




The Easy Read Project



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1The University of East Anglia, 2 Tizard Centre, University of Kent

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"It isn't always easy and I can't always read it" ..so what happens to it??




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Experiences with 'easy read' documents




- going to the doctor,
- about theatre productions,
- about health topics,
- for giving consent to research or other things
- the news,
- recipes
- going for a run
- health procedures
- moving house

I'm sure you can think of more...




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Easy read isn't easy to create well




- length of time it took them to make good, useful 'easy read' material
- expensive it was to ask professional organisations to do it for them
- it was sometimes difficult to agree in groups about the best way to put things down in words.




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'Easy read' means different for different people



all groups (except one) agreed about was having pictures or images in the documents


- Some groups liked photographs, others preferred photos mixed with symbols and drawings
- Others liked to draw their own pictures
- The group that did not want any images used a 'reader' system



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Different things for different people...

People in the groups also had different ways of using 'easy read' material



- Some just flicked through it quickly
- others liked to talk about the pictures,
- some people read the words
- others put it away maybe for later or said they would keep it to show someone at home.

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Sometimes pictures helped but sometimes they didn't

One group had a lot of difficulty interpreting the pictures in a document about 'doing research'.

The more abstract a topic was, the more difficult it was to find appropriate and relevant pictures that everyone would understand.

One of the most important messages that people in the project gave was that 'one size does not fit all'.

They wanted to be able to choose pictures and photos that made sense to them, even if they didn't seem to make sense to other people.



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Without words and out of context what does this picture mean?




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Easy read information is sometimes difficult to understand

We looked at 'easy read' information in groups and also in one to one meetings.

Many people in the groups said that they could not understand the information in the 'easy read' material and asked for some help to understand it.

it was 'boring',
 'like school'
 'too difficult'
 'wasn't interesting'



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Recent legislation in the UK

Health and Social Care Act (2012)
 'Accessible Information Standard'

All organisations in health, social care or who work in the public sector are now legally obliged to make 'reasonable adjustments' to information to anyone who has difficulty understanding it....

BUT

It's easy to tick the 'easy read' box.  

It's not so easy to make sure that people understand the information



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Factors that can affect Health Literacy for people with IDs

- reading and understanding written information
- understanding the language used
- linking what has been read to the real world
- knowing how the information fits into the 'bigger picture' and personal implications of this

Fulfilling the UK legal requirement' for making "reasonable adjustment" to information in health continues to focus on provision of a paper product - most often in the format of 'easy read' 2, 3

Making reasonable adjustments to cancer screening

Easy-read summary



The NHS runs three cancer screening programmes. These are:

- breast screening
- cervical screening
- bowel screening



It can be difficult for people with learning disabilities to take part in cancer screening.



It is important to find out if people have cancer as early as possible. This makes it easier to treat the cancer.



The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use the services. This means they need to change their services so they are easier to use.

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Who creates it and how do they know they are doing it well?




Government agencies
Local health clinics and offices
Local advocacy organisations and co-production groups
Non-governmental organisations (charities)
Profit-making organisations

Guidelines –
Department of Health UK
MENCAP UK guidelines
Inclusion Europe guidelines



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Background



Is the ongoing development and production of 'easy read' health material cost effective in terms of making a difference to the *understanding of health information* for people with IDs in so far as it might also *reduce the risks* they experience?

How do we know we are doing it well??

Where's the EVIDENCE?



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What my research was about




 **Set out to find out what parts of the process of using 'easy read' material were successful in helping people to understand information about health...**



The Easy Read Project

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The Easy Read Project



Study A: Survey of features (language, size and style of font, use of space and pictures) in Department of Health (DoH) 'Easy Read' documents and 'Non-easy read' documents (2000 and 2012)


Study B: Comparative analysis of the language used in 'Easy Read' and 'Non-easy Read' DoH documents

Study C: Comparative analysis of the discourse of 'Easy Read' and 'Non-easy Read' DoH documents (the way power relationships were represented)


Study D: Experiment to test how simplifying language and providing support affected the understanding of 'Easy Read' texts.

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Study A: Survey of features in 41 'easy read' and 'non-easy read'




In 'easy read':
Language was (on the surface) simpler
Font size was consistently larger used san serif styles
More white space was used and
More colour was used in pictures and text
More images, photos and pictures were used



In both 'Easy Read' and 'Non-easy read':
Bullet points were used
Consistent use of headings and sub-headings

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Study A: Conclusions... What's the added value?



Easy read material


- Demonstrated clear differences in features compared to 'non-easy read' versions
- Showed a wide variety of interpretation of guidelines
- Was less consistent in use of all features in production compared to 'non-easy read'
- Did show simpler language overall, but some 'easy read' versions scored more highly on readability scores than 'non-easy read'

So... we are creating documents that look different with the aim of serving a different purpose.




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Study B: Analysis of the language used in 'Easy Read' and 'Non-easy Read' DoH documents




On average...

- Sentences in 'easy read' were shorter and used shorter words
- Words used were more familiar, less abstract, more easily visualised and
- Grammar used was simpler
- Range of vocabulary was more limited
- More repetition of words occurred
- Fewer joining words were used
- The same level of repeated 'meanings' were used as in 'non easy read' e.g. health professional / doctor / medical staff



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Study B: Conclusions... What happens to language when we simplify?



Using familiar, less abstract, shorter words with simple grammar means that:

The same words are repeated more often in the same grammatical structure e.g. 'The government said that...'

This limits the content and may limit construction of meaning.


The overall structure of the information can be affected:

It can lose 'flow' and without a beginning, middle and end can be less easy to follow or to understand

Familiar words have more ambiguous meaning e.g. 'people'


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Study C: Analysis of the discourse of 'Easy Read' and 'Non-easy Read' DoH documents



I looked at 5 documents in more detail to examine the way that language represented


- i. people places and events
- ii. author/ reader relationships
- iii. structure of the text for meaning



These can show the way power relationships are represented and are played out in documents...

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Study C: Conclusions – How well balanced were the 'easy read' documents?



Clear imbalances of power were found in all five documents compared to the 'non-easy read' documents where the language showed a different balance

For example in the 'easy read' material:


more language of conditions and obligations was used (e.g. *If you..., you must...,* instead of *'when' or 'you could'*)

The author often framed ideas in a way that clearly placed the reader in a situation with less power and agency than in 'non-easy read' material (e.g. use of *'you'* rather than *'we'*)

Repetition led to higher levels of ambiguity and less overall structure

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Study D: The Easy Read Task Does easy text and support help understanding?





60 participants

Texts and questions were closely designed with a local advisory team from the **Opening Doors Advocacy Group** in Norwich. The topic was 'healthy eating'.

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The Easy Read Task



Participants were randomly allocated according to reading ability to one of four conditions:


text with simple or complex language/ with or without support followed by 8 questions

1. Linguistically simple text with support	2. Linguistically complex text with support	3. Linguistically simple text with NO support	4. Linguistically complex text with NO support
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Support was structured using a pre-prepared script :

- summary,
- clarification of text content page by page pointing to pictures / using gesture where appropriate,
- an example of a question,
- predictive reasoning from text (based on a model of reciprocal reading,


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Study D: Conclusions – Did simple text or support make a difference? 


Simplifying the text nor giving one-off standard explanatory support made any difference to the scores participants achieved in The Easy Read Task

However, NO!

Receptive vocabulary was the most important factor in determining participants' understanding of linguistically simple text, over and above mediating support, the Easy Read document or the reading comprehension ability of the reader.




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How do we make sense of information? 


What's relevant to me?

The **INDIVIDUAL LANGUAGE CAPACITY** OF EACH PERSON directs the construction of what is meaningful to him or her from the information available

- Through the easy read text
- Through explanations
- Through checking back and summarising
- Through attaching information to experience
- Through learning




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What does this all mean for creating 'accessible' information? 

People with intellectual disabilities like 'easy read' material
It clearly serves a function
It's not going to go away!
A lot of industrious effort goes into preparing it
SO
We need to get the 'easy read' document right


- Not too repetitive?
- More structure and more attention to the power that language has?
- Use a bigger variety words and teach their meaning?



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Likeability, readability, usability, learnability... 


I like it
I can read it
I can understand it
I can apply it
I can learn something from it



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THANK YOU

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Any questions?

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Any answers?

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References

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