for the research, they were asked to provide

informed consent to participate. Participants were asked if the session could be recorded with a Dictaphone and a video camera, if the participants agreed they were then asked to initial the consent form related to consenting to being recorded (Appendix M). However, if participants failed the Functional Assessment of Capacity, they were not included in the study.

Data Protection

Participants were informed where their forms and data will be stored when they read the information sheet (Appendix I). Assigning each participant with a unique participant ID and removing participant identifiers from assessments or data included in reports and transcripts ensured confidentiality and anonymity.

All electronic data was stored on an encrypted laptop and adhere to the Data Protection Act and the data protection requirements set by Bangor University. Participants were informed that Dr C Hughes and the researcher were the only individuals who would see or listen to the recordings. The recordings would be transcribed and destroyed within seven days of Session Two. Information on paper would be kept in a locked cabinet in a locked room in Brigantia building for ten years.

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Results

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Two questionnaires, Questionnaire about "Having an Eye Test" and Questionnaire about "All about Health Checks" were used to measure participant understanding after reading two pieces of Easy Read one with and one without support (Figure 1 and 2). Participants were given ten questions and were awarded one point for each correct answer. Participants could get one point for each correct question and zero for an incorrect (Figure 1). There were ten questions and no negative marking. Although no overall significant difference was found between participants understanding and whether or not they received support or no support, there is an individual difference. Participant score and differences are discussed below.

Participant One

Participant one was a 33 year old male who identified as having ASD and an ID. This participants showed little difference between support and no support. Interestingly participant one had a diagnosis of ASD but did not appear to have an ID. The researcher came to this conclusion because the participant had lack of weaknesses in two of the three domains. This participant had strengths in both the conceptual and practical domain, for example he was very knowledgeable in local geography and self managed his own money. Participant one told the researcher he was very confident in his reading skills and felt they were very good as he had completed a general literacy skills improvement course in college. Although participant one was diagnosed with ASD and as previously discussed a trait of this is known to be a difficulties in social interaction participant one appeared to be happy to engage in conversation with the researcher. However, he did not seem comfortable in gaining support from the NI during the intervention, he seemed to be more comfortable with the researcher. This could be because the participant had previously met the researcher and had multiple discussions with the researcher meaning he was more familiar with the research than the NI that he had just met. During the intervention where the participant had no support, one sentence on the Easy Read booklet was missed. This meant although all words read were read accurately due to missing out this sentence meant the participant scored zero as he did not see the information he needed to answer the question.

Participant Two

This participants was a 28 year old male with a diagnosis of DS. This participant showed better results when given support to understand information compared to no support. Anecdotal observations showed that this participants further engaged in reading the Easy Read sample and seemed to process the information in more detail when given support. When reading alone he appeared to be reading out loud but not processing what was being

read as well as when he was given support, the data reflects this. The parent of this

participant stated that he had good reading skills but did not seem to process what was read.

Participant Three

This participant was a 41 year old female with DS who also performed better when

given support to understand information when compared to no support. This participant's

carer stated prior to the research that their daughter could read but not comprehended the

information. Similar to participant two, this participant choose to read out loud when reading

alone and when with support. Figure 4 demonstrates there was a greater understanding when

given support to understand the Easy Read.

Participant Four

Participant four was a 25 year old female with a diagnosis of Down's Syndrome. She

showed little difference between receiving support to read the sample of easy read or reading

the sample of easy read independently. Participant four enjoyed acting and therefore, was

used to memorising scripts. She also liked to read magazines and liked using the internet for

accessing websites such as social media (mainly facebook) or searching (google) for

information about her favourite TV programmes. It was evident through observing

participant four's behaviour during the research that she wanted to understand the

information without support. Participant four told the research that she enjoyed doing the task

independently and was observed to be talking through the information whilst reading instead

of merely reading what was written.

Participant Five

Participant five was a 55 year old female with a self diagnosis of an ID. This

participant showed no increase in either the support or no support intervention. She discussed

her interest in Easy Read in detail with the researcher and she felt it was important that

people with an ID had appropriate access to high quality Easy Read information. She had

good knowledge about Easy Read and had recently been involved with making Easy Read for the local authority about certain services for individuals with an ID. The participant also had an interest in health related knowledge as she felt it was important she understood her health and that she should be making decisions about her health and not someone else. She was not excluded from this research as her knowledge is what the researcher believed every person with an ID should already know.

Participant Six

Participant six was a 25 male who had a diagnosis of ASD and identified as having a mild ID. He showed a better understanding when receiving the piece of Easy Read without support. During a conversation with the researcher, participant six stated that he enjoyed reading fictional books and was reading popular young adult books. He also liked acting so was used to seeing and memorising scripts. During the intervention participant six appeared more relaxed when reading independently compared to when he received support. He seemed more focused on task not having to take social cues from the NI. The researcher also had difficulty trying to get the participant to engage in conversation as he had to be prompted to begin discussions and the research had to find a specific interest of the participant (such as the young adult books) to begin a conversation. Therefore, he seemed more comfortable without support to read the Easy Read document. This is consistent with previous research, that individuals with ASD have difficulty with social interaction.
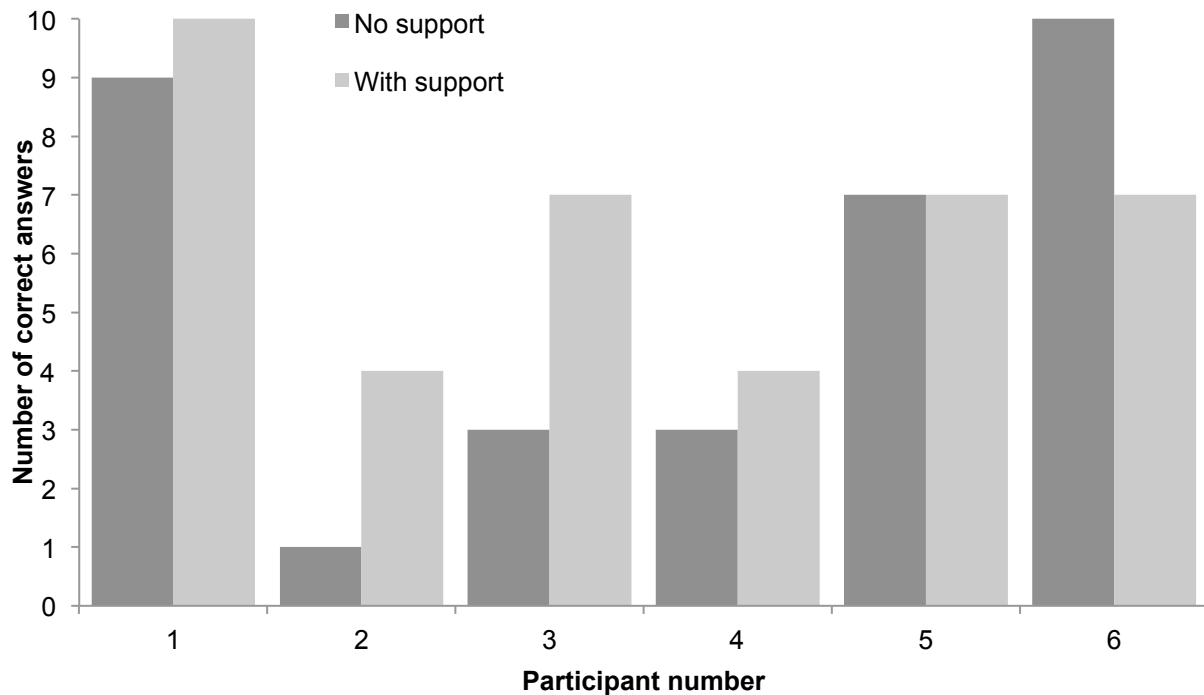
Figure 1. Number of correct answers for each participant after reading with and without support.

Figures 2 and 3 show the mean score for each Easy Read sample pre-test and post-test and with or without support. Participants had four of the same questions pre-test in the Baseline Health Questionnaire and post-test with either the questionnaire about "Having an Eye Test" or questionnaire about "All about Health Checks". Participants could score one mark for each question. Participants who had support had a higher mark post-test than participants who had no support. The mean improvement for participants who read the Easy Read sample "All about Health Checks" with support was of 1.66 (pre-test M=0.67, post-test M=2.33). The mean improvement for participants who read the Easy Read sample "All about Health Checks" without support was of 0.33 (pre-test M=1, post-test M=1.33). The mean improvement for participants who read the Easy Read sample "Having an eye test Part A" with support was of 1 (pre-test M=1.67, post-test M=2.67). The mean improvement for participants who read the Easy Read sample "Having an eye test Part A" without support was of 0.33 (pre-test M=2.67, post-test M=3). A Wilcoxon Signed-Ranks Test was used to

compare the post-test score of participants both with and without support. Results indicated that there was no significant difference ($z. = -1.60, p < .109$) between participants post-test score with and without support.
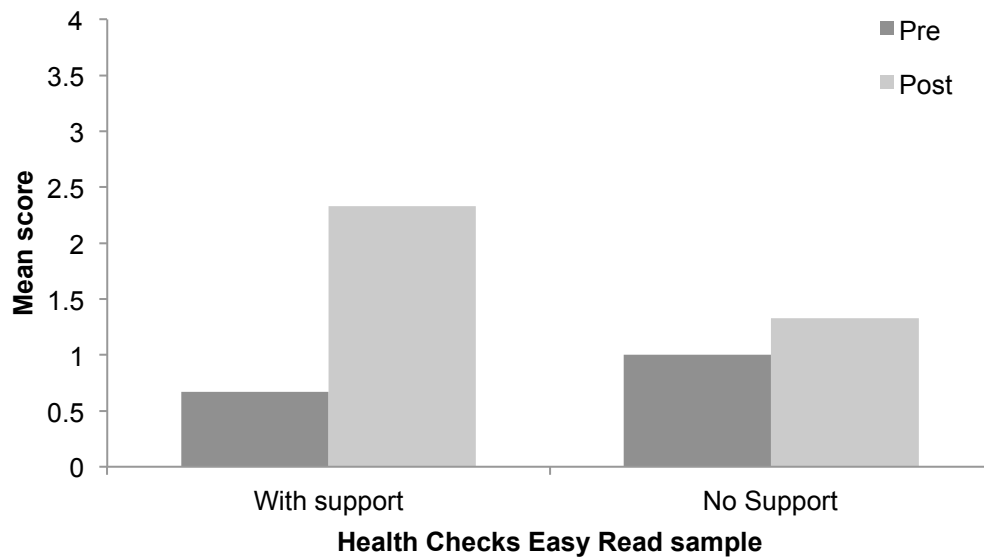
Figure 2. Mean pre-test and post-test scores for with support and no support in reading the Easy Read sample "All about Health Checks".
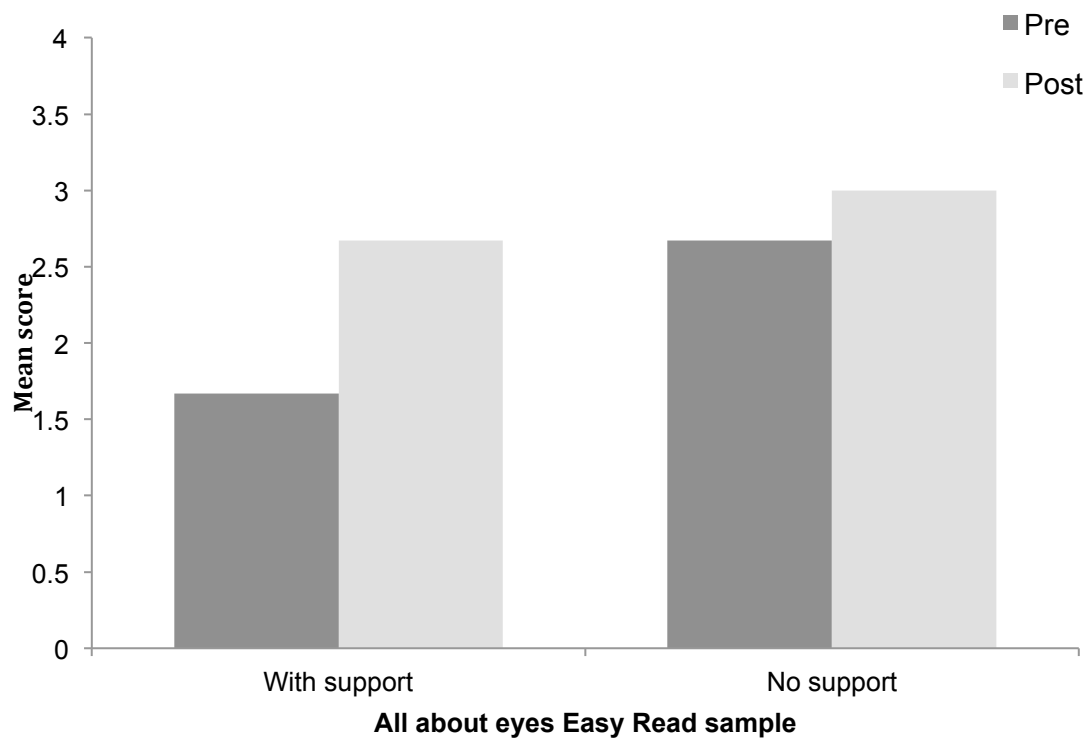
Figure 3. Mean pre-test and post-test scores for with support and no support in reading the Easy Read sample "Having an eye test Part A".

Discussion

The main aim of this study was to see the difference in health related knowledge gained by participants at baseline and after two interventions; reading a sample of easy read either with or without support. The overall result of this study suggests that individuals respond differently to support based on their individual needs. Individual differences and observational findings support the need for individuals with an ID to have the right level of support through individualised support in order to help the individual understand new information. Overall mean pre-test and post-test scores for with support and no support in reading both Easy Read samples showed a positive trend for participants. Although the majority of participants gained more knowledge in the support condition, this was not the case for all. This highlights the importance of individualised packages to ensure everyone understands the information they have been given, especially when this is in relation to as something as important as health care. However, the numbers in this research are small so we need to hold this with some caution. The Wilcoxon Signed Ranks Test did not show any significant results. This does differentiate to the function and practical conclusion of the results as discussed above. It must be questioned if this would show as significant if the sample size was greater.

Excluded participants

Due to the inclusion criteria four participants were removed from the final analysis. Participant seven received the Easy Read sample with support to begin with but when the second intervention was being conducted (where the individual was asked to read the Easy Read sample independently) he refused due to lack of his reading ability and reading confidence. He discussed with the research that he felt that the way he had been taught in

school is not the way people actually read. Participant seven performed better during the second sample of easy read with support, this may have been due to the NI having experience supporting this individual in the first sample of Easy Read had a better understanding of how to explain the information to the individual. The participants refusal to read without support is consistent with research from previous researcher such Forts and Luckasson (2011) and Browder, Gibbs, Ahlgrim-Delzell, Courtage, Mraz and Flowers (2008) who have discussed how it has been assumed that individuals with an ID do not have the required skills set to be literate and has resulted with individuals with an ID only been taught "survival" reading skills, such as their home address.

Participant eight needed constant interaction throughout the research otherwise he would disengage. He liked constant interaction and seemed to loose attention and interest if you did not regularly engage with him. Participant eight completed Phase One with support, the NI read to the participant and explained the words and concepts. During Phase Two without support the participant managed to read independently with minimal reassurance and support to pronounce words and asked to have some concepts explained to him. Due to the support received in the phase where no support was suppose to be given the participants data was discounted. When the data was analysed it appeared that participant eight performed better in Phase Two. Out of both Phase the second form of support was the most effective type of support for this individual. This is consistent with research by Buell (2015a; 2015b), Oldreive and Waight (2013) and Walmsley (2013) who all concluded that every individual with an ID needs an individualised support plan, especially when they need to understand and learn new information significant information.

Participant nine was bilingual and requested to have both Welsh and English versions of the Easy Read samples during the phase with support. During the intervention phase of reading the Easy Read booklet without support, the participant asked for support and only

wanted the English copy. The NI just read the information to the participant and did not explain any concepts or words to the participant. This is different to what happened in the Phase with support but the was still discounted as the researcher felt it could potentially be bias data. There was no significant different in knowledge gained in either scenario.

Participant ten had a diagnosis of an ID and he had language difficulties which meant that responding verbally to questions verbally given to him required a lot of effort on the participants behalf. It became evident that the task demand was too much for the individual and he began to become disengaged and frustrated with the task. Therefore the researcher made the decision to change the format of the questions to multiple choice, as it was becoming clear that the previous format was not suitable for this individual. When he was supported to read the East Read sample the NI read to the participant and he followed with his finger and when asked if he wanted something explaining again he would indicate so by answering "yes" and pointing at the particular concept. Although not used in the final analysis, his results showed that more knowledge was gained during the intervention where support was given compared to when support was not given.

Limitations

Due to the small sample size the results of this study cannot be generalised to the wider population, however it can be argued that although a small sample size it seems evident that to produce information the can be comprehended by individuals with ID, the information need to be tailored made for the individual; much like the research conclusion of Buell (2015a; 2015b), Oldreive and Waight (2013) and Walmsley (2013).

A possible limitation of the validity of the research was that there was no suitable standardized measures on the topic chosen (health). Searching for standardized measures that was appropriate and fitted into the criteria of this research proved to be difficult. The research found that the ones that were available too long or too off topic to be used. It would have

meant adding another session into the research meaning non-validated assessments were used to assess participants' knowledge pre- to post-intervention. Due to time constraints it was not possible to validate this assessment before the research was carried out. The Easy Read used in the research did not produce an ethical issue however, if the research was to be replicated with more time available Collis (2012) guidelines would have been used to create custom Easy Read.

Another limitation during the intervention was the different levels of prompting and encouragement that participants needed to be able to understand the Easy Read information. The NI was not always the same person for each participant, although trained in delivery and used similar techniques to support the individuals with an ID, they were vastly different in their personality and interaction with participants with an ID and this could been seen as a limitation to the research. This again highlights the need for interventions to be tailored made to suit the individual's needs and different interventions are being explored. For example, Ferguson and Murphy (2014) as previously mention concluded that participants gained more information about their medication and an increased ability to consent to medication by taking part in three training sessions. They argued that information may need to be presented to some individuals in training sessions as they would be more effective than leaflets.

This research relied on the person with an IDs own opinion of if they could read well or not. It was decided early on in the research that using measures to test reading and comprehension of the participants would be time consuming and potentially off putting to the participants due to the other forms of data collection being conducted. There was a visible and vast difference in the levels of reading, this was a potential limitation and strength to the research. There were participants that signed up who were very strong readers and therefore showed an obvious need for no support and participants who were not able to complete both

scenarios because they needed support in reading. This made the data very variable but also showed how different individuals levels of reading are and the support they need.

Another factor that affected the results is that although the participants with ASD that signed up to the research did not have an ID, although these participants considered themselves to have an ID they had no formal diagnosis of an ID and appeared to not have an ID. Similar to what was discussed previously in the research by The National Autistic Society (2015), participant one and six may have had associated learning difficulties such as ADHD or dyslexia but not an associated ID. They also both seemed to prefer reading alone which is consistent with behaviour associated with individuals who have ASD.

Strengths

Although there were limitations to this research, there were also many strengths to the research, which could inform future research. This research is unique and is part of a new form of research on Easy Read and accessible information we are seeing emerge from researchers such as Buell (2015a; 2015b), Ferguson and Murphy, (2014), Mander (2015), Oldreive and Waight (2013), and Walmsley (2013).

As discussed above time was a limitation, due to reasons beyond the researchers control there was limited time (one month) for data collection. However, given that in this limited time frame, 10 participants volunteered to partake in this research, with more time the researcher is confident that recruitment of more participants would not have been problematic. A prominent trend and strength throughout the research was the genuine interest and enthusiasm from groups and potential participants regarding the use of Easy Read. The researcher found that groups were very willing to let her come and do a recruitment session at their group, which could highlight that organizations are wanting to aid research in assessing the most effective ways to provide important information.

Another strength from this research was the variety of strong opinions on reading and Easy Read. For example one potential participant from an advocacy group disliked the images and thought they were for children while another potential participant disagreed and thought they were useful. Although these were not formally recorded it did provide a point for future research as discussed below.

Although a small sample size was used in the current research from North Wales, the findings suggest that individuals with ID benefit from individualized tailored made Easy Read information. The current research, although small will serve as a foundation for other research in this fairly new field.

Future research

There are implications from this researcher that will provide as a guide of recommendations for future research into Easy Read and support. General improvements to the methodology of this study and a replication would hopefully produce and provide more significant and generalizable results. An improvement of methodology for future research could be the creation and the validation of a measure of participants baseline health knowledge. An improvement to the current methodology would be the implementation of another Session prior to Session Two which would measure participants literacy levels. Researchers should consider widening to UK wide participant pool and look for any possible cross-county or cross-country influences on results.

Recommendations for future research possibilities using this methodology would be the introduction of a familiar individual (such as a parent or carer) for the support scenario. Data from this could establish if an individual with an ID gains more knowledge with support off an individual who knows them well (such as a parent or carer) or an individual that does not know them well (such as the NI in this research).

The current research suggests that future research should look at individualized support packages when supporting individuals with an ID to understand new information. The research should produce individualized case studies using participants opinions, current knowledge and reading skills to find the most effective way of helping an individual with ID gain new knowledge on health. This research should also take into account the person with an IDs opinion on Easy Read and what they think works for themselves as individuals versus what actually works. For example, introducing a new measure such as a social validity questionnaire or a treatment acceptability questionnaire.

Implications and contributions

The theoretical and applied implications of the current research could have a great impact and contribution to society. As previously mentioned, this research has already contributed to an already limited field of research. Theoretical implications of this research have highlighted improvements that need to be made to the current methodology for future studies and other possible new areas of research, such as the type of support an individual requires to understand new information. We would then have a greater understanding of how best to provide support for individuals with an ID when they need to understand new information, particular about health. As previously mentioned by Ferguson and Murphy (2014), being able to understand health allows the individual with an ID to make informed decision about their own health themselves.

In the introduction it was discussed as how barriers were removed for people with an ID when it came to acts, laws and a change in government attitude towards inclusion when making change. A further theoretical implication of this research would be discussions with the government on how we can further these rights, accessibility of information and use them to improve the quality of healthcare for people with an ID.

An applied implication emerging from this research is the beginning of the conversation with individuals with an ID on Easy Read and how it can help them. By speaking to people with an ID, parents and carers there would be a better understanding of how to put together effective packages of accessible information combined with Easy Read. Although this would cost more to produce, the long term health improvements would potentially provide savings to the NHS as individuals will seek treatment early with minimal medical attention needed. Under such circumstances the prevention effectively would become the cure.

Currently individuals with a mild ID may lack information and understanding on certain health related subjects (Emerson & Hatton, 2014). An applied implication of this research would be to boost the profile of Easy Read. Currently the most accessible way to get Easy Read is online, but this is not easily accessible for some people and not known about. For example making it more readily available in settings such as a GP surgery or local health hubs. By boosting its profile people with and ID, parents and carers would understand where to get it, how to use it and why to use it.

Conclusion

On personal reflection the researcher found this an enjoyable and eye opening experience. The researcher worked with many individuals who had interesting opinions and opened her eyes to the possibility that Easy Read is not the only way to help individuals with an ID to gain new health knowledge. The researcher has discussed strengths and limitations of the research above but she feels the main limitation was time. The research feels she could have yielded stronger results (i.e. more participants) if there had not been issues with timing due to supervisory issues and the process of obtaining ethical approval taking longer than expected. The researcher discovered an unexpected barrier during recruitment that was also very interesting. Many potential participants with an ID did not take part in the research as

they believed the research would be boring or that they had helped other organisations with Easy Read research in the past and did not want to do this again (for example, approving an Easy Read pamphlet for the local authority). In conclusion, Easy Read is a new subject that needs further research before we fully understand how it can truly help the individual and be used as a tool to prevent inequality.

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Appendices

Appendix A

Table 1

Background information of main six participants.

Background information	1	2	3	4	5	6
					Participant	
Gender	M	F	M	F	F	M
Age	33	25	28	41	55	25
Glasses	No	No	No	Yes	Yes	No
Chosen language	English	English	English	English	English	English
Nominated individual	One	Two	One	One	Two	One
Type of Disability	ID & ASD	DS	DS	DS	ID	ID & ASD
Residential setting	Lives with parent/s	Lives with parent/s	Lives with parent/s	Lives with parent/s	Lives in supported accommodation	Lives with parent/s

Appendix B

Participant number…………….

Baseline Questionnaire

1. **How often should you have an eye test? [1 point]**
- One point for reference to every two years.
- Zero point for reference to anything else.

2. **If you have a health check, does the Health care support worker find out if you smoke? [1 point]**
- One point for yes.
- Zero point for no.

3. **When should you clean your teeth? [1 point]**
- One point for reference to the morning and at bedtime.
- Zero point for reference to anything else.

4. **Who can have their eyes tested? [1 point]**
- One point for everyone.
- Zero point for reference to anything else.

5. **Who do you go see to have your teeth checked? [1 point]**
- One point for reference to a dentist.
- Zero point for reference to anything else.

6. **How much does a health check cost? [1 point]**
- One point for reference to saying it's for me.
- Zero point for reference to anything else.

7. **Why do you clean your face? [1 point]**
- One point for reference to dirty face and germs.
- Zero point for reference to anything else.

8. **Is it important to have your eyes tested? [1 points]**
- One point for yes.
- Zero point for no.

9. **What is blood pressure? [1 point]**
- One point for reference to how fast blood moves around the body.
- Zero point for reference to anything else.

10. **What do you use to brush your teeth? [1 point]**
- One point for reference to toothbrush with toothpaste.
- Zero point for reference to anything else.

11. What is an ear blockage? [1 point]
- One point for reference to earwax getting stuck in your ear.
- Zero point for reference to anything else.

12. Why should you clean your hair? [1 point]
- One point to reference to dirty/greasy hair.
- Zero point for reference to anything else.

13. How long will a health check take? [1 point]
- One point for reference towards 30 to 40 minutes.
- Zero point for reference to anything else.

14. How often should you visit the dentist? [1 point]
- One point for reference to once a year.
- Zero point for reference to anything else.

15. Who tests you eyes? [1 point]
- One point for reference towards an optician.
- Zero point for reference to anything else.

Appendix C

Participant number…………….

Having an Eye Test – You need to have your eyes checked

1. **Where can you have an eye test? [1 point]**
   - One point for reference to visiting an opticians or an optician visiting the home.
   - Zero point for reference to anything else.

2. **What do they do in an eye test? [1 point]**
   - One point for reference to checking your eyes.
   - Zero point for reference to anything else.

3. **Why do some people have a free eye test? [1 point]**
   - One point for referencing three or more from the list in the Easy Read sample.
   - Zero point for no.

4. **Can you be too disabled to have an eye test? [1 point]**
   - One point for no.
   - Zero point for yes.

5. **Where can you buy glasses? [1 point]**
   - One point for reference to the optician.
   - Zero points for reference to anything else.

6. **Who can have their eyes tested? [1 points]**
   - One point for everyone.
   - Zero point for reference to anything else.

7. **How often should you have an eye test? [1 point]**
   - One point for reference to every two years.
   - Zero point for reference to anything else.

8. **Who tests you eyes? [1 point]**
   - One point for reference to the optician.
   - Zero point for reference to anything else.

9. **Is it important to have your eyes tested? [1 points]**
   - One point for yes.
   - Zero point for no.

10. **What helps sight problems? [1 point]**
    - One point for reference to wearing glasses.
    - Zero point for reference to anything else.

Appendix D

Participant number…………….

Having a health check questionnaire.

1. **How much does a health check cost? [1 point]**
- One point for reference to saying it's free.
- Zero point for reference to anything else.

2. **What is blood pressure? [1 point]**
- One point for reference to how fast blood moves around your body.
- Zero point for reference to anything else.

3. **Why does your body need cholesterol? [1 point]**
- One point for reference to the body working properly.
- Zero point for reference to anything else.

4. **How old do you have to be to have a health check? [1 point]**
- One point for reference to aged 40 or over.
- Zero point for reference to anything else.

5. **If you have a health check, does the Healthcare Support Worker find out if you smoke? [1 point]**
- One point for yes.
- Zero point for no.

6. **Why does the Healthcare Support worker check your heart? [1 point]**
- One point for reference to how fast the heart is beating.
- Zero point for reference to anything else.

7. **Who sends you a letter inviting you for a health check? [1 point]**
- One point for reference towards a GP.
- Zero point for reference to anything else.

8. **If you have a health check, does the Healthcare Support Worker find out if like animals? [1 point]**
- One point for no.
- Zero point for yes.

9. **If you are unhappy what should you do? [1 point]**
- One point for reference towards saying no/stopping.
- Zero point for reference to anything else.

10. **How long will a health check take? [1 point]**
- One point for reference towards 30 to 40 minutes.
- Zero point for reference to anything else.

Appendix E

Having an Eye Test

You need to have your eyes checked

See Ability
Seeing **beyond** disability

Version 2 - Nov 2010   SeeAbility Easy Read Factsheet

Opticians test your eyes.

They are also called optometrists.

We call them opticians in this factsheet.

Having your eyes checked is called an eye examination, an eye test or a sight test.

We will call it an eye test in this factsheet.

You should have an eye test every 2 years.

Your doctor or optician will tell you if you need your eyes checked more often.

2011   2013

Everyone can have their eyes tested.

You don't have to be able to read or speak to have an eye test.

There are different ways to check your eyes. No-one is too disabled to have their eyes checked.

Many people can get free eye tests.

Some of the reasons people get a free eye test are:

- You are aged under 16.

- You are under 19 and in full-time education.

- You are aged 60 or over.

- You are registered as blind or partially sighted.

- you have diabetes or glaucoma. Glaucoma is an illness that stops you seeing properly.

- You are 40 or over, and your mother, father, brother, sister, son or daughter has been diagnosed with glaucoma.

- You have been advised by an eye doctor that you're at risk of glaucoma.

- You receive benefits like Income Support or Jobseekers Allowance.
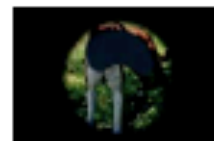
Having your eyes tested is very important.

An eye test can find out if your eyes are healthy. An eye test also checks for illnesses like diabetes.

An eye test can check that your sight is okay and whether you need new glasses.

People with a learning disability are 10 times more likely to have a sight problem.

Wearing the right glasses can help sight problems.

We need good sight to help us to communicate, to be independent and to enjoy work and activities.

You can choose to have an eye test at any optician.

You can take a supporter with you for your eye test.
If you need glasses you can buy these at any optician.

There are opticians who can visit you at home. Ask your doctor or optician about this.

Appendix F

Introduction

This leaflet is about your **free** Health Check.

Because you are aged between 40 and 64 years of age you have been invited to have a **free** health check.

You do not have to be ill to have a health check. You could have a health problem that you do not know about.

Having a health check can lower your chance of getting a serious health problem.

What will happen?

You can ask someone to come to the health check with you if you want.

A health check will take 30 to 40 minutes.

You can say no to any part of the health check if you are unhappy.

The Healthcare Support Worker will find out:

- how much you weigh

- how tall you are

- if you do any exercise

- what kind of foods you eat

- if you smoke

- if you drink alcohol – like beer or wine

- if you are feeling happy or sad

- what medicine you are taking

- if you have any illnesses that run in your family.

The Healthcare Support Worker will check:

- your **blood pressure**

Blood pressure is how fast blood moves around your body. If it moves too fast or too slow, there could be a problem.

- your heart - to see how fast it is beating

- your blood – a little bit of blood will be taken from your finger to check your blood sugar levels and **cholesterol**.

Your body needs **cholesterol** to work properly, but too much or too little can cause illnesses.

After your health check

The Healthcare Support Worker will talk to you about your health. They will give you advice about how to lower the chance of getting ill.

You might need to have more tests, or see someone else who can help you with your health.

How to get a health check

You will be sent a letter inviting you for your health check by your GP.

Remember to bring your glasses if you use them.

Please bring a list of any medicine you are taking.
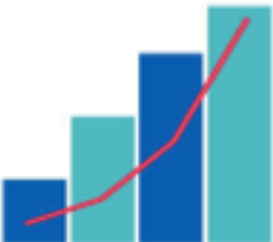
This document was made into Easy Read by
Learning Disability Wales using Photosymbols 5.

Appendix G

Does Easy Read help people with

Intellectual Disabilities?

	Do you have an intellectual disability (learning disability)?
	Can you read?
	Would you like to take part in research?

	Would you like some more information?
	You can phone us on 01248 38 86 62
	You can email us on psp521@bangor.ac.uk

01/04/2015

Appendix H

Does Easy Read with support or without support improve how much you understand about health?

Lowri Wyn Rowlands- MRes student

Dr Carl Hughes- Supervisor

kess
Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

PRIFYSGOL
BANGOR
UNIVERSITY

ESF
Ewrop & Chymru: Buddsoddi yn eich dyfodol
Cronfa Gymdeithasol Ewrop
Europe & Wales: Investing in your future
European Social Fund
Llywodraeth Cymru
Welsh Government

Info

What is my research about?

- Easy Read

- Easy Read with support

- Easy Read without support

- Understanding health

01/04/2015   Version 1   2

I am sorry you **cannot take** part if:

- You do not understand some of the questions we ask you (Assessment of Capacity).

- You are under the age of 18.

- You cannot read.

- You have problems talking (speech and language difficulties).

- If you cannot see with or without glasses.

- You have problems hearing (hearing impairment).

01/04/2015   Version 1   3

I would like you to take part if:

- You have an intellectual disability.

- You are aged 18 or over.

- You can read.

- You have no visual impairment.

01/04/2015   Version 1   4

- I will record your answers using a dictaphone and a video camera.

- I need to record and film you so that I can make notes.

- I will only keep the recording until I have written my notes

- Dr Carl Hughes and I are the only people who will listen to and watch the recording.

01/04/2015   Version 1   5

Why should you take part in my research?

- Research is important!

- Does Easy Read help?

- Improves health of people with an intellectual disability.

- Improves the lives of people with intellectual disabilities

01/04/2015   Version 1   6
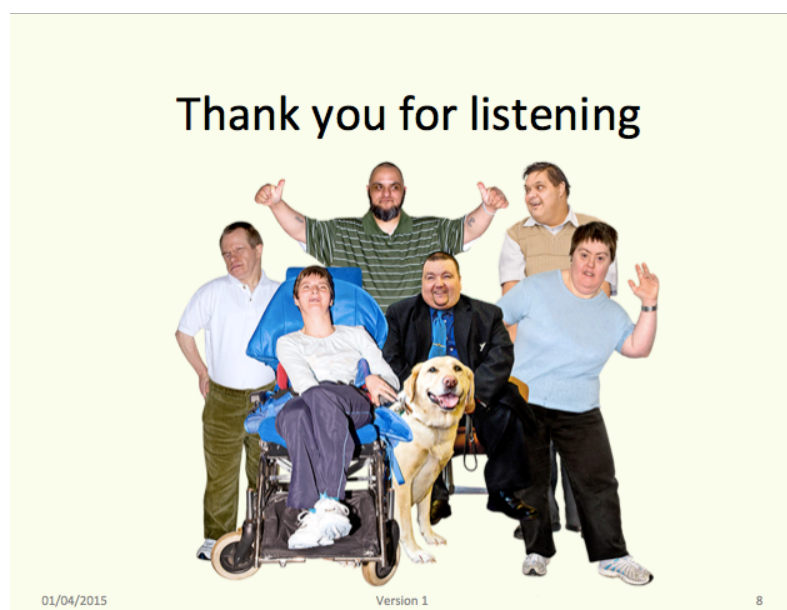
Appendix I

Participant Information Sheet

	Hello, my name is Lowri Rowlands.
	I am a student at Bangor University.
	I am supervised by Dr Carl Hughes Supervision is when someone watches what you do to keep others safe and to help me learn.
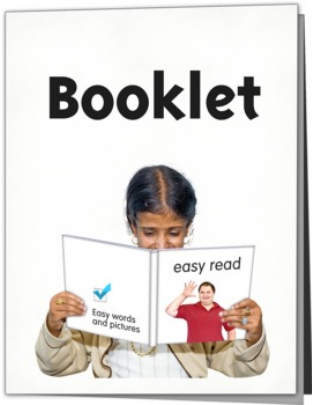
This is an information sheet about my research.

Can I take part?	
	I would like you to take part if: • You have an intellectual disability. • You are aged 18 or over. • You can read. • You have no visual impairment.
	I am sorry you cannot take part if: • You do not understand some of the questions we will ask you in session 2 (Assessment of Capacity). • You are under the age of 18. • You cannot read. • You have problems talking (speech and

	language difficulties). • If you cannot see (visual impairment). • You have problems hearing (hearing impairment).
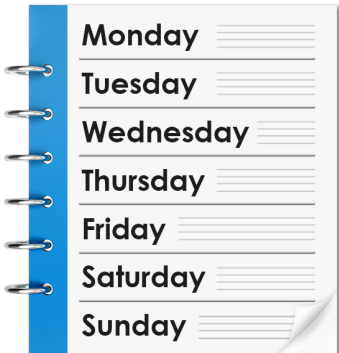
What would we like to know	
	We would want to find out if reading Easy Read information is helpful for people with intellectual disabilities (learning disabilities).
	We will be looking at the difference between reading Easy Read information with support and Easy Read information without support.
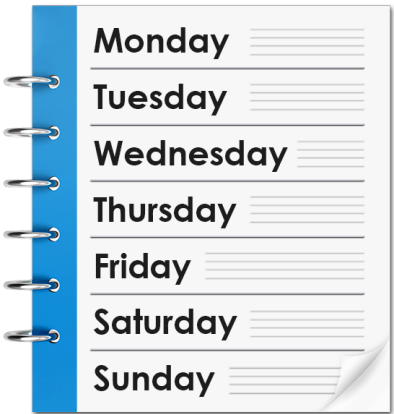
Booklet	Support is when another person helps you read through the Easy Read information with you. Support is when another person helps you understand the Easy Read.

What will happen

Monday Tuesday Wednesday Thursday Friday Saturday Sunday	My research takes 3 sessions.
1	I will meet you during session 1. This is when I will come to your group to talk about my research.

	If you are interested in taking part in my research you can ask me any questions you want during or after my talk.
	If you decide you want to take part on the day I will take your details. I will then arrange a time to come and see you in the next 3 to 10 days. This is session 2.
	You will also be given a form with my contact details.
	You can use the form to contact me if you need more time to think about taking part.

	You can use the form to contact me if you have questions you want to ask me about the research.
	If you decide you want to take part in the research you can use the form to contact me.
	If you have decided that you want to take part you will need to contact me. I will arrange to meet with you. We will meet within 3 to 10 days. This is session 2.

	You do not have to take part in my research if you do not want to. It is ok to say no.
	You do not have to contact me if you do not want to take part in my research.
	During session 2 we will meet somewhere that is comfortable and quiet, like your home. You can have a supporter with you if you wish.

	Anthony Green the Regional Officer from Mencap Cymru will also take part in the session.
	We will go through this information form.
	I will ask you for your consent. Consent means you say it's ok for me to do my research with you.

	I will record your answers using a dictaphone and a video camera. I need to record and film you so that I can make notes.
	I will keep your recordings on a password protected laptop. I will only keep the recordings until I have written my notes. I will then destroy the recordings.
	Dr Carl Hughes and I (Lowri) are the only people who will listen to and watch the recording.

	I will ask for your consent to record and film you. Consent means you say it's ok for me to record and film you.
	I will ask you some questions about health. You do not have to answer a question if you do not want to.
	The research will then be split into 2 parts. It does not matter what part you take part in first. This makes my research fair. You could take part in part 1 and then part 2 or you could take part in part 2 and then part 1. This is called a mixed method design.

	We will have a break between both parts.
	In part one In part one Anthony Green will give you the Easy Read Information.
	He will ask you to read the Easy Read information by yourself. Anthony or I will not help you.
	Anthony will ask you questions after you finish each section. You do not have to answer a question if you do not want to.

	I will sit away from you and Anthony. I will watch what you are doing. I will not talk.
	You will then have finished part 1.
	In part 2. Anthony Green will then give you a piece of Easy Read information. Anthony will support you to read the Easy Read information.

	Support means that Anthony will read the information with you. Support means that Anthony will explain any questions you have about the information. Support means that Anthony will explain any words that you find difficult.
	Anthony will ask you questions after you finish each section. You do not have to answer a question if you do not want to.
	I will sit away from you and Anthony. I will watch what you are doing. I will not talk.

	This is then the end of part 2 and session 2.
	I will then give you a debrief sheet. A debrief sheet thanks you for taking part in the research. It explains why we are doing the research and how to contact us if you have any other questions.
3	I will then arrange to phone you in 3 to 10 days. This is session 3.
	During session 3 I will phone you. I will answer any other questions you may have.

| | That is then the end of the research. |

What will happen to my information?

	We will put your information onto a laptop. The laptop is password protected.
	We won't use your name, your age or where you live.
	We will keep your information safe. All forms will be kept in a locked storage cabinet in a locked room.

	If you agree to us looking at your information, we will use this information to help us understand more about Easy Read. We will share this information with people who are interested in Easy Read.

Is there any risk?

	No. We are not aware of anything that could go wrong or hurt you during our research.

Ethics

	My research is ethical. Ethical research is research that is good and will not hurt other people.

| | Bangor University say that my research is ethical.

North West Wales Research and Ethics Committee say that my research is ethical. |

Can I say no?

| | Yes you can say NO.

You can say no whenever you want. |
| | If you change your mind you can say no. |

	You can say no by telling me.
	You can say no by telling my supervisor.

Dr Carl Hughes |
| | You can say no by telling someone who supports you like a family member or a support worker. |

Questions?

	You can ask anything you would like to now.
	Or you can contact me another time again if you think of any other questions. My contact details are on the contact form.
	You could also phone my supervisor. Dr Carl Hughes 01248 383 278
	Or you can ask some who supports you, like a family member or support worker to phone me or my supervisor.

Complaints	
	If you are not happy about something that happened during my research you can complain.
	Please contact my supervisor. Dr Carl Hughes.
	You can phone him. 01248 383 278

	You can email him. c.hughes@bangor.ac.uk
	Or you can contact Hefin Francis. He is the School of Psychology Manager.
	You can phone him on 01248 338 339

	You can email him h.francis@bangor.ac.uk

Thank you for reading this information sheet.

Appendix J

CONTACT FORM

	My name is Lowri Wyn Rowlands
	You or a supporter can contact me if you have any more questions about my research.
	You or a supporter can contact me if you would like to take part in my research.

	You or a supporter do not have to contact me if you do not want to take part in my research. It is ok to say no.
	My telephone number is 01248 383 278
	My email address is psp521@bangor.ac.uk

| FREEPOST | You or a supporter can post me the postal form.

There is a freepost envelope with this form. |

Appendix K
POSTAL FORM

I would like more information about the research.

Yes

No

I have a question about the research.

Yes

No

I would like to take part in the research.

Yes	No	Not sure
☐	☐	☐

Name:………………………………………………………..

Phone number:……………………………………………..

Address:……………………………………………………

………………………………………………………………

………………………………………………………………

Appendix L
Guidelines for the Functional Assessment of Capacity

Diagnostic Threshold
The Mental Capacity Act (2005) acknowledges that if there is an established diagnosis of mental illness, intellectual disability or some other condition, then this is sufficient to confirm "impairment of disturbance of the mind".

Nature of decision
Assessors should record the key decisions facing participants/patients

Test
1. **Understanding the information**
   The assessor is required to help the person understand the information relevant to the decision. Information should be presented in a clear and simple way or with the use of visual aids. Cultural and linguistic considerations should be included and family, friends, carers or support staff of the person being assessed should be used to assist the process.

2. **Retaining the information**
   Information only needs to be held in the mind of the person long enough to make the decision.

3. **Use or weigh the information**
   Some people can understand the information, but an impairment stops them from using it. Whereas others may make a decision without understanding it. A person capable of using or weighing the information would also need to demonstrate that they could foresee the consequences of making, or failing to make, that decision.

4. **Communicate the decision**
   Communication can be whatever the assessor accepts. Assessors should consider using specialist workers to assist in communication (for sensory impairment etc).

Protocol for Assessing Capacity

1. Read the information sheet once to the participant.

2. Read the following part of the information sheet: **"My name is Lowri Rowlands. I am student from Bangor University""**

Ask the participants **"Who am I?"**

Score 1 if the person gives an answer similar to **"Your name is Lowri Rowlands. You are a student from Bangor University"**

Score 0 if the answer is irrelevant or too vague.

3. Read the following part of the information sheet: **"We want to find out if reading Easy Read information is helpful for people with intellectual disabilities (learning disabilities)."**

Ask the participant **"What do I want to find out"**

Score 1 if the person gives an answer similar to **"We want to find out if reading Easy Read information is helpful for people with intellectual disabilities (learning disabilities)."**

Score 0 if the answer is irrelevant or too vague.

4. Read the following part of the information sheet **"We will be looking at the difference between reading Easy Read information with support and Easy Read without support."**

Ask the participant **" What will we be looking at?"**

Score 1 if the person gives an answer similar to **We will be looking at the difference between reading Easy Read information with support and Easy Read without support."**

Score 0 if the answer is irrelevant or too vague.

5. Ask the participant: **"Do you want to take part in my study"**

Answer Yes or No

6. Ask the participant: **"Are you happy for me to share what I find in this research with others?"**

Answer Yes or No

For consent to be given the participant needs to answer Yes to <u>both</u> questions.

7. Read the following part of the information sheet: **"It is ok to say no.**
You can say no whenever you want.
If you change your mind you can say no."

Ask the participants **"What will you do if you change your mind?"**

Score 1 if the person gives an answer similar to **"Tell you No".**

Score 0 if the answer is irrelevant or too vague.

Overall Scoring

If the participant scores 0 to any of the questions under items 2,3, 4,5, or 8, then the participant is assessed as not having the capacity to consent in this specific context. If the participant does not have the capacity to participate then the researchers should not use this participant in the research.

If the participant score 1 in every question under items 2,3,4, 5 and 8 and answer "Yes" to both questions under item 6 and 7, the participant is assessed as having the capacity to consent and he/she is indicating their wish to participate in this research.

If the participant score 1 in every question under items 2,3,4,5 and 8 but answers "No" in question 6 and 7, the participant is assessed as having the capacity to consent but is indicating his/her refusal to participate.

This protocol is based on the procedure followed by Arscott, Dagnan & Kroese, 1998.

Arscott, K., Dagnan, D,. & Kroese, B.S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities,*11(1), 77-83.

Appendix M

Consent Form

Participants need to initial the boxes <u>not</u> tick

I have been given information about the study.

YES

NO

I have been able to ask questions if I wanted.

YES

NO

I know that I can say no at any time.

YES

NO

I am happy for my information to be used.

YES

NO

It is ok to use a Dictaphone.

YES

NO

It is ok to use a video camera.

YES

NO

<u>Participant</u>

Consent

Signed……………………………………………………………

Date & Time………………………………………………………

<u>Researcher</u>

Name……………………………………………………………….

Researcher signature…………………………………………...

Date & Time……………………………………………………

If applicable.

Supporter

Consent

Signed…………………………………………………………

Date and time …………………………………………..

Researcher

Name……………………………………………………….

Researcher signature…………………………………...

Date & Time………………………………………………

Appendix N

DEBRIEFING FOR PARTICIPANTS

	Thank you very much for taking part our research.
	Our research is about Easy Read.
	We would like to find out if reading Easy Read information with or without support is helpful for people with intellectual disabilities (learning disabilities).
	All the information you have given to me will be kept private. We will use your results, without using your name to write reports about the research.

	If you would like to know more about the research or have any questions you can phone, email or write to me.
	Phone: 01248 38 36 62
	Email: psp521@bangor.ac.uk
	Write: Lowri Rowlands c/o Dr Carl Hughes *Brigantia* Building, *Bangor* University, *Bangor*, Gwynedd. LL57 2AS

Thank you very much for taking part in the research.