

THE RESPONSIBILITY OF MAKING INFORMATION ACCESSIBLE

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Introduction

Agencies such as health and disability services have an obligation to provide accessible information, this is articulated in the UN Convention on the rights of persons with disability (UNCRPD). Easy read, also known as easy English, is one strategy used by agencies to support people with intellectual disability to understand information. Disability organisations use easy read in many aspects of service provision, for example planning service goals or in brochures about their service. The purpose of easy read is to make information easier to understand by distilling difficult or complex messages into simple, short sentences with corresponding pictures.

In recent years there has been much debate about the technicalities of easy read design and effectiveness that have been acknowledged internationally (Chinn & Homeyard, 2017; Sutherland & Isherwood, 2016). Putting aside the design and technical dilemmas, there are other considerations about how easy read is made and used that are worth contemplating. Questions about who has decided what information to translate into easy read and/or how to frame the messages within accessible documents are important to consider. This article focusses on the responsibility that rests with agencies in supporting information access and the need for greater transparency when simplifying information.

The right to information

The UNCRPD sets out that everyone has a right to accessible information as a foundation on which many other rights rest. For agencies, this understanding of accessible information moves the task of creating accessible resources from an administrative activity to a legal and ethical obligation. Information provided in accessible formats has far reaching potential to enhance knowledge and broaden options available for people with intellectual disability to consider. Information is a platform for activities such as understanding more about health, service options, planning and making decisions. The potential for accessible information to enable inclusion reinforces the responsibility of agencies who create easy read to provide appropriate resources to support information access.

Agencies need to provide accessible information suitable for the people with intellectual disability who use their services. The communication needs of service users vary, and for some people with intellectual disability, easy read is not their preferred communication strategy. However, for other people with intellectual disability easy read enables them to access information independently or with support. UK experience using easy read highlights the importance of easy read, yet also cautions against viewing easy read documents as a tool which facilitates information access for all people with intellectual

disability (Kean, 2016). UK researchers have demonstrated that providing easy read as a standalone tool is not sufficient to meet the obligation to provide access to information articulated in the UNCRPD. (Mander, 2016). Agency obligation to provide access to information, with easy read as one of many communication strategies available, underpins the discussion which follows.

Who decides which information is made accessible?

Many agencies create easy read information to meet the needs of people with intellectual disability, but how these easy read documents are produced is often unclear. Decisions about which information is needed in accessible formats and key messages to be included or omitted are often not clearly articulated or documented. Chinn (2019) found that in the UK, the way that decisions about easy read content are made are often ad-hoc. At times easy read material was created as an administrative obligation, which determined the content. On other occasions, easy read was made in response to advocacy group requests and at other times the origin was unclear. The issues raised in the UK highlighted that the ways decisions were reached about who created easy read material, why and how were often unclear (Chinn, 2019). Similarly, in Australia there is little consistency or guidance available about the content decisions for creators of accessible resources.

Decisions about how to frame accessible messages are often left with the creators of easy read with varying outcomes. The messages that easy read creators choose to convey can be determined by many pressures and influences. Factors such as agency priorities, funds, skills, time pressures, the creator/s' values -either deliberately or inadvertently, can all influence easy read content. Simplifying information from complex concepts to brief sentences is difficult and capturing the depth of issues can be challenging (Buell 2015). UK researchers have found that accessible information often omits background information, creating a list of things to do and limiting choice rather than enhancing it (Bunning & Buell, 2012). Sometimes easy read creators have the end user in mind or work with end users, but at other times they are not aware of the audience, or exactly how the document will be used (Buell 2015; Chinn, 2019). This is often the case when external agencies contract for translation of information to easy read, for example. The often ad-hoc nature of easy read development has potential to limit the information contained in the document to that which the creator/s have deemed essential.

Including people with intellectual disability in easy read development is one way that agencies seek to ensure the accuracy and appropriateness of messages contained in easy read documents. Many easy read developers are committed to engaging people with intellectual disability in the process of developing easy read material in Australia and internationally. For example, NHS easy read guide in the UK or Scope Easy English Guide in Australia. Chinn (2019) noted that in practice people with intellectual disability were often consulted about aesthetics or technicalities such as suitability of picture type to convey a specific message rather than the broader content suitability or accuracy. Additionally, Chinn and others have noted that people with intellectual disability are sometimes treated as a homogenous group when consulted about the suitability of documents despite the vast variation in preferences and needs (Buell, 2015; Chinn, 2019). Collaborating with people with intellectual disability is recognised as important when developing appropriate information, but often their role in easy read creation is unclear.

Transparent processes

Without guidance about how to decide what to include in easy read documents the responsibility often rests with people who create it. In the UK the lack of consistency and transparency in how easy read is developed has been reinforced by researchers (Chinn, 2019). Easy read creators in Australia reflected the UK experience, emphasizing the weighty responsibility that rested upon easy read developers. They

highlighted the need for greater guidance and accountability when determining the content of easy read documents. The key issues raised about how easy read content is determined can be divided into four areas. These related to transparency about origin, collaboration, quality and the potential role of supporters. Each of the areas are listed below with some examples of questions which may be worth asking:

- **Origin** Who requested the easy read document? Was it funded? Does the requester have any governance over content or use?
- **Collaboration** Were people with intellectual disability consulted in the development of the document's content? Were they representative of service users who will use the easy read ?
- **Quality:** Is the document evidence based? Where was the evidence obtained? Did a subject matter expert read over the finished document? Are the authors and date of production included in the easy read document?
- **Support:** How do the document creators envisage it will be used? How can the document be used independently? What is the potential role of supporters?

The purpose of this article is to raise these issues to encourage discussion rather than to provide a comprehensive framework. The questions above are provided as examples to encourage greater consideration of how easy read content is determined. Transparency about the origin, collaboration, quality and role of supporters could act as both a safeguard for people with intellectual disability and easy read creators. Greater transparency could provide an opportunity for experienced easy read developers a platform to share their knowledge. Most significantly, greater transparency and collaboration could increase the availability and quality of resources available to people with intellectual disability.

Conclusion

There is a growing awareness that guidelines and transparency about how the content of easy read is determined is lacking. More transparency in the processes surrounding easy read development could go some way to providing wider access to accurate, appropriate information. The obligation of agencies to provide accessible information suitable for people with intellectual disability underscores the need for greater accountability when developing easy read information.

Key points

- People with intellectual disability have a right to information and agencies have an obligation to provide it
- Using easy read is one way agencies make information easier to understand
- Decisions about what to include in easy read and what to leave out can significantly impact people with intellectual disability's access to information
- Researchers in the UK have found that there is very little transparency about how the messages included in easy read are decided upon
- It would be good to do more research about what Australian agencies do to decide what to include in easy read documents and how people with intellectual disability are involved in this process

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Her PhD explored how easy read is used to make information about mental health

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