

Easy read health information for people with intellectual disabilities: A linguistic discourse analysis. What happens to language when it is simplified?

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Abstract

Introduction: Easy Read health documents prepared for people with intellectual disabilities are often generated from Standard Texts. Language in Easy Read versions is typically assumed to be simpler. However, simplification of language may have unintended consequences. This study aimed to explore the differences in language used between Easy Read health material and the Standard Text versions of the same material produced for the general population.

Methods: Five Easy Read/Standard Text pairs were sampled and analysed using Systemic Functional Linguistics. This addressed: how people with intellectual disabilities and others were represented by language, the author stance in relation to the reader and the overall organisation of the text.

Results: The Easy Read versions often used language that was less empowering and inclusive.

Conclusion: Increased awareness of author power and better knowledge of the impact of language choice could help to redress these issues.

KEYWORDS

easy read, empowerment, health, intellectual disabilities, linguistic discourse analysis, simplification

1 | INTRODUCTION

Improving access to written information for people with intellectual disabilities has been attended to at societal and government levels over the past two decades (Chinn & Homeyard, 2016; Sutherland & Isherwood, 2016). This has given rise to the extensive production of Easy Read versions of documents prepared for the general population. Primarily for use by adults with intellectual disabilities, Easy Read is material that has been adapted through the simplification of language, the addition of coloured picture support, variations in layout, a larger font size and a reduction in text density. Various guidelines on developing Easy Read material are available in the U.K. (e.g., Change, 2015;

Department of Health, 2010a, 2010b; MENCAP, 2002; Rodgers et al., 2004); and Europe (Freyhoff et al., 1998). They focus mainly on vocabulary, sentence length or word length and syntax to achieve improved readability of written information. The movement to create accessible versions of information also has an international reach (Easy-to-read Association, 2002; Lindholm & Vanhatalo, 2021), is used in Australia Germany, Poland and Taiwan and by the World Health Organisation (WHO, 2011). However, notwithstanding, the importance of information dissemination during the COVID pandemic, and despite production of Easy Read material, people with intellectual disabilities reported being left behind regarding information critical to their health and wellbeing (Terras et al., 2021).

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Research has demonstrated that although Easy Read material is the most common health resource produced for people with intellectual disabilities in the UK (Tuffrey-Wijne et al., 2014) it does not equate with understanding. Chinn (2019) highlights the limited evidence that Easy Read health material promotes understanding and this is supported by Waight and Oldreive (2020) who introduced technology as a way to address the challenges of reading. There is growing recognition that effective understanding of Easy Read health material requires responsive mediation by a familiar other person that can be tailored to the person's needs (Buell et al., 2020). Callus and Cauchi (2020) reported that support workers who were involved in filling in forms with people with intellectual disabilities did not think that an Easy Read version was necessary if close mediation and support was an option. This raises a question around the purpose of Easy Read information.

1.1 | Power and mediation

The dual purpose of Easy Read material as encapsulating legal principles in the UK (Disability Discrimination Act, 2005; Equality Act, 2010; National Standard for Accessible Information, 2015), and as a vehicle for accessing health information means that its impact moves beyond the person with intellectual disabilities, to those who support and mediate, and further, to wider society. Closely allied to the self-advocacy process (Ward & Townsley, 2005), the development of Easy Read material forms part of work of third sector organisations such as People First, providing a pathway to empowerment (Walmsley, 2010).

Coproduction of Easy Read material combines the values, experiences and abilities of people with intellectual disabilities with the knowledge and interpretive skills of people providing support (Chinn & Pelletier, 2020). The impact of the first 'accessible, easy to understand' (Ward & Townsley, 2005:59) government paper in the UK (*Nothing about us Without Us* Department of Health, 2001b) was noted as positive. By providing relevant resources in the form of Easy Read information, people with intellectual disabilities were supported to engage with the social and individual processes that drive engagement with choice and change (Moran et al., 2017). However, it was also recognised that power imbalances may have occurred between those who compiled information and those who used it.

If Easy Read information is viewed as a valid and useful product that has educational benefits for a wider population concerning the importance of the social role and value of people with intellectual disabilities, it becomes an important tool in advocacy and raising awareness. In particular, the language that is used within Easy Read material and how it is interpreted through mediation has the power to shape how people with intellectual disabilities view themselves and how they are viewed.

1.2 | Language and text simplification

Retaining the tone, overall meaning and power balances of a Standard Text versions through the simplification process required for Easy

Read versions is an ongoing challenge (Learning Disability England, 2022). It requires managing a balance between production of a version of Standard Text that is easier to read a production that also uses empowering language (Chinn, 2019).

There are several ways of evaluating the language used in texts. Readability scores (Flesch–Kincaid grade scores, 1947) have frequently been used in research to check the accessibility value of Easy Read documents against an educationally defined (United States Grade Level) reading age (Benjamin, 2012; Gal & Prigat, 2005; Hurtado et al., 2014; Iacono, 2004; Morgan & Moni, 2008; Poncelas & Murphy, 2007). While these provide common currency in the preparation of texts for certain target groups, readability measurements are based on superficial features of language: number of words, the number of syllables in words and lengths of sentences. They do not provide information on the deeper cognitive construction of meaning through language (Crossley et al., 2014). Linguistic discourse analysis aims to capture patterns in language use beyond the superficial aspects of word length, length of sentence and complexity of sentences. For the reader, sense-making is affected by a combination of vocabulary employed, structures used and the linguistic context in which the information is read (Schleppegrell, 2013:21). Discourse analysis aligned to the construction-integration model (CI) of reading comprehension provides a theoretical basis for exploring texts on a deeper level (Kintsch, 1998). It looks at how language is used to build cohesion (the way language creates links and references) in text and also coherence (the meaningful integration of the overall message) from text. This can be done through automated analysis using software packages (for example CohMetrix 3.0 n.d) or through hand-annotation.

Automated linguistic analysis using software such as Coh-Metrix can often provide insights into patterns of discourse in text. However, these systems do not always identify the nuances of how human beings read, process and contextualise texts. In contrast, linguistic discourse analysis carried out through annotation can tap into the deeper levels of a text. It examines how the choices made in language shape and are shaped by the contexts in which we live (Schleppegrell, 2013). For example Chinn (2017) and Vanstone & Kinsella (2010) showed how expressive language and visual choices not only affected the impact of health messages, but also shaped the reader's social identity as either an active contributor to their healthcare or as a passive recipient of the actions of health experts.

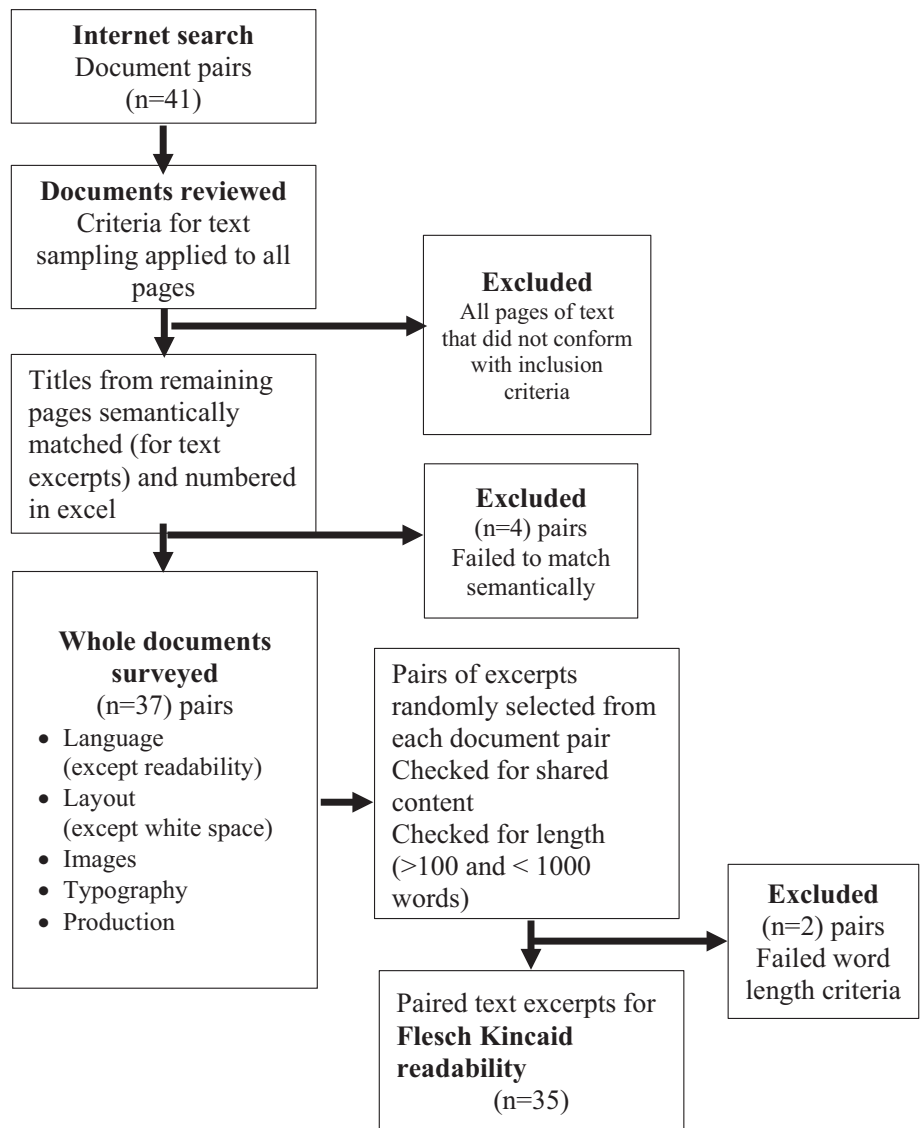
Drawing on the principles of Systemic Functional Linguistic discourse analysis (described below), the main research question addressed was: How do Easy Read versions of information compare with their Standard Text counterparts in terms of the language used?

2 | METHOD

2.1 | Design

A qualitative research design was adopted employing methods drawn from Systemic Functional Linguistics (Halliday & Matthiessen, 2004). The focus was informational documents published by the UK

FIGURE 1 Consort diagram for document selection and text sampling.



Department of Health over a 12-year period (2000–2012). The purpose was to examine the discourse of language used in typical Easy Read material compared with that used in the original Standard Text versions.

2.2 | Sampling and data collection

All Easy Read documents prepared for people with intellectual disabilities were identified on the UK Department of Health (DoH) website (replaced in 2012 by gov.org). Any material produced by the DoH or Central Office for Information (COI) and labelled as ER, ‘with pictures’, ‘for learning disabilities’, ‘accessible’, ‘easy access’, ‘easy to read’, or ‘easier to read’ was included with the corresponding Standard Text version. This resulted in 39 document pairs (Figure 1).

The document pairs were reviewed and sections of text were matched systematically by comparing titles, which were then manually checked to ensure a shared topic focus. This yielded 35 pairs of text

samples of between 100 and 10,000 words in length. Samples were processed to establish their Flesch Kincaid readability grade scores (see Appendix A – Table A1 for all 35 readability measures). These scores relate to Educational Grade Levels in the USA where Grade 4 would be equivalent to a child’s reading age of 8 years old and Grade 14 and above would be University level and beyond. Each document pair ($N = 35$) was numbered and rank-ordered in a prepared Excel spreadsheet from easy to difficult based on surface level ‘ease’ using the Flesch–Kincaid readability grade scores (Flesch, 1947) of the Easy Read versions of each pair (see Appendix B). This provided a measure of superficial linguistic changes to text of the kind that might be expected if following UK Easy Read guidelines for production. (The full cohort of Easy Read and Standard Text excerpts has been analysed quantitatively using Coh-Metrix automated software. Data and results are forthcoming in an article on quantitative linguistic characteristics).

To ensure a representative sample of surface level ‘easy’ and ‘difficult’ text pairs, five pairs were selected: the two with the lowest

TABLE 1 Easy read and standard text document titles.

Code	Document name
1ER	Questions to ask when you go to the doctor or to a hospital
1ST	Questions to ask
2ER	All about Personal Health Budgets
2ST	Understanding Personal Health Budgets
3ER	Caring for our future: Reforming Care and Support: White Paper
3ST	Caring for our future: Reforming Care and Support: White Paper
4ER	Valuing People Now: The Delivery Plan
4ST	Valuing People Now: The Delivery Plan
5ER	Valuing People and Research: The Learning Disability Research Initiative
5ST	Valuing People and Research: The Learning Disability Research Initiative

readability scores were identified, the two with the highest scores and the excerpt with the median score. These, along with their matching Standard Text samples made up the entire sample ($N = 10$: Easy Read = 5; Standard Text = 5) for the qualitative discourse analysis (see Appendix B for excerpts). All of the documents were genre-classified as 'informational' (Butt et al., 2003: 9) but varied in terms of topic complexity. Table 1 lists the headings of the five sampled text pairs.

2.3 | Data analysis

A detailed Systemic Functional Linguistic discourse analysis (Halliday & Matthiessen, 2004) was performed on the sample of Easy Read and Standard Text excerpts. This involved displaying both document versions in a pair, side by side. They were then systematically reviewed line by line to identify language that expressed three components as functions of language: (i) referential, (ii) interpersonal and (iii) textual as described below.

- i. Referential function. Nouns and verbs used in each version to represent people, places and events were highlighted, for example, NHS authorities, health and social care professionals, Social Services or Government bodies and the public (people with and without intellectual disabilities) and how their roles and actions are represented in text (e.g., verbs such as: *spend, arrange, ask, write, understand, decide*) and frame the agency of the reader (i.e., actor or acted upon).
- ii. Interpersonal function. Words that demonstrated the positioning of people with intellectual disabilities in relation to the authors or to those in power were then identified. Specific framing of the reader's status in relation to the author were defined through the way they were addressed. The positioning of author and

reader is often represented by use of 1st, 2nd and 3rd person pronouns. Inclusive 'we', for example, represents the inclusion of the author within processes, whereas 'they' and 'you' may distance them. Observations of unequal power relationships were additionally identified through the choice of expression of obligation and certainty (or lack of them), including the use of modals (*may, must, should*) and imperatives (*ask your doctor; bring your medicines*).

- iii. Textual function. Finally, each text was scrutinised and annotated to show patterns of cohesion and coherence (how language was used to develop linguistic meaning and the overall sense of the text). The structure of the text was analysed with attention to the effectiveness of cohesive elements used and whether these combined to reproduce the original purpose of the text (e.g., persuasive or simply informative), whether the same main information was forefronted in both Standard Text and Easy Read versions and how this might have influenced overall coherence and function of the text.

Although it was useful to review any relevant expressive differences by these main three language functions, significant shifts in representation at the level of power and agency typically implicated combinations at all three functional levels, as presented in the results section. The analyses were conducted independently by the two first authors for purposes of interrater reliability. Where discrepancies occurred, they were resolved through discussion until consensus was achieved.

3 | RESULTS

3.1 | Readability

Paired sample t-tests were conducted to compare Flesch-Kincaid Grade Level readability measures across the two groups. These represented surface level linguistic features. Results demonstrated a significantly overall reduced Grade Level score for Easy Read material compared to Standard Text material (Table 2).

However, as shown in Table 3, readability scores between the five Standard Text and Easy Read text excerpts were variable with some scores for Standard Text (3ST and 4ST) producing lower measures than one of the Easy Read versions (5ER).

3.2 | Discourse analysis

The results of the discourse analysis are presented with annotated examples of three of the five paired texts. For each of the three functions, (representational, interpersonal and textual), the text pair that demonstrated the clearest differences has been presented side by side with an accompanying summary. All five original texts can be found in the Appendices A and B.

TABLE 2 Mean readability measures for easy read and standard text samples ($n = 35$).

	ER ($n = 35$)		ST ($n = 35$)		Diff (CI 95%)	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Flesch Kincaid (Grade Score)	8	6	13	5	5.31	.001

TABLE 3 Flesch–Kincaid readability scores for included excerpts.

Code	Document name	Flesch–Kincaid readability grade score
Key	Standard Text = ST Easy Read Text = ER	
1ST	Before your Appointment (Department of Health, 2007a)	4.8
1ER	Some things to do before you go to the doctor or to a hospital (Department of Health, 2007a)	4.8
2ST	Understanding Personal Health Budgets (Department of Health, 2012b)	10.8
2ER	All about Personal Health Budgets (Department of Health 2012b)	5.1
3ST	Caring for our future: Reforming Care and Support: White Paper (Department of Health 2012a)	12.4
3ER	Caring for our future: Reforming Care and Support: White Paper (Department of Health 2012a)	7.6
4ST	Valuing People Now: The Delivery Plan (Department of Health 2010b)	12.8
4ER	Valuing People Now: The Delivery Plan (Department of Health 2010b)	11.3
5ST	Valuing People and Research: The Learning Disability Research Initiative (The Department of Health 2007b)	20.5
5ER	Valuing People and Research: The Learning Disability Research Initiative (The Department of Health 2007b)	14.1

3.3 | Referential function

Differences were observed between Easy Read versions compared to Standard Text versions in the way that nouns and verbs were used to represent people with intellectual disabilities and their actions. The text ‘Before you go to the hospital’ (1ER) is used to demonstrate these differences in Table 4.

The perceived needs and requirements of people with intellectual disabilities were reflected in the use of the action words ‘ask’ and ‘write’. Readers were invited to do this (through imperative forms of the verb) with reference to dealing with a doctor’s appointment. However, ‘ask’ was used 12 times in the Easy Read version and only six times in the Standard Text version implying a greater need by those with intellectual disabilities. This may reflect the different levels of perceived support required by this group rather than a pattern of disempowerment through language, although the assumption has still

been made about one readership needing to ‘ask’ more than the other. The instructions given to the readers are very similar (‘write’, ‘ask’ and ‘check’) but there is more emphasis on what to say and ask in 1ER, assuming that readers may need help formulating questions. There is also slightly more frequent reference in 1ER to the role of others (‘doctors’, ‘hospital’, ‘family’ and ‘friends’) as intermediary for the readers’ actions (e.g., ‘Ask your doctor or hospital for someone to support you’ in line 1). In 1ST more detailed instructions of what to write down (‘questions’ and ‘symptoms’) and what to bring (‘medicines and pills’) is given at the beginning. This could have been included in 1ER for the sake of clarity.

What is particularly obvious is the difference in the inclusion of circumstances. Both texts refer to the time and place when the actions are appropriate (e.g., ‘at the doctor or hospital’ or ‘before you leave the doctor or hospital’) but, in 1ER, the frequency of the conditions introduced by ‘if’ is much higher (e.g., ‘If you do not hear quickly about your next appointment’ at the end). This may provide additional support to readers who may worry about copying with unpredictable situations.

In both texts reference is made to the possibility that readers may not understand and be afraid to ask, assuming that this is very likely to happen at the doctor’s or hospital. In 10E the potential lack of understanding is emphasised in the list of questions suggested to the readers. In these questions readers directly refer to their difficulties (e.g., ‘What do the results of my tests mean?’).

Overall, the differences in representation are arguably suited to the respective target readers even though some of the readers of 10E may be put off by the implication that there may be a lot they do not understand and have to ask.

3.4 | Interpersonal function

Differences were also identified between the Easy Read and Standard Text excerpts in terms of the way the author related to the assumed target audience. Text pair 2ER and 2ST has been used to demonstrate the nature of the most common differences in the use of pronouns and author stance identified in Table 5.

In this analysis, modal expressions of obligation (‘have to’ and ‘must’) emphasise restrictions imposed on the help and support that may be provided under the new plan in 2ER: these may only be provided for ‘things that keep you healthy and safe’ and what they are is decided by the local NHS. The recipients of ‘help’ are held to account (‘have to tell us’). The frequency of ‘if’ clauses used by the author adds to sense of uncertainty and restriction. Minimal choice is granted to the target readers through the use of ‘can’ but authors make it clear that the budget is ‘held by a third party’. In 2ST modality is

TABLE 4 Referential function comparison: Easy Read1 (1ER) and Standard Text1 (1ST).

1ER some things to do before you go to the doctor or the hospital	1ST before your appointment
<p>Ask your doctor or hospital for <i>someone to support</i> you IF you want help at the doctor or hospital. Ask a friend or family member to <i>come</i> with you, IF YOU LIKE. At the doctor or hospital don't be afraid to <i>ask</i> IF you don't understand. Say: 'Can you say that again? I still don't understand.' IF you don't understand any words, ask the doctor to explain them. You <i>could ask the doctor</i> to write down any difficult words so you can look them up LATER. <i>Write things down</i>, or ask a family member or friend to do this. BEFORE YOU LEAVE the doctor or hospital <i>check</i> that you have done everything on your list, you know what should happen next and when it should happen. <i>Write it down</i>.</p> <p>Ask 'Can I just check I understood what you said?', 'Who should I ask if I have any more problems or questions?'</p> <p>Ask 'WHERE can I get more information?', 'Are there any support groups that could help me?', 'Are there any letters written about me? I would like to see copies of these.'</p> <p>AFTER YOU LEAVE the doctor or hospital <i>write down what you talked about and what happens next</i>. <i>Keep your notes</i>. <i>Book any tests</i> that you can, and put the dates in your diary. IF you do not hear quickly about your next appointment, ask 'What is happening?' IF you don't get the results when you expect them, ask 'Can I have the results of my tests? IF it is not clear, ask 'What do the results of my tests mean'.</p>	<p><i>Write down</i> your two or three most important questions.</p> <p>List or bring all your medicines and pills – including vitamins and supplements.</p> <p><i>Write down details of your symptoms</i>, including WHEN THEY STARTED AND WHAT MAKES THEM BETTER OR WORSE.</p> <p>Ask your hospital or surgery for an interpreter or communication support IF NEEDED.</p> <p>Ask a friend or family member to come with you, IF YOU LIKE. DURING your appointment, don't be afraid to ask IF you don't understand. For example, 'Can you say that again? I still don't understand.' IF YOU DON'T UNDERSTAND ANY WORDS, <i>ask</i> for them to <i>be written down and explained</i>. <i>Write things down</i>, or <i>ask a family member or friend</i> to take notes.</p> <p>BEFORE YOU LEAVE your appointment <i>check</i> that you've covered everything on your list, you understand, (for example 'Can I just check I understood what you said?'), you know what should happen next and when.</p> <p><i>Write it down</i>. Ask who to <i>contact</i> IF you have any more problems or questions about support groups and where to go for reliable information, and for copies of letters written about you – YOU ARE ENTITLED to see these. AFTER YOUR appointment, <i>don't forget: write down what you discussed and what happens next</i>. <i>Keep your notes</i>. <i>Book any tests</i> that you can and <i>put the dates</i> in your diary.</p>

Note: **Nouns and noun phrases** are identified in bold; *verbs and verb phrases* in italics; reference to when and how actions take place is underlined. Any ADVERBS AND PREPOSITIONAL PHRASES are in capital letters.

mainly used to present the list of what 'you' 'will' and 'will not' be able to do under the new plan as a set of rules, without referring to the source of the imposition.

In both texts, the target readers are addressed directly throughout and emphasis is placed on ownership through the frequent use of the second person possessive determiner ('your'). The frequent use of 'we' and 'us' in 2ER does, however, create a divide between help providers and recipients, which is completely absent in 2ST.

There are no explicit expressions of evaluation in either text.

3.5 | Textual function

How a text is foregrounded, the elements that are linguistically accentuated and how ideas, concepts, people and entities are referred back to and developed can shape the way a document is understood and evaluated in terms of what might be important and what is not. Text 3ER and 3ST are used to demonstrate some of the typical patterns found in the excerpts analysed and how they differed across the two text types (Table 6).

Both texts serve to inform the reader. In this sense, they serve the same purpose. However, the links that help the reader to progress through the texts to make sense of the content are distinct. The terms 'care and support' are the first words in both texts and are repeated as a phrase three times in 3ST, all at the end. This allows the reader to refer back to the previous explanations and examples of 'care and support' that have been given throughout the text. 'Care' (as separate from 'support') and words related to it

(carer, caring) are used 3 times in 3ST, and the word 'support' on its own is repeated 5 times in the body of the text, demonstrating how this text expands around a discussion of separate constructs of 'care' and 'support'. In 3ER, however, the full term 'care and support' is repeated 5 times after the initial introduction of the theme. 'Support' is not used as a separate term in the text and 'caring / care / carers' is repeated 3 times.

While repetition of the full phrase 'care and support' in 3ER should provide the reader with prompts to refer back to prior information, there is little content about 'care and support' in the text to refer back to. In contrast, the two terms are divided in 3ST and the topic is expanded, leading finally to 'a full and active life'. In 3ER the information defining 'care and support' is limited to 'help to get out of bed, get dressed or washed, eating or cooking meals, help with seeing friends and family'. the theme here of 'care and support' is less well developed than in 3ST. This is not only evident in the repetitive use of the phrase 'care and support' but in the number of times the author uses non-specific language such as 'people', 'others', 'someone', and 'different'. The 'conclusion' states only who the paper is for in 3ER but does not refer or summarise the content. This creates weak textual cohesion and less progression compared to 3ST. In 3ST, the theme is stated at the beginning, the terms divided and explained, and finally the theme reiterated along with a positive summarising conclusion.

Overall, Text 3ST provides a wider scope and an inclusive focus with a natural progressive elaboration of information whereas 3ER is limited in the language used with superficial repetition of the main theme.

TABLE 5 Interpersonal function comparison: Easy Read2 (2ER) and Standard Text2 (2ST).

2ER all about personal health budgets	2ST understanding personal health budgets
<p>You must spend the money on things in your care plan that keep you healthy and safe.</p> <p>The local NHS <i>has to</i> agree that these things support your health. <i>If</i> things are working well at the moment, you do not have to change them. But a personal health budget means you can change things <i>if you</i> want to.</p> <p>We think personal health budgets could work in 3 ways:</p> <p>Notional budget: <u>We tell you how much money there is for your care.</u> <u>You say how you want us to spend the money.</u> If your local NHS team agrees this meets your needs they arrange the care and support for you.</p> <p>Real budget held by a third party: An organisation, like a charity, looks after the money for you and helps you decide how you want to spend it. They are called the third party. <i>If</i> the local NHS agrees with how you want to spend your money, the organisation buys the care and support for you.</p> <p>Direct payment for healthcare: <u>We give you the money to buy and manage your own healthcare and support.</u> Your local NHS team <i>must</i> agree that this meets your needs. <u>You have to tell us</u> what you spend the money on. You can already have a notional budget or real budget held by a third party. We are testing out direct payments in certain places in England</p>	<p>A personal health budget is an amount of money to support your individual healthcare and wellbeing needs, planned and agreed between you or your representative and your local NHS team.</p> <p>At the centre of your personal health budget is your care plan. This plan helps you decide your health and wellbeing goals, together with the local NHS team who support you, and set out how your budget will be spent to enable you to reach them and keep healthy and safe.</p> <p>If you have a personal health budget, you will be able to use it for a range of things to help you meet your goals, for example therapies, personal care and equipment. <u>You will not be able</u> to pay for emergency care and care you normally get from a family doctor. You are also not allowed to spend the money on gambling, debt repayment, alcohol or tobacco, or anything unlawful.</p> <p>You don't have to change the healthcare and support that is working well for you, but if there's something that isn't working, you can change that.</p> <p>We think personal health budgets <i>could</i> work in three ways, or a combination of them:</p> <ol style="list-style-type: none"> 1. Notional budget. <u>No money changes hands.</u> You find out how much money is available and talk to your local NHS team about the different ways to spend that money on meeting your needs. They will then arrange the agreed care and support. 2. Real budget held by a third party. A different organisation or trust holds the money for you and helps you decide what you need. After you have agreed this with your local NHS team, the organisation then buys the care and support you have chosen. 3. Direct payment for healthcare. You get the cash to buy the care and support you and your local NHS team decide you need. You have to show what you have spent it on, but you, or your representative, buy and manage services yourself. 4. Options 1 and 2 are possible now. Direct payments for healthcare are being tested in some areas of England.

Note: **Personal pronouns** are identified in bold, *modal, conditional or explicitly evaluative expressions* in italics and the use of interrogatives and imperatives are underlined.

4 | DISCUSSION

Readability measures (Flesch-Kincaid 1947) showed that the process of simplification did create distinct differences on a superficial level between Standard Text and Easy Read versions. Words and sentences were shorter in all of the Easy Read versions with the exception of 1ER and 1ST which had similar word and sentence lengths. However, the linguistic discourse analysis of the Easy Read and Standard Text versions through annotation revealed differences not obviously identified through readability measures. (These differences were also not revealed through a previous automated comparison of the same texts using CohMetrix (Buell, 2017). In comparison, Easy Read versions did not always reflect the same positive linguistic representations of people with intellectual disabilities, the author stance or the overall coherence of information that was found in the Standard Text versions. These three aspects (representation, author stance and coherence) are discussed in turn, in line with both the analysis and findings sections. In addition, consideration is given to how all three aspects interact with each other within each text to create unique complexity regarding the way that people with intellectual disabilities may respond to the language of Easy Read. As discussed, the final product can influence ease of reading and the understanding of a text as well as shape perceptions of autonomy and agency.

4.1 | How language represents people with intellectual disabilities

The representation (through language choices) of people with intellectual disabilities and their actions in the Easy Read texts had the effect of limiting their roles in society as demonstrated by the framing of their difficulties and lack of knowledge (1ER compared to 1ST). Reduced agency of people with intellectual disabilities was implicated in all except one of the Easy Read texts analysed. (Document 5ER – see Appendices A and B) Here, rather than limiting roles, active, participatory roles are ascribed to people with intellectual disabilities in doing research. It is possible that the linguistic simplification process has led to unintended consequences in the way that people with intellectual disabilities are represented, for example, requiring more support, but also framed as having less agency (i.e., they are not told to write down symptoms and questions or to bring in their medicines as advised to the general public in the ST version of 'Questions to Ask'). In line with Zimmerman and Warschausk's (1998) theory of empowerment, people with intellectual disabilities and mediators who interact with Easy Read material may be influenced by this potentially disempowering language. The process of interaction with Easy Read documents itself shapes the way people with intellectual disabilities are viewed and may view

TABLE 6 Textual function comparison: Easy Read3 (3ER) and Standard Text 3 (3ST).

3ER caring for our future	3ST caring for our future
<p>Care and support means lots of different things for <i>different people</i>. It depends on what <i>each person</i> needs, but can include things like help to get out of bed, get dressed or washed, eating or cooking meals, help with seeing friends and family, caring for <i>others</i>. We all know someone who needs care and support, and <i>most people</i> will need some care and support themselves at some time in their lives. Care and support comes from lots of <i>different people; family, friends, people in the community</i>. Depending on how much money <i>people</i> have, the Government helps to pay for some parts of care and support. This White Paper is for <i>people who are 18 or older, the people who work in care and support, family carers and others who care for someone</i>.</p>	<p>Care and support enables <i>people</i> to do the everyday things that most of us take for granted: things like getting out of bed, dressed and into work; cooking meals; seeing <i>friends</i>; caring for our <i>families</i>; and being part of our <i>communities</i>. It might include emotional support at a time of difficulty or stress, or helping <i>people who are caring for a family member or friend</i>. It can mean support from <i>community groups and networks</i>: for example, giving others a lift to a social event. It might also include state-funded support, such as information and advice, support for carers, housing support, disability benefits and adult social care. Care and support is something that affects <i>us all</i>: 76 per cent of <i>older people</i> will need care and support at some point in later life. We will all know <i>someone, a family member or friend</i>, who needs some extra care or support to lead a full and active life.</p>

Note: Linguistic links (or cohesive devices) referring to repeated concepts have been identified in bold. that refer to the *people or participants* in the text are identified in italics.

themselves; less as agents of change and more as dependents on the socio-political structures that contain them. These unconsciously perpetuate a disempowering status quo through the vehicle of Easy Read material.

A culture of disablement versus one of enablement comes into view. Rather than building on the values laid down early in the history of Easy Read material that emphasised valuing roles and community inclusion throughout the 1970s and 1980s (Walmsley, 2010, 2013), Easy Read has defaulted to being part of a required service provision. The focus is on the simplification of information rather than on how the information will be received and interpreted. The results of this analysis suggest that producers of Easy Read material could pay closer attention to the way language is used; whether this frames people with intellectual disability as having agency and autonomy within an inclusive culture or whether it does the opposite.

4.2 | The author stance

Related to the argument of underlying culture, are the power differentials identified through the interpersonal function analysis (author stance in relation to reader) in Text 2ER. This was apparent in the way

that the people receiving direct payments were linguistically held to account by the NHS through the use of expressions of obligation that were not evident in the Standard Text. Verbs of obligation were used more often in all five of the Easy Read versions (e.g., 'must' or 'have to') compared to the Standard Text versions. The tendency to use obligations ('must' and 'have to') in the Easy Read versions may be associated with aim of simplification or of making something 'easier' to understand. However, the resulting impact of directive language on the overall tone and message of the Easy Read excerpts is one of control and reduced agency. Furthermore, the distance created between author and the target readers (in this case people with intellectual disabilities who are addressed as 'you' against the NHS who are addressed as 'we' and 'us' in 2ER sets up a power imbalance). This is noteworthy in the face of no such 'we' and 'you' divide created in 2ST. The imposition of conditions combined with directive language and frequent use of terms of obligation and reduction in agency seems counterpoint to the drive towards social and political equality advocated by organisations that first introduced Easy Read material (Townsend, 1998; Walmsley, 2010; Ward & Townsend, 2005) and perpetuates an axis of disempowerment where the aim was quite the opposite.

4.3 | Text organisation

In addition to language in Easy Read material ultimately shaping levels of autonomy and empowerment for people, the organisation of information throughout a text (coherence) can affect how both depth and detail of meaning are lost or retained (McNamara et al., 2010). Contrary to anticipated outcomes, Easy Read versions in this study were less coherent overall compared to their Standard Text pairs in the textual analysis. In part this is due to the way that referents are organised and also because the simplification process is characterised by word repetition and limited explanations (Beck et al., 1984; Fajardo et al., 2014). There is for example, overt repetition of 'care and support' in 3ER that lacks the explanatory content found in the Standard Text version (3ST). One consequence is that the Easy Read versions read more like lists, without the same attention to the development of meaning and message compared to the Standard Text versions. By default, readers of Easy Read documents are being given information that is curtailed compared to the Standard Text versions without the explanations that provide explicit meaning. Readers are therefore disadvantaged in terms of meaningfully connecting with information that provides enough detail and depth for making decisions or influencing change. Much of the benefit of the intrapersonal processes of empowerment (Zimmerman & Warschausky, 1998) such as perceived competence (of understanding) and control (over knowledge) that could be gained through the mechanism of Easy Read are thereby lost.

4.4 | Limitations

Whilst the study sample provides some useful illustrations of phenomena related to Easy Read material, it does not cover the scale of

problematic outcomes of language simplification in the wide range of Easy Read material produced in the UK and internationally. The nature of the methodology used (linguistic discourse analysis) can only be applied to a small number of short texts and this restricts the generalisability of findings. While the methodology is systematically undertaken, there is a risk of variability in interpretation of distinct linguistic aspects. This has been somewhat mitigated by using comparator Standard Text versions. Quantitative linguistic analysis of the same data for comparison would also be useful (forthcoming). Further research is required to establish with more precision the extent of the problem around how language used in Easy Read material shapes empowerment processes. It would be useful, for example, to check whether unhelpful representations and unequal power relations are less likely to occur in original Easy Read documents compared to those that been translated from documents prepared for the general public.

5 | CONCLUSIONS

People with intellectual disabilities ask for, look for and participate in creating Easy Read information (Chinn, 2017; Rodgers et al., 2004; Terras et al., 2021). Its promotion aims to represent equality, inclusion and participation. However, the objectives of simplification (to empower people and to make documents easier to understand) often appear to get lost in translation (Chinn & Pelletier, 2020). Meanings change and roles and agency are affected in ways that may alter the readers' views of themselves and the way that others view them. This may be attributable to a focus by authors on the presentational features of text whereby sentences are shortened, referents are repeated, a high number of directives are used and verb constructions are simplified, such that the agency of a piece is overlooked. The simplification process or shortening of text may also be associated with an evident compromise on detail. The outcome is a text that imposes limits on a readership that Easy Read material is designed to empower. As argued and illustrated in this study, these problematic shifts may be limited by drawing the producers' attention to their nature and potential occurrence. For production teams and individuals who create Easy Read material, increased awareness of author power in relation to the target audience and better knowledge of the impact of linguistic representation (through word choice) could help to redress the apparent gaps in current models of Easy Read documentation towards a revised definition of best practice.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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REFERENCES

- Benjamin, R. (2012). Reconstructing readability: Recent developments and recommendations in the analysis of text difficulty. *Educational Psychology Review*, 24(1), 63–88.
- Beck, I. L., Mckeown, M. G., Omanson, R. C., & Pople, M. T. (1984). Improving the comprehensibility of stories: The effects of revisions that improve coherence. *Reading Research Quarterly* 19 (3), 263–277
- Buell, S., Langdon, P. E., Pounds, G., & Bunning, K. (2020). An open randomized controlled trial of the effects of linguistic simplification and mediation on the comprehension of "easy read" text by people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 33(2), 219–231.
- Buell, S. (2017). Health-based information for people with intellectual disabilities: an investigation into the linguistic properties of 'easy read' literature and its contribution to the construction of meaning. The Easy Read Project. Thesis submitted for award of Doctor of Philosophy PhD, University of East Anglia accessed 20.08.24 at https://ueaeprints.uea.ac.uk/id/eprint/65618/1/Susan_E_Buell_Thesis_2017.pdf
- Butt, D., Fahey, R., Feez, S., Spinks, S., & Yallop, C. (2003). *Using functional grammar, an explorer's guide* (2nd ed.). McQuarrie University Sydney.
- Callus, A. M., & Cauchi, D. (2020). Ensuring meaningful access to easy-to-read information: A case study. *British Journal of Learning Disabilities*, 48(2), 124–131.
- Change. (2015). How to make Information Accessible: A Guide to Producing Easy Read Documents. Available at: <http://www.changepeople.org/>. Accessed 15 May 2015
- Chinn, D. (2017). Learning how to be (a) patient: Visual analysis of accessible health information leaflets for people with intellectual disabilities. *Disability and Society*, 32(10), 1485–1509.
- Chinn, D. (2019). Talking to producers of easy read health information for people with intellectual disability: Production practices, textual features, and imagined audiences. *Journal of Intellectual & Developmental Disability*, 44(4), 410–420.
- Chinn, D., & Homeyard, C. (2016). Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review. *Health Expectations*, 20(6), 1189–1200. <https://doi.org/10.1111/hex.12520>
- Chinn, D., & Pelletier, C. (2020). Deconstructing the co-production ideal: Dilemmas of knowledge and representation in a co-design project with people with intellectual disabilities. *Journal of Intellectual & Developmental Disability*, 45(4), 326–336.
- CohMetrix 3.0. (n.d.). Coh-Metrix. <https://soletlab.asu.edu/coh-metrix/>. Accessed 23/07/24
- Crossley, S. A., Yang, H. S., & McNamara, D. S. (2014). What's so simple about simplified texts? A computational and psycholinguistic investigation of text comprehension and text processing. *Reading in a Foreign Language*, 26(1), 92–113.
- Department of Health. (2001a). Valuing people: A new strategy for learning disability for the 21st century. A White Paper. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf. Accessed 17 March 2015
- Department of Health. (2001b). Nothing about us without us, London, Department of Health.
- Department of Health. (2007a). Getting the Most out of your Appointment. Questions to Ask. Available at: <http://www.dh.gov.uk/health/search?q=Easy%20Read%20>. Accessed 4 December 2012

- Department of Health. (2007b). Valuing people and research: The learning disability research initiative. Available at: <http://www.dh.gov.uk/health/search?q=Easy%20Read%20>. Accessed 4 December 2012
- Department of Health. (2010a). Department of Health Guidelines: Making written information easier to understand for people with learning disabilities. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123766. Accessed 7 November 2012 Revised edn.
- Department of Health. (2010b). Valuing people now: The delivery plan 2010–2011. Available at: <http://www.dh.gov.uk/health/search?q=Easy%20Read%20>. Accessed 4 December 2012
- Department of Health. (2012a). White Paper, Caring for our Future; Reforming Care and Support. Available at: <http://www.dh.gov.uk/health/search?q=Easy%20Read%20>. Accessed 4 December 2012
- Department of Health. (2012b). All about personal health budgets. Available at: <http://www.dh.gov.uk/health/search?q=Easy%20Read%20>. Accessed 4 December 2012
- Disability Discrimination Act. (2005). Disability Discrimination Act. Available at: <http://www.legislation.gov.uk/ukpga/1995/50/contents> Accessed 25 May 2013
- Fajardo, I., Avila, V., Ferrer, A., Tavares, G., Gómez, M., & Hernández, A. (2014). Easy-to-read texts for students with intellectual disability: Linguistic factors affecting comprehension. *Journal of Applied Research in Intellectual Disabilities*, 27(3), 212–225.
- Flesch, R. (1947). A new readability yardstick. *Journal of Applied Psychology*, 32(3), 221–233.
- Freyhoff, G., Hess, G., Kerr, L., Menzel, E., Tronbacke, B., & Veken, K. V. D. (1998). *European guidelines for the production of easy-to-read information for people with learning disability*. Informe Técnico ISLMH.
- Gal, I., & Prigat, A. (2005). Why organizations continue to create patient information leaflets with readability and usability problems: An exploratory study. *Health Education Research*, 20(4), 485–493.
- Halliday, M. A. K., & Matthiessen, C. M. (2004). *An introduction to functional grammar* (4th ed.). Routledge.
- Hurtado, B., Jones, L., & Burniston, F. (2014). Is easy read information really easier to read? *Journal of Intellectual Disability Research*, 58(9), 822–829.
- Iacono, T. (2004). Accessible reading intervention: A work in progress. *Augmentative and Alternative Communication*, 20(3), 179–190.
- Kintsch, W. (1998). *Comprehension: A paradigm for cognition*. Cambridge University Press.
- Learning Disability England. (2022). UK COVID Research - information. accessed 20.08.24 at <https://www.learningdisabilityengland.org.uk/welcome/projects-and-partnerships/uk-covid-research/>
- Lindholm, C., & Vanhatalo, U. (2021). *Handbook of easy languages in Europe* (p. 661). Frank & Timme.
- McNamara, D. S., Louwerse, M. M., McCarthy, P. M., & Graesser, A. C. (2010). Coh-Metrix: Capturing linguistic features of cohesion. *Discourse Processes*, 47(4), 292–330.
- MENCAP. (2002). Am I making myself clear? Available at: <http://www.mencap.org.uk/sites/default/files/documents/200804/make%20it%20clear%20Apr09.pdf>. Accessed 21 February 2013
- Moran, T. E., Gibbs, D. C., & Mernin, L. (2017). The empowerment model: Turning barriers into possibilities. *Palaestra*, 31(2), 19–27
- Morgan, M. F., & Moni, K. B. (2008). Literacy: Meeting the challenge of limited literacy resources for adolescents and adults with intellectual disabilities. *British Journal of Special Education*, 35(2), 92–101.
- NHS England. (2015). *Making health and social care information accessible*. National Standard for Accessible Information. Available at: <http://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/>. Accessed 25 July 2015
- Poncelas, A., & Murphy, G. (2007). Accessible information for people with intellectual disabilities: Do symbols really help? *Journal of Applied Research in Intellectual Disabilities*, 20, 466–474.
- Rodgers, J., Townsley, R. J., Folkes, E. S., Tarleton, E. J., Mears, C. J., Levy, G., & Thurman, S. (2004). Information for all: Evidence based guidance on producing accessible information for people with learning disabilities.
- Schleppegrell, M. J. (2013). Systemic functional linguistics. In *The Routledge handbook of discourse analysis* (pp. 47–60). Routledge.
- Sutherland, R. J., & Isherwood, T. (2016). The evidence for easy-read for people with intellectual disabilities: A systematic literature review. *Journal of Policy and Practice in Intellectual Disabilities*, 13(4), 297–310. <https://doi.org/10.1111/jppi.12201>
- Terras, M. M., Jarrett, D., & McGregor, S. A. (2021). The importance of accessible information in promoting the inclusion of people with an intellectual disability. *Disabilities*, 1, 132–150. <https://doi.org/10.3390/disabilities1030011>
- The Equality Act, (2010) UK Public General Acts accessed 20.08.24 at <https://www.legislation.gov.uk/ukpga/2010/15/contents>
- The Easy-to-Read Association, 2002, accessed 20.08.2024 at <https://www.legislation.gov.uk/ukpga/2010/15/contents>
- Townsley, R. (1998). Information is power: The impact of accessible information on people with learning difficulties. In L. Ward (Ed.), *Innovations in advocacy and empowerment for people with intellectual disabilities* (pp. 77–90). Lisseux Hall Publications.
- Tuffrey-Wijne, I., Goulding, L., Giatras, N., Abraham, E., Gillard, S., White, S., & Hollins, S. (2014). The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: Evidence from a mixed-methods study. *British Medical Journal Open*, 4(4), 6–10.
- Vanstone, M. & Kinsella, E. A. (2010). Critical reflection and prenatal screening public education materials: A metaphoric textual analysis. *Reflective Practice: International and Multidisciplinary Perspectives*, 11(4), 451–457.
- Waight, M., & Oldreive, W. (2020). Investigating accessible information formats with people who have learning disabilities. *Learning Disability Practice*, 26(3), 23–30.
- Walmsley, J. (2010). Access in mind: A review of approaches to accessible information for people with learning disabilities. In J. Seale & M. Nind (Eds.), *Understanding and promoting access for people with learning difficulties* (pp. 23–44). Taylor and Francis.
- Walmsley, J. (2013). Commentary on “Enabling access to information by people with learning disabilities”. *Tizard Learning Disability Review*, 18(1), 16–19.
- Ward, L., & Townsley, R. (2005). ‘It’s about a dialogue...’ working with people with learning difficulties to develop accessible information. *British Journal of Learning Disabilities*, 33, 59–64. <https://doi.org/10.1111/bld.12128>
- World Health Organisation. (2011). The world report on disability, easy read version inspire services: UK. Accessed at https://www.who.int/disabilities/world_report/2011/world_report_disability_easyread.pdf?ua=1 on 12/08/19
- Zimmerman, M. A., & Warschawsky, S. (1998). Empowerment theory for rehabilitation research: Conceptual and methodological issues. *Rehabilitation Psychology*, 43(1), 3–16.

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APPENDIX A

TABLE A1 Rank ordered ER documents showing selections (shaded) for inclusion.

Extracts rank ordered by readability scores	
Easy read document title	Flesch Kincaid grade level
Questions to ask when you go to the doctor or to a hospital	4.755
All about Personal Health Budgets	5.062
Mental Capacity Act	5.634
MRSA Screening	5.816
Direct Payments from the Council	6.002
No Health without Mental Health	6.007
Joint Investment Plans	6.104
Individual Wellbeing and Choice	6.139
Flu Vaccine	6.408
MRSA: A positive result	6.451
Our Health, Our Care; White paper	6.644
Swine Flu	6.663
Healthy Lives Healthy People	6.784
The Information Revolution	6.993
No Excuses	7.189
Better Services for People with ASD	7.421
Valuing Employment	7.521
Caring for our Future; White paper	7.588
Deprivation of Liberty Safeguards	7.698
Valuing People: Transfer Responsibility	7.801
Mental Health Consultation	8.18
Safeguarding Consultation	8.272
Positive Practice Positive Outcomes	8.427
Partnership Working	9.133
Valuing People New Strategy	9.231
Winterbourne View Final	9.54
Liberating the NHS	10.222
Bourne Wood Safeguards	10.442
The Cold Weather Plan for England	10.55
Valuing People Report 2010	10.693
The Winterbourne Concordat	10.708
Choosing Health	10.999
Mental Health Bill	11.091
Valuing People Now: The Delivery Plan	11.278
Valuing People in Research: The Learning Disability Research Initiative	14.127

APPENDIX B

B.1 | EASY READ (ER) AND STANDARD TEXT (ST) EXCERPTS ANALYSED

1ER Things to ask when you go to the doctor or the hospital

Flesch–Kincaid Grade 4.7

Words: 262

Excerpt sub-heading: Things to Ask

Ask your doctor or hospital for someone to support you if you want help at the doctor or hospital. Ask a friend or family member to come with you, if you like. At the doctor or hospital don't be afraid to ask if you don't understand. Say: 'Can you say that again? I still don't understand.' If you don't understand any words, ask the doctor to explain them. You could ask the doctor to write down any difficult words so you can look them up later. Write things down, or ask a family member or friend to do this. Before you leave the doctor or hospital check that you have done everything on your list, you know what should happen next, and when it should happen. Write it down.

Ask 'Can I just check I understood what you said?', 'Who should I ask if I have any more problems or questions?'

Ask 'Where can I get more information?', 'Are there any support groups that could help me?', 'Are there any letters written about me? I would like to see copies of these.'

After you leave the doctor or hospital write down what you talked about and what happens next. Keep your notes. Book any tests that you can, and put the dates in your diary. If you do not hear quickly about your next appointment, ask 'What is happening?' If you don't get the results when you expect them, ask 'Can I have the results of my tests?' If it is not clear, ask 'What do the results of my tests mean?'

1ST Things to ask when you go to the doctor or the hospital

Flesch–Kincaid Grade 4.8

Words: 254

Excerpt sub-heading: Before you leave your appointment make sure you know the following:

Write down your two or three most important questions.

List or bring all your medicines and pills – including vitamins and supplements.

Write down details of your symptoms, including when they started and what makes them better or worse.

Ask your hospital or surgery for an interpreter or communication support if needed.

Ask a friend or family member to come with you if you like.

During your appointment, don't be afraid to ask if you don't understand. For example, 'Can you say that again? I still don't understand.' If you don't understand any words, ask for them to be written down and explained. Write things down or ask a family member or friend to take notes.

Before you leave your appointment check that you've covered everything on your list, you understand, (for example 'Can I just check I understood what you said?'), you know what should happen next and when.

Write it down. Ask who to contact if you have any more problems or questions about support groups and where to go for reliable information, and for copies of letters written about you – you are entitled to see these. After your appointment, don't forget:

Write down what you discussed and what happens next. Keep your notes. Book any tests that you can and put the dates in your diary.

2ER All about Personal Health Budgets

Flesch Kincaid Grade 5

Words: 234

Excerpt Sub-heading: How personal health budgets work

You must spend the money on things in your care plan that keep you healthy and safe.

The local NHS has to agree that these things support your health. If things are working well at the moment, you do not have to change them. But a personal health budget means you can change things if you want to.

We think personal health budgets could work in 3 ways:

Notional budget: We tell you how much money there is for your care. You say how you want us to spend the money. If your local NHS team agrees this meets your needs they arrange the care and support for you.

Real budget held by a third party: An organisation, like a charity, looks after the money for you and helps you decide how you want to spend it. They are called the third party. If the local NHS agrees with how you want to spend your money, the organisation buys the care and support for you.

Direct payment for healthcare: We give you the money to buy and manage your own healthcare and support. Your local NHS team must agree that this meets your needs. You have to tell us what you spend the money on. You can already have a notional budget or real budget held by a third party. We are testing out direct payments in certain places in England.

2ST Understanding Personal Health Budgets

Flesch Kincaid Grade 10.8

Words: 177

Excerpt sub-heading: What are personal health budgets?

A personal health budget is an amount of money to support your individual healthcare and wellbeing needs, planned and agreed between you or your representative and your local NHS team.

At the centre of your personal health budget is your care plan. This plan helps you decide your health and wellbeing goals, together with the local NHS team who support you, and set out how your budget will be spent to enable you to reach them and keep healthy and safe.

If you have a personal health budget, you will be able to use it for a range of things to help you meet your goals, for example therapies, personal care and equipment. You will not be able to pay for emergency care and care you normally get from a family doctor. You are also not allowed to spend the money on gambling, debt repayment, alcohol or tobacco, or anything unlawful.

You don't have to change the healthcare and support that is working well for you, but if there's something that isn't working, you can change that.

We think personal health budgets could work in three ways, or a combination of them:

Notional budget. No money changes hands. You find out how much money is available and talk to your local NHS team about the different ways to spend that money on meeting your needs. They will then arrange the agreed care and support.

Real budget held by a third party. A different organisation or trust holds the money for you and helps you decide what you need. After you have agreed this with your local NHS team, the organisation then buys the care and support you have chosen.

Direct payment for healthcare. You get the cash to buy the care and support you and your local NHS team decide you need. You have to show what you have spent it on, but you, or your representative, buy and manage services yourself.

Options 1 and 2 are possible now. Direct payments for healthcare are being tested in some areas of England.

3ER White Paper Caring for our future

Flesch Kincaid Grade 7.5

Words: 132

Excerpt sub-heading: What is care and support?

Care and support means lots of different things for different people.

It depends on what each person needs, but can include things like help to get out of bed, get dressed or washed, eating or cooking meals, help with seeing friends and family, caring for others.

We all know someone who needs care and support, and most people will need some care and support themselves at some time in their lives.

Care and support comes from lots of different people; family, friends, people in the community.

Depending on how much money people have, the Government helps to pay for some parts of care and support.

This White Paper is for people who are 18 or older, the people who work in care and support, family carers and others who care for someone.

3ST White Paper Caring for our future

Flesch Kincaid Grade 12.4

Words: 156

Excerpt sub-heading: What is care and support?

Care and support enables people to do the everyday things that most of us take for granted: things like getting out of bed, dressed and into work; cooking meals; seeing friends; caring for our families; and being part of our communities. It might include emotional support at a time of difficulty or stress, or helping people who are caring for a family member or friend. It can mean support from community groups and networks: for example, giving others a lift to a social event.

It might also include state-funded support, such as information and advice, support for carers, housing support, disability benefits and adult social care.

Care and support is something that affects us all: 76 per cent of older people will need care and support at some point in later life. We will all know someone, a family member or friend, who needs some extra care or support to lead a full and active life.

4ER Valuing People Now: The Delivery Plan 2010-2011

Flesch Kincaid Grade 11

Words: 113

Excerpt sub-heading: Employment

Valuing Employment Now aims to increase the number of people with learning disabilities in paid work by 2025.

In 2010/2011, Government departments and agencies will work together to deliver the commitments made in Valuing Employment Now.

The cross-Government team will support the Getting a Life Programme and make sure that best practice about ways into employment for young people are shared.

The cross-Government team will support the new Project Search sites and share best practice.

The cross-Government team will support the new Employment project for people with complex needs.

The cross-Government team will work with people with learning disabilities and family carers across the country to raise aspirations about getting a paid job.

4ST Valuing People Now: The Delivery Plan 2010-2011

Flesch Kincaid Grade 12.8

Words: 579

Excerpt sub-heading: Employment

Having a real, paid job that you enjoy is the best route to a full life. If we are serious about equality for people with learning disabilities, employment must be a top priority. Real jobs make people better off financially, as well as growing people's confidence, social life and improving health. However, the first national data on employment for people with learning disabilities showed the employment rate to be even lower than expected, at just 7.5%.

Valuing Employment Now aims to radically increase this by 2025, especially for people with moderate and severe learning disabilities who have been left behind the furthest. As many as possible of these jobs should be 16 h or more per week, because this is when people will be financially better off and will achieve greater social inclusion. The aspiration in Valuing Employment Now is to close the gap between the employment rate of people with moderate and severe learning disabilities and that of disabled population as a whole, which in today's terms would mean 48% of people with moderate and severe learning disabilities in work.

We know that young people are much more likely to get a real job after school or college if they have had meaningful work experience and support from a supported employment provider from age 14, underpinned by person-centred planning and reviews. Research also shows the importance of parents and carers who view employment as a positive and possible option for the young person. These factors can be built into a comprehensive transition pathway, which will lead to employment for young people with learning disabilities when they leave school or college.

In 2010/2011, DH, DWP, DCSF, BIS, ODi, Department for transport, Lifelong Learning UK, Jobcentre Plus and the cabinet Office will deliver the commitments made in Valuing Employment Now. The priorities for the cross-government valuing Employment Now team in this year will be: work with the Getting a Life demonstration sites to publish and implement the pathway to employment for young people locally, share good practice regionally and report to government on the remaining barriers to young people going into jobs and getting full lives; support the new Project search sites to go live in September 2010 and lead a full evaluation; support the work of the sustainable Hub for innovative employment for people with complex needs; work with the Jobs First sites to demonstrate and evaluate how personal budgets can be used for employment; set national targets and milestones for Valuing Employment Now in line with the baseline set by PSA 16 in July 2009 and subject to future priorities in the next spending review; develop and publish national standards for supported employment and job coaching, and work with BIS and the appropriate sector skills councils to develop job coach qualifications; add to the Valuing Employment Now resource hub in line with feedback from regions and local areas; work with people with learning disabilities and family carers across the country to promote the aspiration and expectation of employment; Progression through Partnership will be updated and a delivery plan will be published setting out actions for national implementation.

It is essential that the public sector leads by example in recruiting people with learning disabilities. Thirteen Government Departments are committed to developing policies and procedures that will lead to the recruitment of people with learning disabilities throughout the civil service. a similar commitment is in train within the NHS, beginning with a project that will target 10 trusts throughout England.

5ER Valuing People and Research: The Learning Disability Research Initiative

Flesch Kincaid Grade 14

Words: 257

Excerpt sub-heading: Including people with learning disabilities in research

Our Health, Our Care, Our Say said the Government would work with the Disability Rights Commission on deciding on the best services. This is called 'commissioning'. In Chapter 1 we told you how people were involved in deciding what research to give money to. People were involved in saying what research was good and deciding who got the money.

One of the Valuing People research projects involved researchers with a learning disability. They visited the 12 research projects to see how they had involved people with learning disabilities in their research. The researchers found that all the research projects had used people with learning disabilities as experts in many ways: as advisers and on management groups, collecting information, making sense of the data, supporting other people with learning disabilities to be involved in the research, writing reports.

Some projects involved people more than others. But more people with learning disabilities are involved in research than ever before. Things that could help in getting people with learning disabilities involved in research: rules for writing research ideas, doing research and reports in

easy words and pictures, other accessible formats and different forms such as plays, making sure support matches the jobs people with learning disabilities have to do as researchers, recognising the costs of involving people with learning disabilities in research and the cost to them, understanding and recognising the value of different forms of knowledge, knowing how to make the research help both researchers and those they research without the research having a bad effect on either group.

5ST Valuing People and Research: The Learning Disability Research Initiative

Flesch Kincaid Grade 20.5

Words: 401

Excerpt sub-heading: User involvement in research (Chapter 8)

The LDRI was a bold initiative in promoting an inclusive approach to research commissioning and research management. Researchers were invited to think about how they might embrace inclusive principles but were left to gauge how far these were 'fit for purpose'. A team of people with learning disabilities was expressly commissioned to assess the experiences of the remaining 12 studies in involving people with learning disabilities in the research process. The LMI study describes the findings. The LDRI has demonstrated that people with learning disabilities can play important roles in commissioning research. For the future, challenges are likely to include the following: developing standards by which to judge inclusive research proposals; customising the support needs of service user research commissioners; addressing the ethical issues faced by service user peer reviewers; ensuring that service users are involved in the pre-commissioning stages in helping to design research tenders. In relation to service user involvement in managing the research programme, attention should focus on: publishing better guidance for research contractors about the requirements and standards for easy-read research proposals and final reports; the intellectual, logistical and economic factors involved in producing easy-read research outputs, tied to an appreciation of the rationale and goals of knowledge dissemination and utilisation; further exploration and evaluation of the potential for more creative methods of research dissemination through performance arts, and their effects in transforming people's views and behaviours; service user involvement in research governance, which is useful in continuous testing of how emergent evidence is going to benefit the service user community and policy.

The LMI study contributed evidence about the opportunities and challenges of engaging people with learning disabilities in the remaining 12 LDRI studies. It showed that there is a need to think about who funds pre-protocol work undertaken by service users; the economic and non-economic costs to service users of becoming involved in research in different roles; ethical challenges that can and do arise in inclusive research, so that their effects can be mitigated or their chances of occurring can be avoided altogether; the added value of inclusive research, requiring some assessment of different types of knowledge and of standards or frameworks for assessing these different types of knowledge. This is a very challenging agenda, and one upon which much rests; a code of good practice for inclusive research, based on a recognition of the different contributions people with learning disabilities are making to research.