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Title

A Commentary on “First-hand Experience of Accessible Information”

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Biographical information

Susan Buell works as a lecturer in speech and language therapy at the University of East Anglia where she is undertaking a PhD to investigate ‘easy read’ information and its use. She draws on 25 years of experience of working with people with learning disabilities and their families.

Abstract

Purpose: To provide a commentary on Mander’s paper on first-hand experience of accessible information.

Design/ Methodology/ approach: The commentary reflects on some of the findings presented by Mander and builds on these, with particular emphasis on what it means to understand information.

Findings: Everything from initial product design to building capacity and constructing knowledge requires expertise and attention to detail.

Originality/Value: There are no quick fix solutions to achieving understanding of information by people who have learning disabilities.

Key Words:

Learning disabilities, intellectual disability, access, information, design, understanding

Article Classification:

General review

Mander's article comes as a timely addition to the gathering momentum of recent draft proposals and consultations by the NHS for a national 'standard' in accessible information to be recognised and implemented across the UK for anyone that requires it (NHS England 2014). In a recent commentary in this Review, Walmsley (2013) lamented the lack of empirical research into an area that was then burgeoning, specifically that of 'easy read' literature. Since then, the 'easy read' market continues to grow. Mander takes a wider view of accessible information, presumably including any access tools available such as 'easy read' text and pictures, audio, audio-visual, sign and perhaps objects, and draws attention to the process involved in 'delivering' information in a way that can be understood.

My own interactions both with learning disability researchers and local self-advocacy groups suggest that finding a way of increasing the understanding of information is often an after-thought once the 'real' work of gathering information together has been completed. It seems that most people are looking for a quick and simple way of effectively passing on information before carrying on with the work in hand, be it securing ethical approval or a campaign for caring for ones' teeth. Mander's findings demonstrate that there is no easy, simple or quick fix for achieving this. It requires time and a certain level of knowledge, even 'expertise'. Both of these have a financial cost. Below, I outline three arguments for why there is no simple solution to closing the gap between the product for accessing information and the 'process' of delivery as described by Mander. The first relates to the product and explores the notion that good design is never easy but it is important. Secondly, I note that the way human beings understand information and conceptualise ideas is complex. Thirdly, the heterogeneity of the target audience for 'accessible information' is vast and, therefore, over-reliance on a universal design is unrealistic and probably ineffective.

Good design is never easy

Perhaps it is artificial to divide product design from its delivery to the target audience. Good design, as professional graphic and health information designers show (Wright 2003), starts with an analysis of the target audience, their cognitive abilities, preferences and current understandings. An analysis to ascertain baseline knowledge, gaps in knowledge and what knowledge is required serves as a starting point (Strydom et al 2001). Including service users in the production team is not a new idea but, as Mander demonstrates, this does not always occur. Reasons for this can only be speculated, but the consideration of time and cost within current health and social care systems almost certainly influences the level of importance given to information production, its reliability and ecological validity. Decisions about layout, font, images (in 'easy read'), or voice, accent, speed of speech and pausing, visuals, clips, images and layout (in dvds, websites and audio versions), and the way information is grammatically constructed are all the domain of product design. These choices impact on how information in the final product will be interpreted. Overloading a document or website with too many headings or too much colour, for example, will counter any positive aspects for access (Schraver 1989) and render the information too much effort to process. Mander comments on the support some people need for understanding and interpreting information and this raises a further question about who the target audience really is. How will the images, language used and formatting be interpreted by the carer or family member providing this support? The final stage in good design is performance testing the product with a sample of people with learning disabilities (and/or their carers) in the real world. This is distinct from the opinions and views of service users with learning disabilities who are on the production team. As Mander has alluded to in her paper, attention to the

product requires design expertise and a strong ability to appraise the needs of the target audience. I would add that knowledge of the architecture of language and a willingness to make revisions on the basis of performance testing are also crucial. The implementation of such a time consuming and expensive process in real life is possibly an unattainable ideal within current systems. However, it goes some way to show how far current processes for producing effective, valid and reliable 'accessible information' fall short of the ideal.

Understanding information and ideas

As mentioned above, interpretation of the product is key, and visual or cognitive overload can render 'access' ineffectual. As human beings, the way we understand information is complex. It involves several interacting cognitive processes. It depends on our ability to first decode the information using language skills, and then to construct understanding out of our own prior knowledge and experience, the evidence presented to us, and any contextual clues that are relevant to us at that point in time (Sperber & Wilson 2002). It is largely accepted (as Mander has found) that the main outcome of 'accessible information' should be an improved understanding. Sperber & Wilson (2002) argue that we naturally engage most effectively with information that is the most accessible to us and therefore easy to construct meaning from (relevance theory). Information (spoken, written or symbolic) that requires the least effort will have the biggest and fastest cognitive effect and will therefore be successfully understood. Cognitive gain needs to balance or outweigh the effort involved in 'access'. One of the criticisms of 'easy read' information devised for people with learning disabilities is that it does not take into account the cognitive level of some service users who might not have the ability to understand complex concepts (Walmsley 2013). Additionally, Hurtado et al (2014) demonstrate how split attention between pictures and text may create a situation where more effort is required from participants with stronger reading skills because they are trying to process and integrate two types of input. They understood less than those presented with the same material but whose more limited reading skills may have led to their concentrating more on the images. In both examples effort outweighs cognitive gain and the person 'accessing' the information might quickly decide that there is little value in continuing to pursue the information. It follows that creating 'accessible information' where cognitive gain outweighs effort should be the overall aim. The chosen tool for providing 'access', be it 'easy read', audio visual support, or audio versions make up part of the evidence that goes into the process of constructing meaning and understanding through interpretation. In relation to the effort involved in understanding, Grove (2014) demonstrates the variation in our interpretation of different images, by showing different representations of the concept 'meeting'. These include a line drawing, a complex photo, a symbolic representation and a mix of photo and image. Without clearly establishing the meaning in context, each of the images could be interpreted to mean something different. The intended interpretation of the author and whether the inferences provided are explicit or implicit are key to the inferential understanding of the image. Only the most explicit inferences will require minimum effort. However, making inferences explicit when faced with complex concepts might involve deeper work around these to arrive at a place where cognitive gain is at least on a level with effort. Grove (2014) uses examples of the co-construction of meaningful understanding of complex concepts such as 'citizenship'. Only by working together within a group or individual's zone of proximal development (Vygotsky 1978), building on what they already know, can meaningful understanding and definitions be developed. Research on access to information often fails to recognise the value of learning. Ferguson & Murphy (2014) demonstrate how increasing capacity for knowledge through tailor made

training sessions with small groups of people with learning disability can be more successful than health information leaflets. The study focused on information about the possible side effects and consequences of taking medication for long term conditions, or of refusing medication. Clear evidence suggests that increased capacity and knowledge in this study led to better, more informed choices, and reduced risk for participants. By acknowledging that someone cannot immediately understand or access a concept or an idea, space is created for adult learners to increase their participation and voice in society through gaining new knowledge and developing understanding of new concepts. Again, this argument supports the 'multi-faceted' aspect of accessible information central to Mander's paper and it demonstrates the complex process of understanding information where we incorporate all the evidence available, internal and external, past, future and present to make optimal sense of the new message. There is no simple or quick fix to achieving understanding but it can become part of a larger, more interesting and more enjoyable process of ongoing learning and development.

Heterogeneity of the target audience

The personalisation of information to make it easier for individuals to understand has been proposed by Oldrieve & Waight (2013), reinforced by Walmsley (2013) and is further supported here by Mander. The discipline of health literacy has expanded to include individual assessments of a person's level of health literacy using frameworks such as that developed by Chinn & McCarthy (2013) that incorporate an evaluation of interaction and understanding. Overall literacy skills for people with learning disabilities are shown by Morgan et al (2011) to be unique to each individual. Words that can be sight read are often linked to personal experience and interest, as are pictures and symbols. Someone who seems unable to read might be able to capture and understand a text very well, if given literature that is of interest and covers familiar topics. Wright (2003), in her work on the design of health literature, argues for personalised health information and warns that, although it might be more expensive, failure to take account of needs and requirements at an individual level could be dangerous. This is further supported by Ferguson & Murphy's (2014) study on medication where the personal experience of participants was key (capitalising on relevance to each individual) and where cognitive demand (effort) was reduced by responding to individual queries and concerns as they arose. Most importantly, the focus was on increasing knowledge and capacity rather than simply transferring information. Relevance theory (Sperber & Wilson 2002) recognises that individual construction of understanding has a different starting point for each person and possibly for each interaction. It follows, therefore, that a more individualised approach to the understanding of 'accessible information' is indicated when working with a heterogeneous group that demonstrates such a wide variation of language skills, cognitive ability and life experience.

Conclusion

In summary, there are no quick fix solutions to achieving the understanding of information by people who have learning disabilities. The product (leaflet, dvd, video etc.) requires an analysis of the target audience, attention to detail and subsequent revisions to have the optimum chance of providing relevant information that is unambiguous. The more complex task is that of constructing understanding using the product as a tool, particularly if the information contains complex or abstract concepts. Finally, there will always be a requirement to build understanding based on an individual's current level of cognitive ability and preference.

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