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Talking to producers of Easy Read health information for people with intellectual disability: production practices, textual features and imagined audiences

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Abstract

Background: Concerns about health inequalities experienced by people with intellectual disability have led to many health information materials being created in an 'Easy Read' format. This study aimed to understand the practices involved in making information accessible.

Methods: Individual, pair and group interviews were conducted involving people with and without intellectual disability based in non-profit organisations, academic and health service settings. Thematic analysis addressed the creation of Easy Read

health resources, the format and content of the texts, and how producers imagine the texts are received by potential audiences.

Results: Little consensus emerged of the best way to produce Easy Read health information. Lacking systematic feedback, participants described imagined audiences and contexts for their reception.

Conclusions: Production of Easy Read resources has become widespread despite current limited evidence of impact. Interactions between social groups involved in the production process and the wider policy and legislative context contribute to this situation.

Keywords: Easy Read, Accessibility Practices, Disability, Resource Design

Background

Easy Read has become a worldwide social phenomenon. This term is synonymous with others used across the world (Easy English in Australia; Leichte Sprache in Germany, Selko Kielen in Finland). Guidance on the production of accessible Easy Read information for people with intellectual disability is widely available and recommends technical adjustments to the design of materials: attention to reading age, length and complexity of sentences, layout, well placed illustration, and appropriate road testing by potential end users (Department of Health, 2010; Mencap, 2008).

Historical and Policy Context

The emergence of Easy Read as a technology for rendering information accessible that is associated with inclusion and human rights for people with intellectual disability has happened in a specific historical context. The winding down of large-scale institutional care for people with intellectual disability in the 1970s and 1980s was both a result of transformation in policy and practice for disabled people, and also gave further impetus to developing discourses emphasizing citizenship and human rights for people with intellectual disability (Brown & Smith, 1992). People with intellectual disability were invited to take part in developing policy (Department of Health, 2001), making decisions about aspects of their care, planning for their futures, and joining projects to research their lives and experiences. All this required a rethinking of how people with intellectual disability could meaningfully engage with the informational resources, particularly written texts, that were an integral part of these initiatives (Walmsley, 2010).

On the international stage, the Convention on the Rights of Persons with Disabilities emphasises the importance of access to information in accessible formats as a human right (The United Nations, 2006: Articles 4,9,21). In the UK, the Equalities Act (2010) can be seen as a milestone in the promotion of accessible information for people with intellectual disability by establishing the necessity for providers of services to make “reasonable adjustments” – alterations to their provision that remove access barriers for disabled people. The publication of the NHS Accessible Information Standard (AIS) (NHS England, 2015) has sought to operationalize the legislative requirements of the Equalities Act in relation to communication in care settings.

Such advancements in policy and legislation and discourses around access and empowerment have consequently created a demand for ERHI (Walmsley, 2013). Easy Read texts are designed and disseminated in the UK by many NHS health trusts, by large design and communication businesses and small charities/not-for-profit organisations that have histories of working with and for people with intellectual disability. This third group was the focus for the research reported here.

Research on Easy Read

Despite the prima facie appeal of using accessible information formats, and many anecdotal reports of these being helpful and acceptable for people with intellectual disability, as yet there is a lack of conclusive research evidence that changing the way information is presented as recommended by Easy Read guidance necessarily makes it easier to understand for people with intellectual disability (Sutherland & Isherwood, 2016). It is also difficult from the available evidence to conclude how Easy Read

resources are being used in real life settings and how use of these materials impacts on outcomes relating to wellbeing (Chinn & Homeyard, 2016).

Moreover, although a number of researchers and practitioners have described projects leading to the production of Easy Read resources (Porter et al., 2012; Russell, 2006), often details of the production process and clear rationales for design decisions are lacking. Little is known about the accessibility practices (Seale, 2004) associated with Easy Read production or the tacit understandings, institutional routines or social contexts that underpin these (Williams et al., 2018).

The aims of this study were to therefore to understand from those immersed in the design and creation of Easy Read health information (ERHI) i) which practices they prioritised in the creation of ERHI; ii) what elements they felt were most important in deciding on the content of ERHI; iii) how they anticipated how their materials might be used in real-life situations.

Methods

This was a qualitative study involving analysis of individual and group interviews. The recruitment strategy was purposive regarding including a variety of different types of producers and started with an internet search for organisations that offered services creating Easy Read information as a key work activity. Out of the 23 organisations or individuals contacted, representatives from 7 English third sector not-for-profit organisations (TSOs) agreed to take part. As accessibility of information has also become a research topic in its own right, two participants who also had many years experience of producing Easy Read information were also recruited from

academic settings. An NHS manager provided expertise on the perspectives of commissioners of ERHI (See Table 1).

Table 1 here

Interviews were structured using a topic guide, with questions about the participants' backgrounds in creating ERHI, what they thought were the key principles guiding the design of ERHI, how they involved others in the process such as people with intellectual disability and health professionals, and how the materials they made were commissioned, disseminated and evaluated. At the end of the interview the researcher and participants together reviewed and reflected on an example of an ERHI resource that the participant's organisation had created.

Ethical approval for the study was granted by the national Social Care Ethics Committee. All participants with intellectual disability were given time and opportunities to discuss their participation in the research within their organisations, and were deemed to have the capacity to give informed consent to take part.

Audio recordings were made of 8 individual and 2 pair interviews and 3 group interviews. The individual and pair interviews were all with employed staff, including one person with intellectual disability who has a role as a service user consultant. The group interviews were with people with intellectual disability and supporters who were involved in the organisation's Easy Read work and were conducted in three of organisations where individual interviews had been completed. Interviews lasted between 42 and 92 minutes and were transcribed verbatim.

An overall frame for analysis used Rose's identification of the three sites where multimodal texts might be examined (Rose, 2016): the site of production of the text, the site of the text itself and its constituent features, and the site of reception and audiencing, where the text is received. Within the three 'sites' an inductive thematic analysis (Braun & Clarke, 2006) was used.

The validity and robustness of the study findings were addressed through a recursive process of reviewing the interview transcripts in the light of the emerging codes and themes, through discussion with expert readers of the text in progress and through researcher reflexivity particularly regarding her professional and political positioning in relation to this research (Bourdieu & Wacquant, 1992).

NVivo 11 software was used to allocate descriptive codes to short stretches of interview data. The codes were then sorted into collections corresponding to the three sites and themes and subthemes were then identified.

Results

The site of text production

Subthemes relating to the site of text production reflected the accessibility practices (Seale, 2004) engaged in by participants: "translating" texts into accessible formats, and involving different stakeholders in the process.

Translation practices

A good deal of accessible information designed for people with intellectual disability can be described as generic or public communication (Askehave & Korning Zethsen, 2003), as an institutional response to the legislative or regulatory requirements of the Equalities Act and the AIS that their communications be accessible to people with disabilities. Graham, from TSO1 called this “*broadcast mode*”. Staff from the TSOs were pragmatic about the motivations of these health and social care commissioners whose dissemination of Easy Read versions of their texts might amount to essentially a public relations exercise:

They look like they're a kind of caring organisation and, you know, and I feel a bit bad that our resources allow them to do that, they pay us x quid and they tick a box

Graham, director TSO1

The dynamics between the commissioners and the producers were described as market driven. The TSOs described how they were dependent on this income to fund their other activities such as self-advocacy and community work and also to pay people with intellectual disability involved in the production process. Moreover, these small organisations acknowledged they were competing against each other for commissions; participants explained that this situation made it more likely that each developed a unique “brand” to distinguish itself from the competition.

We need to stick with what we know to work and what we also know is recognisable as [our organization].

Chloe, staff member TSO4

Staff from the TSOs describe the process of “putting a report into Easy Read” as *translation*; a process of pruning the text of jargon and selecting images to clarify the meaning. They described adapting these sorts of official documents as somewhat “*mechanistic*” (Carole, nurse academic) (“*we churn it out*” commented one interviewee from TSO6) and time consuming. Participants mentioned the challenges of conveying more abstract terms in concrete language and the risks of oversimplifying complex ideas, an issue raised by Walmsley (2010). Trying to include all the key points of a document could lead to long and unwieldy outputs. This work was often conducted with minimal input from people with intellectual disability as staff were often required to work with long, complex texts and to tight deadlines. Interviewees felt that these commissions addressed the letter, rather than the spirit of the law; they could be counted as reasonable adjustments but were not part of a systematic approach to improve the accessibility of health systems:

Quite often we will get a request for Easy Read and it will be: we want to put our five-year strategy into Easy Read...a health Trust contacted us about that...But what they don't have in place is an Easy Read system for their appointment letters.

Hugh, director, TSO2

Co-production

...good Easy Read ...is about that co-production process; the fact that people with learning disabilities must be involved in developing the information as Easy Read otherwise how do you know it's effective.

Jocelyn, NHS Commissioner

Participants argued that the involvement of service users as co-producers of EHRI was essential to ensure not only the readability of texts, but also as a way of representing the concerns and life experiences of people with intellectual disability, a point made by Brian below.

Interviewer: So tell me how you got interested in doing this sort of work?

Brian: I suppose it's because I go to a day centre and I know what people want. I know what they're looking for.

Brian, service user consultant

Chloe from TSO6 described projects in which the themes for resources came from consultations with service users and this was seen as the ideal context for production of resources by staff from TSOs, though a more customary reliance on paid commissions meant having to adapt to external agendas with respect to topics and key content. Perhaps because of her access to academic funding and a research focus the nurse academic, Carole, described being able to work more “from scratch” with ideas for texts generated by people with intellectual disability.

Within the TSOs, people with intellectual disability were described as “quality checkers” who reviewed drafts of EHRI and suggested amendments, though as Jocelyn, the NHS commissioner, pointed out, the actual processes and practices driving co-production were rarely actually spelled out. Common practice was reading through a text to identify linguistic trouble spots, with responsibility for creating the finished texts taken on by the TSO staff:

And then they would test like me or Carolyn, you know the ones that could read to see if we could read it and if it were clear for us. And then if we couldn't then they would change it and put it more simple

Val, self-advocate, TSO3

Despite the normalising endorsement of co-production of ERHI there were some dissenting voices. Graham (TSO1) argued that his years of experience working with people with intellectual disability, his design expertise and knowledge of visual technologies and visual literacy gave him an understanding of what worked regarding Easy Read resources; he viewed others' insistence on involvement of people with intellectual disability as in part an ideological move which also promoted what he called “*vested interests*”.

Medical expertise

There were also mixed views about the contribution of health professionals in the design of ERHI and different practices around incorporating expert biomedical voices. Some participants used materials created by medical experts as the starting point for their materials, which were then adapted/translated into Easy Read. Others

engaged medical experts in a role analogous to the service user quality checkers' to ensure the validity and accuracy of the information.

However, although there was respect on the whole for the professional voice, the participation of health professionals was viewed as presenting complications in some instances. Keith from TSO5 mentioned encountering problems when different health professionals did not agree, and Kelly from TSO7 had struggled to secure consistent input from a group of midwives. At times, there did not appear to be a comfortable match between the practices, priorities and institutional contexts of the health staff and the producers of ERHI. The participants suggested that supporting the creation of ERHI was not necessarily viewed by health staff as a key aspect of their role, or they lacked relevant understandings of the information needs of people with intellectual disability. Kelly from TSO7 described how health staff might take a somewhat protective stance in deciding what sort of information was suitable for people with intellectual disability:

I think individuals sometimes find, um, professionals...don't want to say that something might cause death, they don't want to scare them, that sort of thing.

The site of the text itself

There was a great deal of variability in the formats and texts produced by the different organisations. This meant it was hard to abstract overarching principles of how to judge the quality of ERHI texts. Two subthemes describe how participants argued for the merits of particular resources: "*Common-sense*" understandings of readability, and *social representations*.

Common-sense understandings

Participants referred to the required design components of ERHI found in guidance documents (Change, 2015; Department of Health, 2010), such as placing of images in relation to text, type, size and colour of font, lexical and grammatical features etc. For some respondents the guidance appeared to represent common sense universally applicable understandings of how readers tackle written information. They presented their views as factual statements about how literacy worked for people with intellectual disability that did not require further reinforcement through empirical evidence:

Like we understand like people read from like left to right so if there's an image on the left hand side that like represents the writing then they'll going to understand more.

Samantha, staff member, TSO3

Chris: Some of them [illustrations] are funny. Instead of formal. I think people prefer...more informal. It makes it more open for people to like learn about something.

Chris, self-advocate TSO3

What counted as a common-sense judgement about good Easy Read was shaped by local cultural contexts; familiarity with the formats used in a particular setting coloured assumptions about the quality and appropriateness of the resources the organisation was producing and also perpetuated local practices.

It looks familiar to them because many of them have been volunteering here for a long time, so this document is immediately recognisable to somebody as being created by [us].

Chloe, staff member, TSO4

Social Representations

Aside from the design considerations, participants judged the quality of ERHI on the implicit social positions a resource might present for people with intellectual disability, rather less tangible issues that were not always emphasised in documents providing guidance on the design of ERHI:

[the guidance]’s not saying things about age appropriateness, it’s not saying things about the ideology of information, who is doing what to whom, it’s not saying about power dynamics.

Graham, director, TSO1

Graham here extends the concern voiced by different participants that ERHI should avoid being “*patronising*” or “*treating disabled people like children*” to emphasise how these resources project ideologies of health communication which are predicated on particular power relations between creators and recipients of health messages.

Research participants conceded that the ERHI frequently operated within the ideology of biomedical authority represented in a traditional model of health education, which emphasizes compliance with medical advice (Nutbeam, 2000):

So [cancer charity] are thinking right we need to give people information about cancer but they haven't thought about, you know, the fact that someone might not want to have treatment.

Jess, staff member TSO4

It has been noted elsewhere that ERHI is rarely formatted to promote informed decision-making in the light of the risks as well as benefits of treatments (Chinn & Homeyard, 2016). This limitation was acknowledged by some participants, though usually only in response to probing by the interviewer. More frequently a case was made for using ERHI persuasively to promote involvement in health care, given the health inequalities experienced by people with intellectual disability and their perceived low uptake of preventative health measures.

The site of reception

Because of the practices involved in commissioning and producing the ERHI, producers acknowledged there were limited opportunities for them to receive feedback about how their resources were being used by people with intellectual disability and the impact they were able to make on people's lives. As one producer (Hugh, TSO2) put it "*we develop stuff and then we have to move on to the next thing*". Producers had to rely on general assessments from people with intellectual disability and others, and specific anecdotal examples where an individual had been seen to benefit from using ERHI. When participants described ways that their resources might be received in sites of reception, they were therefore generally

describing “imagined audiences” and ways that they anticipated their materials might be used (“contexts of use”).

Subtheme 1: Imagined Audiences

The audience for ERHI was conceptualised variously as a) everyone; b) diverse groups with communication needs, and c) people with intellectual disability identified as a specific group.

a) EHRI is for everyone

A number of participants emphasised not only the importance, but also the intuitive appeal of presenting information in a way that was universally accessible.

It's not exactly rocket science - just put something in plain English... Why can't it just be done anyway, why do you need to give this advice?

David, self advocate TR03

Producers used the affordances of design elements to reach out to this universal imagined audience. Producers might strive for high-end production values or avoid an overt mention of intellectual disability in the resource. Some resources used stock photographs, which as Machin (2004) suggests, convey an assumption of ordinariness and genericity, (albeit somewhat idealised).

Participants reported that wider audiences responded favourably to having access to Easy Read material, especially when the usual version was complex and hard to understand. However, this was not always the case, and a couple of participants

recounted instances where people who did not have the label of intellectual disability looked askance at being given Easy Read resources, for instance as minutes recording a meeting.

Jocelyn: One of the things we will do when we go to meetings I'll take the Easy Read update as opposed to the standard one. And you will still get a couple of people around the table who will go, "What the hell is that?"

Interviewer: With that face?

Jocelyn: They're offended by it, like completely offended...

Jocelyn, NHS commissioner

Other barriers to normalising ERHI “for everyone” cited by informants were the impact of customary, bureaucratic practices, and failures to disseminate the ERHI materials as the standard version of relevant information by the bodies that had commissioned it. The adoption of Easy Read formats as standard and universal ways of representing health information was seen, with regret, as an unreachable ideal.

In an ideal world the standard letter, information, everything would be in Easy Read... But that would require a huge cultural and administrative change.

Jocelyn, NHS Commissioner

b) Diverse groups with communication needs

Chloe: We know that Easy Read information benefits people with learning disabilities, older people, people with visual impairments.

Jess: People whose first language isn't English.

Chloe: Speakers of other languages...or people with lower literacy levels.

Jess: Or just find reading hard, don't like to read

Chloe and Jess, staff members TSO4

Extending ERHI to diverse groups with communication needs was described not so much as a result of decisions relating to commissioning, design or distribution of materials, but more a fortuitous outcome, once the materials were out in the world. The ERHI often “ended up” being offered to or taken up by various groups who encountered difficulties with the standard versions. Informants suggested extended use of ERHI beyond users with intellectual disability was an argument for viewing investment in these materials as good value for money.

One specific group who were seen to benefit from access to ERHI were the supporters or carers of people with intellectual disability, who for a variety of reasons including limited educational experiences, or having English as a second or additional language, might struggle with accessing and making sense of health information:

*I think a lot of Easy Read is aiming to increase the knowledge of supporters;
it's one of the benefits of Easy Read. It's the trickledown effect.*

Hugh, Director, TSO2

c) EHRI is specifically for people with intellectual disability

A contrasting view among the research participants was that EHRI was primarily for people with intellectual disability. The EHRI producers recognised that the legal protection available to disabled people under equalities legislation meant that arguments could be made for funding the creation and dissemination of EHRI to people with intellectual disability as a duty to provide reasonable adjustments to standard practice. There is no enforceable legal requirement to assess and meet the communication needs of other users of health services, and the NHS Accessible Information Standard makes it clear that it applies only to 'protected groups' with recognised disabled status.

Therefore, EHRI was seen to provide opportunities for individuals who as a group have often received poor care to speak up about their needs and preferences and redress inequities in their access to public services:

I think also it's sending out a clear message that this group of people have an equal right to access health services...

Hugh, director,TSO2

However, imagining the audience as 'people with intellectual disability' presented challenges, as participants acknowledged that this category includes people of very

diverse capabilities and experiences who are likely to have a variety of preferences regarding how they receive information.

The research we've done has said that people prefer line drawings. But then other research has been done that people prefer photographs. And it's very difficult because what works for one person doesn't work for another person ...one size doesn't fit all

Jess, staff member TSO4

Subtheme 2: Contexts for use

Participants described different ways that they anticipated the EHRI they created would be used; either by people with intellectual disability reading the resource on their own, or having their access to the material facilitated by a supporter.

Independent use

One of the aspirations for ERHI articulated by the research participants was that it could enhance the independence and autonomy of people with intellectual disability. Instead of needing someone to decipher health information for them, they could do this unaided for themselves.

Interviewer: I mean if you wanted to know more about diabetes would you like someone to sit down and read this with you or would you like to look at it by yourself?

Brian: With me I like to look at it myself. Because I can read some of these words easy.

Brian, service user consultant

Participants also gave more concrete examples of the benefits of independent use of EHRI. Removing the need for assistance in reading materials from health providers could make life simpler for people with intellectual disability, and preserve their privacy.

Interviewer: When you have something to look at like a leaflet...do you prefer to look at it by yourself or do you prefer to have someone there to look at it with you?

Steve: No I look at it by myself... Don't like nosey parkers.

Steve, self-advocate TSO3

Mediated use

Research participants acknowledged the crucial role of a supporter or 'literacy mediator' for many people with intellectual disability: "*someone who makes his or her literacy skills available to others, on a formal or informal basis, for them to accomplish specific literacy purposes*" (Baynham, 1993). Jess from TSO4 described the mediator as providing technical help, implying that a more active and interpretive role for the mediator might put the person with intellectual disability into a more subordinate position.

We will help them with [a] word if they get stuck on it, so that they're taking the lead on it and the person is literally just there to support.

Jess, staff member TSO4

Hugh describes a different role for the literacy mediator, working together with the Easy Read artefact to initiate conversations with the person with intellectual disability. The outcome is better communication and understanding for the person with intellectual disability. In his account, the skilful interaction lead by the mediator can be more important than the resource itself.

I always think that Easy Read is there to promote communication; it's a spark that gets communication going and gets people talking and understanding and stuff.

Hugh, director TSO2

When participants discussed mediators they generally characterised them as family or paid carers. Jocelyn however, explored the possibility of others with intellectual disability taking on this role:

And I think there's some interesting stuff around the kind of role of self-advocacy groups in supporting groups of people with learning disabilities to get access to and read and take on board, if you like, Easy Read information.

Jocelyn, NHS Commissioner

Few of the ERHI producers explicitly addressed mediators through the design of the resource itself by including advice or guidance on how to use it, perhaps with the expectation that facilitating appropriate access to the resource would come “naturally” to the mediator.

I mean you'd hope that, you hope that it would be just a natural instinct to hone into the person you're supporting.

Kelly, staff member TSO7

However, as one participant pointed out, staff from mainstream services with less experience of working with people with intellectual disability might be lacking strategies and time to take on the mediator role.

But that's just based on assuming people kind of have an understanding of how to support others. But then if it's a reception staff at a doctor's office they might not and they probably wouldn't take the time anyway. [They're] just handing somebody the information.

Chloe, staff member TSO4

Discussion

The first aim of this study was to identify the practices engaged in by producers of ERHI that they felt were most effective and important in creating ERHI. Though there were one or two dissenting voices, most of the participants emphasized the involvement of people with intellectual disability and principles of co-production. Co-production is a term that is used to refer to projects where service users take the

lead or control the agenda to different degrees (Bovaird, 2007). However, an important overarching principle is that service users are positioned as possessing expertise and competence (Boyle & Harris, 2009).

The findings suggest that though co-production with people with intellectual disability in ERHI might be held up by participants as the ideal, the social and economic realities of how ERHI is produced can present barriers. Producers of ERHI were often relying on commissions where the brief was to “translate” existing documents into Easy Read, and therefore at the mercy of demand factors, rather than having free rein to decide on topics of greatest concern to people with intellectual disability. Because of time pressures and length and lack of intrinsic interest, such commissions were often undertaken without the involvement of people with intellectual disability.

When they were involved people with intellectual disability appeared to be acting primarily as “quality checkers” and focusing on textual features of documents, rather than being encouraged to decide on than the overall meaning content of the texts, or to critique the context of their production. They were not invited to reflect, for example, on the directive tone of much ERHI (Chinn, 2017) and the way many texts position potential readers as deficient in knowledge and motivation (Dixon-Woods, 2001). As one participant noted, what constitutes coproduction and how to do it is rarely spelled out. There is currently a lack of research about the micro-practices and negotiations between lay and expert/professional participants in co-production that are most conducive to the stated goal of equal partnership (Fenwick, 2012).

A final point about coproduction is its capacity to enhance citizens' capabilities and skills (Boyle & Harris, 2009). In this study the potential for involvement in production of Easy Read as a path to people with intellectual disability gaining additional, employable skills, for instance in copy writing or illustration, was not highlighted by participants.

The second question related to the design elements that participants felt were important in creating ERHI. Participants referred to the sorts of features strategies that are highlighted in existing guidance documents (Change, 2015; Department of Health, 2010b) that seem to have common sense validity, such as explicating new concepts by "*breaking them down*" and avoiding jargon or adding images. However they acknowledged that these strategies set up their own difficulties. Texts could become long and unwieldy and images could be ambiguous and hard to decipher. Empirical research on the effects of using these strategies suggests that longer Easy Read documents can be no easier to understand than standard versions (Buell, Langdon & Bunning, 2016), and pictures presented alongside words may be distracting and can impede comprehension (Hurtado, Jones, & Burniston, 2013).

However, experimental research on reading capabilities may obscure the very wide individual differences between readers within the category of intellectual disability who are necessarily treated as a homogenous group when ERHI is disseminated as generic or public information (Askehave & Korning Zethsen, 2003). There are

different ways to respond to these dilemmas; either exploring the possibilities of a technical fix underpinned by a deeper understanding of linguistic elements, for instance using insights from computational linguistics (Yaneva, 2015); or designing accessible resources that are expressly intended to be individually tailored to the communication requirements of individual users (Oldreive & Waight, 2013).

The third question relates to the audiences for ERHI and contexts for its use how these are anticipated by producers of these materials. The findings suggest that producers of ERHI tend to develop their own local audiences of people with intellectual disability. The different brands of ERHI produced by TSOs with distinctive design elements become familiar to local service users and represent for them 'good' Easy Read. Even so, producers of ERHI have few opportunities to evaluate the reception of their outputs, especially with more distant audiences, and receive little feedback about how their products are used in real life settings.

Indeed, there is limited research regarding the everyday literacy practices of people with intellectual disability, either as independent readers (Morgan, Moni, & Cuskelly, 2013) or when their access to written texts is mediated by others. It does seem likely that literacy mediators can greatly enhance the engagement of people with intellectual disability with written texts (Flewitt, Nind, & Payler, 2009). On the other hand they can also impose their own agendas or anxieties in ways that limit how far interacting with an ERHI text can support someone with intellectual disability to make choices or explore their own feelings (Jones, Tuffrey-Wijne, Bernal, Butler, & Hollins, 2007; Mander, 2016). The current research therefore reinforces arguments rehearsed

elsewhere (Sutherland & Isherwood, 2016) that greater attention should be paid to the role and activities of supporters in facilitating the access to people with intellectual disability to informational resources (Walmsley, 2013) and the interactional contexts of their use. The idea that self-advocates with intellectual disability might take on this facilitating role is worth exploring further.

For some of the participants, the imagined audience for ERHI was “everyone”, consistent with the principles of *universal design*. Universal design is defined as “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (Mace, 1988). It is part of the mainstreaming agenda; diminishing the need for segregated solutions and special services that run the risk of institutionalising the view that impairments are stigmatizing conditions, rather than instances of shared human experience. This approach suggests that provision of health information that projects values such as friendliness, respect and ease of comprehension would be valued by everybody – as one participant with intellectual disability complained “*why do they have to make it difficult in the first place?*” Perhaps because users of health services are required to fit in with biomedical forms of language and systems of care that are designed around institutional priorities (professional status, regulatory affinity, cost savings) rather than patients’ own preferences?

However, informants implied that non-disabled audiences may dismiss EHRI for their own use because of its association with a disabled identity that was associated with negative characteristics and impaired or stigmatised social status (Goffman, 1963).

Other barriers to normalising ERHI “for everyone” cited by informants were the impact of customary, bureaucratic practices, and failures to disseminate the ERHI materials as the standard version of relevant information by the bodies that had commissioned it. The adoption of Easy Read formats as standard and universal ways of representing health information was seen, with regret, as an unreachable ideal.

As well as providing insights into the accessibility practices associated with the production of ERHI, this study also revealed how these practices were located within the wider socio-economic context. As has been noted elsewhere, the financial crisis of 2008 and the imposition of austerity measures, accompanied by an ideological commitment to neo-liberalism – the prioritisation of the market and the downplaying of welfare configurations of wealth redistribution - has adversely affected people with intellectual disability and their supports (Malli, Sams, Forrester-Jones, Murphy, & Henwood, 2018). Small TSOs, lacking reliable public funding, now face precarious futures and production of ERHI has emerged as one income-generating opportunity that was allowing them to stay afloat. Moreover, participants’ accounts suggest that the market environment puts pressure on these organisations to develop a unique offer to distinguish themselves from their competitors, rather than adhering to more standardised practices.

Large health and social care organisations that commission ERHI are also sensitive to market forces as they compete amongst themselves for sources of income in the mixed economy of care (Goddard, 2015). Commissioning ERHI means they comply with legislative and regulatory demands, and also present a “*caring face*”, as one participant put it. The commitment of time and energy by people with intellectual

disability as producers of EHRI and the imprimatur of authenticity conveyed by their participation is at risk of becoming a commodity that can be monetized in the marketplace without necessarily giving opportunities to people with intellectual disability to dictate the terms of engagement.

In the previous section we saw how participants' with intellectual disability described the way that being able to use EHRI without assistance gave recognition to the reading skills they possessed, thus including them in what Kliever (Kliever, Biklen, & Kasa-Hendrickson, 2006) called the "literate community", and preserved their privacy and a space for individual reflection on the information. This may be particularly valued in care setting where support and aid are offered in ways that are likely to be experienced as intrusive and controlling.

The emphasis on the role of ERHI in promoting the independence and autonomy of people with intellectual disability in some participant accounts in this study can also be found in Easy Read guidance and policy documents (NHS England, 2015). This conception of ERHI also fits with the neoliberal frame within health services policy and provision, which emphasises the requirement for patients and publics to be self-managing consumers of health knowledge and services who take responsibility for their own health care, rather than relying on state support (Kendall & Rogers, 2007). Paradoxically, in order to achieve this position of independence, this reader with intellectual disability is dependent on producers of ERHI to adapt texts on their behalf, and is also expected to 'choose' to follow the health advice recommended in the texts. This is the dilemma of inclusion politics, as Altermark and Michalko amongst others have cogently argued. When policies target people with intellectual

disability in order to include them in the citizenry, the “otherness” and deficiency of the category of intellectual disability must be upheld and made relevant, in order to constitute a subject who can be made the recipient of these special measures (Altermark, 2017; Michalko, 2009)

Conclusions

This has been the first study aiming to understand the current “state of the art” regarding the production of ERHI. Nevertheless, it has some notable limitations. Despite expressing initial interest, participants from large commercial communication and translation business that are increasingly fulfilling Easy Read commissions (Brinkley, personal communication) were not successfully recruited. An observational ethnographic study would have provided more in-depth data on the culture and workings of ERHI individual production groups.

Nevertheless, the findings of this study do help explain why EHRI continues to be produced and disseminated at volume despite the lack of clear evidence for its impact and the lack of consensus between stakeholders about key principles for its production and dissemination as was evident in this study. Perspectives from the social construction of technology (SCOT) (Bijker & Law, 1992; MacKenzie & Wajcman, 1986) argue that new technologies do not succeed necessarily because they are objectively provide the best solution to human needs. They trace how technologies develop through processes of negotiation and contestation between “*relevant social groups*”; sets of individuals who share the same set of meanings associated with the technology or artefact in question, who have a common

understanding of what the problem is that needs to be solved. These negotiations are shaped by background conditions of socio-cultural and political arrangements that determine distribution of power and resources (Klein & Kleinman, 2002).

In this study the relevant social groups are public organisations that commission and pay for the ERHI, staff and managers (without intellectual disability) in the TSOs, people with intellectual disability (those who were involved in production of the ERHI and others who were constituted as its audience), carers and supporters of people with intellectual disability, and health professionals. Participants' accounts in this study show how accessibility practices (Seale, 2004) in the production of EHRI are developing against a backdrop of ongoing debate and negotiation between these social groups and within the wider socio-economic milieu of twenty first century welfare politics.

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Conflicts of Interest

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Table 1 Participants

	Organisation	Nature of organisation – main activities	Individual interview participants	Group interview participants
TSO1	Third sector organisation	Creation of Easy read and accessible resources	Director	
TSO2	Third sector organisation linked to larger service agency	Creation of Easy read and accessible resources.	Director	Director and four service users
TSO3	Third sector organisation linked to larger service agency	Creation of Easy read and accessible resources	Staff member	Ten service users and two supporters
TSO4	Third sector organisation	Creation of Easy read and accessible resources Research and campaigning		Two staff members
TRO5	Third sector organisation	Creation of Easy read and accessible resources	Easy Read design group coordinator	
TRO6	Third sector organisation	Creation of Easy read and accessible resources Advocacy and self-advocacy		Two staff members
TRO7	Third sector organisation linked to larger service agency	Creation and collation of accessible resources	Staff member	
	University	Research, teaching	Nurse academic	
	University	Research, teaching	Service user consultant	
	NHS Commissioning department	Commissioning	NHS commissioner	