

**Deconstructing the co-production ideal: dilemmas of knowledge and representation  
in a co-design project with people with intellectual disabilities.**

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## **Abstract**

Background: The co-production concept holds out the promise of forging new relationships between professionals and service users with intellectual disabilities. However, little empirical research explores the embodied practices these projects occasion. We identify two key tensions intrinsic to such projects; the tension between expert/professional knowledge and lay/experiential knowledge, and between co-producers as different from or typical of the public they are representing.

Methods: We explored how these tensions were manifested and responded to in ongoing interactions by analysing video recordings of co-design groups where people with intellectual disabilities engaged in the production of Easy Read materials.

Results: We noticed the instability of participants' claims to expert/professional knowledge, and the challenges of attending to and mobilizing participants' experiential knowledge within the constraints of the group task.

Conclusions: Interactional dynamics were managed to preserve consensus and homogeneity within the groups, with the potential for reinforcing a limited identity associated with 'intellectual disability'.

## **Key words**

Co-production, co-design, intellectual disabilities, discourse analysis, Easy Read, accessible information

## Background

Over the last decade or so, the concept of co-production has moved into the mainstream of health and social care discourse (Boyle & Harris, 2009). The drivers of initiatives that promote a greater role for service users in the design or operation of services are varied, and include higher service quality, democratization, cost efficiencies, increased social cohesion and levels of social capital, personalization of services, and increased levels of innovation and competitiveness in the marketplace of service provision (Bovaird, 2007; Facer and Enright, 2016; Fledderus et al., 2014). Furthermore, co-production offers social positionings to service users as active, competent, knowledgeable and skillful, rather than 'passive' and needy (Dunston et al., 2009; Radnor et al., 2014).

However co-production projects tend to lack detail regarding the practices used to actually embody their stated ideals. There is now an expanding body of research and scholarship that has taken a more critical approach by seeking to look inside the 'black box' of co-production at what happens in settings where co-production is performed, including how it is done interactionally (Kirkegaard & Andersen, 2018; Olesen & Nordentoft, 2013). Areas of concern include the involvement of only the more acquiescent participants, or the 'usual suspects' - those already socialized into local co-production practices (El Enany et al., 2013); the marginalization or exclusion of discourses that challenge existing institutional norms (Hodge, 2005); and the potential for collaborative projects to conceal the workings of power in favour of already established interest groups (Cooke & Kothari, 2001; Palmas & von Busch, 2015).

These issues are arguably linked to unavoidable tensions and contradictions inherent in the co-production project itself (Martin, 2009; Phillips et al., 2013). In this article we wish to focus on two tensions in particular: first between varying conceptualisations of what constitutes ‘useful knowledge’ contributed by professionals and service users, and second between the participants and the publics they are meant to represent or be typical of. We identify these tensions through a detailed examination of the participants’ language use – a reflection of i) the ‘discursive turn’ and growing interest in how design happens through conversation and interaction in participatory design literature (Luck, 2003, 2007) and ii) an ongoing theme in participatory design regarding how power is exercised and shared (or not) between facilitators and end-users (Bratteteig & Wagner, 2012).

Our concerns can also be understood in relation to Martin’s work (2008; 2009) on the discursive representations of lay/service user knowledge and expertise in different co-production projects in healthcare. At times the ‘ordinariness’ of lay participants is emphasized as well as their lack of specialist knowledge or skills compared to their ‘experiential knowledge’ as a form of embodied insight. At other times, their ability and willingness to reflexively engage with the language and expert knowledge of health professionals is called on and made relevant (see also Epstein, 1995; Pols, 2014). Here we examine how these tensions are marked and responded to in the context of the co-design of Easy Read texts for people with intellectual disabilities (ID).

### The co-design of Easy Read texts

Easy Read is the name commonly used in Australia and the UK to describe formats for written texts designed for people with ID. Guidance on creating Easy Read texts

(Change, 2015; Department of Health, 2010) advises using straightforward, linguistically less complex and ‘jargon-free’ language as well as symbols, drawings and photographs to facilitate understanding. These materials have proliferated in care settings (Chinn, 2017), in part as a response to legislative requirements for health and social care providers to make ‘reasonable adjustments’ to their provision for people with ID (Equality Act, 2010; NHS Accessible Information Standard, 2015).

These guidance documents, as well as accounts from individuals engaged in their production, emphasize the importance of involving people with ID in the Easy Read design process (Chinn, 2019; Department of Health, 2010; Norah Fry Research Centre, 2004). The rationale for this tends towards a functionalist/technocratic justification; people with ID as co-designers can make sure that the Easy Read texts are intelligible and fit for purpose. The dilemmas we describe above are rarely foregrounded in existing discourse about Easy Read production. The expertise of co-designers with ID is claimed to lie in their familiarity with Easy Read as a technology (Reuben & West, 2005); they are also seen as ‘experts by experience’ in living with a label of ID who can contribute their unique understandings of what kind of information they need based on their life experiences (Chinn, 2019). Although there has been acknowledgement that power differentials between users’ and professionals’ spheres of knowledge may create tensions in the field of inclusive research (eg Strnadová, & Walmsley 2018), this has not been extensively explored within co-production projects (Ward & Townsley, 2005). Similarly characteristics of co-designers are assumed to mirror those of a wider audience of ‘people with ID’ with issues of representativeness only rarely problematised in policy and guidance documents (Norah Fry Research Centre, 2004).

In exploring the processes involved in the design of Easy Read texts, our aim therefore is to explore how issues and dilemmas arise as Easy Read co-production groups go about their work, and how they are dealt with relating to a) different forms of knowledge and expertise – expert and experiential - and b) representation and the relationship between the co-production participants and wider imagined audiences. In this way we hope to contribute to ‘method stories of co-design’ (Hendriks et al., 2015) involving people with disabilities that create opportunities for reflection and methodological refinement among designers committed to co-production (Lee, 2012).

## **Method**

Seven organizations were recruited as part of a study designed to investigate the practices and discourses involved in the production of Easy Read health information for people with ID (Chinn, 2019). The organisations had been offering services creating Easy Read information as a key activity for at least four years and were committed to doing this through co-design groups involving people with ID.

The study was granted ethical approval by the national Social Care Ethics Committee. All participants were given Easy Read information sheets about the project, as well as time and opportunities to discuss their participation in the research within their organisations. All were deemed to have the capacity to give informed consent to take part.

Video recordings took place during naturally occurring co-design group meetings in three of the organisations' offices at which a researcher was also present as an observer. The size of the group ranged from four (Group 3) to nine people (Group 2). There were 21 participants altogether. All of the group facilitators were male and were salaried staff members of the organisations. Other participants were people with ID who were paid on a sessional basis to work on the Easy Read production, other staff members, and in group 2, students from a near by university, one undertaking a research degree and the other doing a work experience placement. In Group 1, co-producing involved choosing a cover picture and a title for a text that had not yet been written, but whose content had already been determined. In Group 2 and 3, it meant reading an existing text and editing it, with group 2 focusing in particular on the selection of appropriate illustrative images, and group 3 focusing on word choices.

#### Data processing and analysis

The audio from the video recordings was transcribed verbatim using pseudonyms for all participants with some additional notation relating to non-verbal aspects of the interactions. The positions of participants in space was noted (in all cases around a table). Analysis of the data was a recursive process, involving a series of engagements with the video recordings, transcriptions and theoretical and research literature and extended discussions from our different disciplinary perspectives. After an initial stage of inductive coding using NVivo, codes were grouped with reference to the two main themes of our research questions (types of knowledge and issues of representation). Our analytic method was informed by Social Semiotics (Van Leeuwen, 2005) an approach to the analysis of meaning that treats communication as constitutive of relationships and

identities. In line with this method, we carried out a fine-grained analysis of how language and other semiotic resources were used by participants to relate to others in the group discussion and present themselves, including how they portrayed or represented their understandings of intellectual disability and its characteristics, particularly with respect to the use of Easy Read texts. At a higher level of abstraction, we were guided by Dowling's (2009) sociological method of 'constructive description', developing schemata to create relational spaces where interactions between phenomena evident in the empirical data, but also shaped by the researchers' engagement with theory, can be explored.

## **Results**

### **1. Establishing a relation to the object of knowledge**

Unlike other co-production groups (Epstein, 1995; Pols, 2014), the participants with ID had not assembled because of individual interest or affectedness regarding the topic under consideration. Under these circumstances, where individuals may have little prior experience of the topic, participants may be invited to assimilate a normative, 'expert' framing of the topic, or be called upon to shape the topic in line with their own 'experiential' life world knowledge and lived experiences of being someone with a label of ID. Participants' relationships to these types of knowledge, manifest in their voiced contributions to the group discussion, might further be interactionally constructed as illegitimate (irrelevant, problematic) or authoritative.



## 1.1 'Expert' knowledge

In Group 1 and Group 3 the facilitators initiated the process of constructing the relationship by 'finding out' what participants 'already know' about the topic: under such conditions, lay participants are potentially placed in the position of needing to construct a relation to the topics under discussion (Felt & Fochler, 2010) before the 'work' of designing the Easy Read leaflet can begin.

These inquiries appear based on the premise that the facilitator already has adequate knowledge of the healthcare topic. It is the participants' level of knowledge that is the object of exploration. This embodies assumptions about the social distribution of knowledge, namely that facilitators are more, and the other participants are less knowledgeable. Moreover, the facilitator can legitimately elicit and evaluate the lay participants' knowledge, but this cannot be reciprocated.

Extract 1: Group 1, prostate leaflet, Geoff (facilitator), Val (staff member), Billy, Simon, Mike, Lee (co-designers)

- 25 Geoff: So what do we know about prostate? Who's got one? ((Geoff raises  
26 his arm))  
27 Billy: All of - just men  
28 Simon: Just men  
29 Jenny: Just men  
30 Mike: k'hee hee Lee  
31 Geoff: You got one? ((looking at Lee))

32 Val: You not got one Lee?

33 Geoff: Yeah you got one

34 Lee: Have I?

35 Val: Yeah

Geoff's first utterance, an open question '*what do we know about prostate*', was a request for knowledge about an area relevant to healthcare. However, it was followed - without time for a response - by a question about participants' experience of prostates: '*who's got one*'. The use of '*we*' (line 25) suggests that Geoff was introducing a search for a collective understanding about prostate in which he was included. As soon as he had completed the question '*who's got one*' he raised his own arm in response, thus changing his footing within the interaction from questioner to respondent. Gerry and Mike also raised their hands as Billy was responding.

As well as including himself as a member of the audience of the question, Geoff's immediate non-verbal responding to his own question took away the 'test' element, although he did monitor the participants' reaction to the question, and singled out Lee as a non-responder and the focus of a second question at line 31, though again Geoff supplied the answer, verbally this time at line 33.

Sam, the facilitator in Group 2, resisted more explicitly the implication that he had authoritative knowledge of the genetic condition that is the topic of the leaflet the group was working on.

Extract 2: Group 2, genetic condition leaflet, Sam (facilitator), Liz (co-designer)

- 2 Sam: This is an information erm booklet about something called [genetic  
3 condition].
- 4 Liz: Eh?
- 5 Sam: Don't ask me what it is. Because we are going to find out by reading  
6 it hopefully. Donna's been putting this together so I haven't read  
7 through this. It's kind of in a half way stage now yet so I don't know  
8 what to expect really
- 9 Liz: So you're new to it are you?
- 10 Sam: I'm new to it as well yeah

Sam described the topic as '*something called [genetic condition]*' thus positioning it outside his area of expertise. The topic was framed as something that everyone in the group would be finding out about starting from the same point of not knowing. Sam reiterated his lack of epistemic authority (lines 8 & 10), the '*as well*' in line 10 marking a posited lack of knowledge as the basis of affiliation with Liz.

Sam did not adopt Geoff's strategy of 'finding out what people know' about the topic, nor did he initiate dissemination of a normative understanding of the topic, instead he positioned himself as a learner alongside the other participants who, like them, was unfamiliar with the information in the draft leaflet. However the other participants repeatedly expressed difficulties with reading the text. They also asked Sam for clarification. So, despite his initial instruction ('*don't ask me what it is*'), he was nonetheless positioned as having expert knowledge.

Extract 3: Group 2, Priti (co-designer), Sam (facilitator), Suki (student)

- 241 Priti: S'cuse me please can I ask what does that mean please
- 242 Sam: Um it's saying that...I was just thinking this bit might work better if
- 243 it's after that picture
- 244 Liz: Yeah
- 245 Sam: On page two
- 246 Priti: What's that mean?
- 247 Sam: Because men and women have different chromosomes
- 248 Suki: Hhhh hhh [laughs]
- 249 Sam: So men have an X chromosome and a Y chromosome. It's quite quite
- 250 technical science here. And women have two X chromosomes.

After Priti's second request for clarification, Sam provided an elaboration of the topic, though he appeared to resist an implication that Priti's general knowledge was deficient by describing the information as '*quite technical*' and not within the remit of everyday experience. Priti may have been the one to position herself as knowledge deficient and Sam as possessing expert knowledge, but Sam eventually appeared to accept this positioning and offered the information as a factual assertion, without any hedging or questioning of his own expertise. Sam's shifting position highlights the difficulty of maintaining epistemic parity: he did not acknowledge Priti's initial question until it was repeated, a repetition which is suggestive of the difficulty of contributing to the production of a text on a topic with which she was not familiar and which the existing text did not make easy for her to understand.

There are occasions where participants with ID also made claims to expert knowledge, but they tended to do so with less certainty and with added disclaimers. Sue, in Group 2, appeared to have quite extensive background knowledge about biology, which she brought to bear in making a criticism of the text and the terminology it uses, specifically the metaphorical term ‘*carriers*’, a term that she asserted she knows is in common use, but which she suggested could be misleading. However, she hedged her contribution with hesitations and qualifiers.

Extract 4: Group 2, Sue, Julie (co-designers), Sam (facilitator)

- 528 Sue: Yeah I know carriers is like the term for this but I think in this um  
529 in in this erm piece of text it’s the erm not misleading but it’s not  
530 the word that would be most usually used? So the the word carried,  
531 maybe something like genes are um er I’m not sure because  
532 I know that’s what you’re talking about carriers then  
533 and that’s not quite er I’m not sure it’s not the usual use of the word  
534 carried is what I’m trying to say.
- 535 Julie: I think I think you’re born with it aren’t you so it’s already there
- 536 Sue: Yeah well you are. Hm I don’t I don’t know people might disagree  
537 with that one.
- 538 Sam: Well I’ll take that back to Donna and see what she says because  
539 she might have changed the word from something to carried.

Julie tentatively (*‘I think, I think’*) entered the debate, downgrading the authority of her assertion with an invitation for others to agree (*‘aren’t you’*). Sue treated her interjection as a possible ‘disagreement’, though again using hedges and mitigating the force of her

stance. The issue was resolved by Sam, not by deferring to Sue or arbitrating on a 'correct' version by claiming the ability to provide definitive information, but by deferring the decision to an authority outside the group (Donna was a staff member who is tasked with liaising with the commissioners of the leaflet and preparing a final version). This maintained solidarity within the group on the basis of an absence of expertise.

## 1.2 Experiential knowledge

In Group 1 and Group 3 there were a number of occasions where participants contributed narrative accounts drawn from their own experiences. In Group 3 these accounts were elicited by the facilitator in ways that meshed with the stated ideals of co-production in that the participants' accounts of lived experience were acknowledged as contributing to the generation of new understandings beyond the 'official' story generated by professionals. The facilitator then moved to integrate these accounts into the outputs of the session, namely the Easy Read resource under construction. However, participants' experiential knowledge was not always elicited or heard in these ways. The 'small stories' (Georgakopoulou, 2006) offered by participants were oriented to as tangential social actions and were usually treated as having limited relevance to the overall project of designing the Easy Read resource.

Extract 5: Group 3, domestic abuse leaflet, Hugh (facilitator), Dennis, Steph, Dawn (co-designers)

- 993 Hugh: I think another thing, because we're aiming this fact sheet  
994 at people with learning disabilities, I think, um how many of  
995 you here share a house with other people with learning  
996 disabilities?
- 997 Others: ((No audible response))
- 998 Hugh: Okay. So, a lot of a lot people live with their family, don't  
999 they? But you're actually more likely to be sharing houses  
1001 with other people with learning disabilities. Um, now,  
1002 has anyone ever had problems with someone they're  
1003 sharing a house with?

Hugh worked towards a reformulation of 'domestic abuse', which is usually associated with 'intimate partner violence', so that it aligned more closely with the usual living arrangements of people with ID, who are less likely to live with an 'intimate partner' than others in the population (Emerson & Hatton, 2008). Hugh was proposing that experiences of abuse perpetrated by housemates should be incorporated into the way that the resource defines 'domestic abuse'. He invited testimony from the participants that would provide examples of this.

Hugh's request for 'problems' associated with sharing accommodation did indeed elicit examples from the participants drawn from their lived experiences of the interpersonal complexities of sharing accommodation with other services users whom they quite possibly did not choose to live with (Bowey & McGlaughlin, 2005). Dawn described





the group? If they were different, including by virtue of being experienced co-producers, how could they maintain a claim to being representative?

The group could therefore constitute its representative qualities on the basis of being the same as the intended audience - meaning, having the same responses to a given text – or as different, including being experienced with co-producing Easy-Read health information texts. Consensus within the group could be claimed, or disagreement recognized in some form. Our analysis suggests a strong orientation towards consensus within the group, sometimes on the basis of being representative of ‘having intellectual disability’ and other times, on the basis of being different – usually more capable in some way – than the external audience.

## 2.1 Representing an external audience through consensus within the group

One way of characterising facilitators’ contributions to the groups was that they worked to establish consensus: the task of the facilitator was then to report back on what was easy-to-read for people with ID. Consensus on the answer to this question was sought in various ways. In Group 1, it involved the deployment of a complex system of voting, in which Geoff asked participants to nominate possible pictures for the front cover of the prostate pamphlet. He then asked each individual to vote on the options over three qualifying rounds, until one picture was identified as the winner. The desirability of consensus on the final image is exemplified in this exchange, which concluded the final round of voting:

Extract 7: Group 1, Geoff (facilitator), Jenny (co-designer)

- 1068 Geoff: So, picture of a urinal then? That's what we are going to have
- 1069 Jenny: Yeah
- 1070 Geoff: Is everybody happy?
- 1071 Jenny: Yes
- 1072 Geoff : Marvelous

Voting meant that everyone in the group exercised a choice, even participants who had been silent up to this point. Voting over three rounds also ensured that nearly everyone voted in at least one round for the winning picture. It is this conjuncture which seemed to secure agreement with the question '*is everybody happy?*' As a technique, voting sustained the exercise of individual choice. It acknowledged disagreement and diversity of opinion, whilst also eroding such differences to produce one group response. Voting thus resolved the dilemma of generating a group response, representative of what was easy-to-read for people with ID, whilst acknowledging disagreement and differences in views within the group.

In Group 2, Sam's concern with checking whether the pictures 'matched' the written text in a drafted pamphlet sustained a different strategy for achieving consensus, in which the group's agreement with individual suggestions was sought:

Extract 8: Group 2, Priti, Liz, Sue, Dan (co-designers), Sam (facilitator)

- 583: Priti: I was just thinking this bit might work better if it's after that picture  
[...]
- 590: Sam: Do people think that that information might work better after the
- 591: Liz: Yeah
- 592: Sam: After it talks about
- 593: Liz: Yeah
- 594: Sam: Men and women having
- 595: Liz: Yeah it will do
- 596: Sue: Yeah
- 597: Dan: Yeah I agree

Sam addressed the whole group, as '*people*', asking whether they agreed with Pitri's suggestion, with the formulation of the question setting an expectation of agreement, which Liz quickly and repeatedly provided. The question turned Pitri's idea into a group idea, subject to its consensual endorsement. Across Group 2's discussion, there were in fact no instance of overt and marked disagreement with a proffered suggestion. It was not just Sam, as facilitator, who worked towards consensus, but all participants: consensus was a collective responsibility, with all participants endorsing each other's suggestions for edits or images.

One consequence of collective efforts to achieve consensus is that differences of opinion were inhibited in their explicit articulation. For example, if we look across the discussion in Group 2, it is clear that participants had a range of experiences and opinions. Some members displayed knowledge of the genetic terminology which the text deploys,

displayed by Sue in Extract 4, whilst others emphasised its lack of familiarity. These differences were homogenised through formulations such as *'do people think'*.

So why was consensus desirable? One way of interpreting this is that it legitimizes the group's existence and ongoing work, enabling the group to 'stand in' for all/any people with ID. An exchange in Group 3 illustrates our point here. After reviewing the text provided by the agency that has commissioned the Easy Read resource on 'domestic abuse', the group was engaged in finding more appropriate ('easier') words for the intended audience.

Extract 9: Group 3, Hugh (facilitator), Dawn (co-designer)

- 951 Hugh: Or shall we just say hurts you? What do you think would be  
952 best? If I write them down, Dawn, if I write down hits or  
953 hurts, which one do you think's the easiest,  
954 Dawn: Erm  
955 Hugh: if someone hits you or someone hurts you?  
956 Dawn: That one.  
957 Hugh: So, hurts you.

Hugh asked Dawn to adjudicate on which is the 'easiest' word and offered her a choice of two alternatives that might be differentially intelligible to the leaflet's audience. He clearly receipted her response as the option that will be integrated into the text they are working on. She was being offered decisional authority here on the basis of her embodied experience of someone with ID who was seen as likely to find less 'easy' words difficult. With reference to our reflections in section 1.2, Dawn's experiential knowledge of what is

easy or difficult to read was treated both as legitimate and authoritative (see Table 2). Indeed, Dawn was not required to justify her choice in any way, nor are the nuances of meanings of the words ‘hits’ and ‘hurts’ explored, or the relative merits of the words in meeting the overall informational goals of the resource.

## 2.2 Representing an audience on the basis of difference from it

Although participants constituted themselves as representatives through consensus opinions and their embodied expertise in identifying ‘easy-ness’ in texts, they also sometimes marked a difference between group participants and others beyond the group, who were then figured as having different, and usually poorer, linguistic resources with which to read texts. For example, in Group 1, discussion about what words to use on the front cover involved the following exchange:

Extract 10: Group 1, Geoff (facilitator), Kevin, Jenny, Gerry, Lee, Billy (co-designers)

- 694 Geoff : Do we need to say, are we going to say prostate or wee?  
695 Kevin: Wee.  
696 Jenny: Well, probably other people don’t know what prostate  
697 is.  
[...]  
1227 Jenny: Keep an eye on your wee wee  
1228 Gerry: But that ain’t the word. That ain’t the proper word to  
1229 say. It’s urine innit. The proper word is urine  
1230 Geoff: It is the proper word, urine, yeah.

1231 Jenny: Pee  
1232 Kevin: Wee  
1233 Lee: Do you understand pee or do you understand wee  
1234 Kevin: Wee  
1235 Billy: The thing is though most people would relate to it as  
1236 wee.

Geoff, the facilitator, asked the group – ‘we’ – which word should be used on the front cover. Jenny endorsed Kevin’s answer by evoking an external audience that would not understand the word prostate. The ‘we’ of the group here was thereby identified as different from the audience which it represents. The same move was subsequently performed by Billy, who evoked an external audience – most people (with ID) - who would find the word ‘wee’ easier to relate to. This resolved the potential difficulty of reconciling different opinions within the group – say, between Gerry and Jenny, or Jenny and Kevin. It also enabled group members to demonstrate a level of expertise in acting as representatives: they demonstrated both expert knowledge of what their non-expert constituents know and also expertise as creators of Easy Read resources. Indeed Geoff prefaced his first utterance with orienting the group to an earlier resource they made on cancer in which a similar issue had arisen in the choice of words for the title.

## **Discussion**

Our first research question concerned how co-design group participants organized displays of expert and experiential knowledge. What is evident from the data is the instability of participants’ relationships to expert knowledge and how it is claimed and

disavowed in unfolding sequences of interaction. We can see that the facilitators, who are permanent salaried members of staff who do not have ID, negotiate a relationship to expert knowledge with particular care. Wakeford and Pimbert describe the role of facilitators as ‘one of the many analytic ‘black boxes’ in the study of participatory processes’ (Wakeford & Pimbert, 2013: 70). The co-production ideal asserts the necessity of a non-hierarchical structure within co-design groups. In practice facilitators have to generate their own strategies to achieve this in settings where group members have widely differing access to forms of epistemological, social and material capital.

Facilitators appeared wary of claiming epistemological authority in terms of access to expert health and biomedical knowledge by using inclusive pronouns (‘we’) and by explicitly resisting positions of epistemological authority or by locating that authority outside the group. They engaged with the ideal of co-production as a technique for ‘dissolving symbolic boundaries’ by blurring the conceptual distinction between participant categories of disabled/non-disabled (Kirkegaard & Andersen, 2018). However, positioning everyone in the group as equally inexpert with relation to biomedical knowledge undermined to some extent the stated goal of the group, namely to render such expert knowledge intelligible to an external audience by ‘translating’ it into an Easy Read format (Chinn, 2019) – a task that would require a priori familiarity with the topic. This presented the facilitators with a dilemma. If they take on the role of ‘expert instructor’ to ensure that every one in the group understands the topic, they risk perpetuating epistemological inequalities, positioning themselves as teachers, who are authorized to test others’ knowledge for instance by asking ‘known answer questions’ (Mehan, 1979). However, disavowing expert knowledge, as Sam does in Extract 2 can create ongoing

problems for the group.

One way to sidestep this dilemma might be to focus on the experiential knowledge of group members with ID. This ‘embodied insight’ (Martin, 2009) through lived experience can be seen as the epistemological capital and understanding of the product’s relevance to their own lives (Luck 2018) that group members with ID bring to the co-production process (Murray, 2018). In our data we noted examples where experiential knowledge was both elicited and (more frequently) volunteered by group members. However, in this study, as in other research on co-production in healthcare (Davies, Wetherell, & Barnett, 2006; Hodge, 2009; Lewis, 2014) it is apparent that experiential knowledge is not easily integrated into the official discourse and outputs of the co-production enterprise. Content is often predetermined by external authorities who commission and pay for the work the group is doing (Chinn, 2019), with a focus on securing compliance with medical and expert advice (Chinn, 2017; Dixon-Woods, 2001).

These dilemmas bring into focus the role of the facilitator. Other researchers in participatory design have also reflected on what ‘successful’ facilitation might entail within a project that has an ideological commitment to transforming the role of the user from product recipient to an engaged design decision-maker (Luck, 2007). The facilitator may have divided loyalties (Pedersen & Olesen, 2008; Bratteteig & Wagner, 2012) - to the ideal of collaboration, but also to his/her organization context and other stakeholders. To date relatively little attention has been given to how to do facilitation well, or the different practices it encompasses.

Our second research question concerned issues of representation and how participants



were represented or represented themselves, explicitly or implicitly as co-producers, as people with ID and as similar or different to their imagined audiences. Dilemmas of representation are perhaps inescapable in co-production groups (Martin, 2008) where membership depends both on having a particular characteristic shared with a wider constituency (as service users, patients etc) and also on asserting a distinctiveness from this constituency by virtue of acquired expertise in co-production and new sets of knowledges required for engagement in this process (Felt & Fochler, 2010). We noted two sets of positions sedimented by interactional practices within the co-production groups; the constitution of group members as similar in terms of knowledge and capabilities via practices to ensure consensus (Davies, Wetherell, & Barnett, 2006), and the subtle reinforcement of differences between the group and the anticipated audience for Easy Read resources they were working on.

When difficulties with reaching consensus about what makes a text Easy Read emerged they were defused by projecting inabilities onto others outside the group. This involves figuring Easy Read texts as expressive of a deficit (Chinn, 2017), notably, the absence of literacy expertise and 'technical' or scientific knowledge (Walmsley, 2013). Whilst this establishes a common ground for participation in the group, it also inhibits the display of specialist knowledge that did seem to be accessible to at least some of the group members who were participating on the basis of their being ascribed an intellectual disability.

Furthermore the category is made into a singular phenomenon, eradicating difference within it. In all of the groups we noted that participants' contributions to the intelligibility of specific words were the focus of group discussion, rather than the intelligibility and usefulness of the text more broadly. We are not suggesting here that participants withheld their critique of the broader features of the text. We are instead pointing to the

consequences of constituting the group on the basis of representing ‘people with intellectual disability’. Although this creates the opportunity for representatives of the intended audience to comment on Easy Read texts, it also restricts their capacities to read and interpret the text on any other basis and from other social positionings.

This is problematic, because the premise of the co-production groups, and indeed the entire Easy Read ‘project’ is that there indeed is an objectively verifiable category we call ‘intellectual disability’ and that people assigned to this category have similar characteristics and needs based on deficits in cognition and social coping intrinsic to them as individuals. An alternative view sees ‘intellectual disability’ as a much more blurred and contested category (Rapley, 2004; Williams, Swift, & Mason, 2015) that is made salient in various relational and institutional contexts (Antaki, Walton, & Finlay, 2007). We would suggest the value of developing approaches which acknowledge the experience of people with ID, but which also open up the possibility of them responding to texts in other capacities, as general readers.

### *Limitations*

We recognize that our study can only claim to be a preliminary investigation into co-production practices. We analysed and presented one session from three co-production groups; inevitably our understanding of group processes and how knowledge is co-created would have been greatly enriched by a longer engagement with each group and involvement with a wider range of groups involved in co-production.

## Conclusions and Recommendations for Practice

Our aim in this article was not to discount the promise of the ‘egalitarian rhetoric’ (Kirkegaard & Andersen, 2018) of co-production, but examine how its exercise, rather than blurring and unsettling the boundaries of the category of intellectual disability, instead reconstitutes this category, albeit in new ways. We showed how micro-practices of interaction framed by specific institutional contexts can lead to positioning people with intellectual disability as possessing/lacking particular types of competence and epistemic authority. This attention to how communication happens in practice can be useful for clarifying stakeholders’ or practitioners’ assumptions about their roles and competencies. Indeed, there is a growing body of work in applied discourse analysis where the examination and reflection on such micro-practices offers practitioners opportunities to ‘change the script’ in ways that result in greater congruence between service ideologies of empowerment and self-determination of service users in everyday service interactions (Finlay et al., 2008; Parry et al., 2018).

In this study the institutional context itself constrained the roles and positionings available to participants. The role of those with intellectual disabilities was largely confined to that of reviewers or quality checkers, with limited influence on the final form of the Easy Read text (Chinn, 2019). This raises, for us, a question about whether there are opportunities for people with ID and other service users to exercise greater authority and influence in decision making, and mobilize a range of areas of knowledge and competencies, if their involvement were elicited at multiple points in the process of creating an Easy Read resource.

Another possibility is to consider how the involvement of a much wider group of participants with a stake in using accessible and Easy Read materials (a sizeable percentage of the population) would sidestep this dynamic of reifying ‘intellectual disability’ as a condition of atypical need for support. Ehn’s work on how objects of design become public things, modified and reshaped through mass participation in their use (eg Ehn, 2008) suggests that processes of co-production and co-design of accessible information might escape the ID ‘ghetto’ (Le Grys, 2004) using new technologies and affordances for participation (Wikis, Youtube) beyond the familiar small groups of designers and end users.

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## Declaration of interests

The authors declare that they have no competing interests

All authors have contributed to, seen, and approved of the manuscript and agree to the order of authors as listed on the title page.

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