


ORIGINAL ARTICLE

Evaluating the usefulness of a wordless picture book for adults with intellectual disabilities about the COVID-19 vaccination programme using co-production: The CAREVIS study

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Abstract

Aim: To explore the usefulness of a co-designed wordless book showing processes of receiving COVID-19 vaccines designed by, and for, adults with intellectual disabilities.

Methods: A qualitative evaluation of the resource using mixed methods. Semi-structured interviews were conducted with people with intellectual disabilities, carers and health professionals about resource content, and use. This was analysed thematically. A survey was circulated to intellectual disabilities networks to understand resource need, use, sharing and content.

Results: Understanding the COVID-19 vaccine was a process, not a single event using one resource. A visual resource had a place in facilitating conversations about vaccines between people with intellectual disabilities and carers. Differing perspectives were expressed regarding personal needs, existing awareness of vaccine programmes and communication preferences. Changes were suggested to improve the suggested storyline and relevance around COVID-19 restrictions changing.

Conclusion: A visual resource may help conversations about the COVID-19 vaccine for people with intellectual disabilities.

KEYWORDS

co-production, COVID-19, intellectual disability, mixed-methods research, vaccination, wordless information

1 | INTRODUCTION

People with intellectual disabilities are a particularly vulnerable group in relation to congenital or acquired physical health issues, including respiratory conditions, obesity and mobility issues; which are accentuated by the accessibility of health care and polypharmacy (Glover et al., 2020; Javaid et al., 2019; O'Dwyer et al., 2018). Hospitalisations

for treatable conditions are higher than those in the general population (Glover et al., 2020). On average, females with intellectual disabilities die 26 years younger (22 years for males) compared with the general population (LeDeR, 2022). Diagnostic overshadowing is a recognised complication whereby new symptoms of mental or physical ill-health are misattributed to an individual's intellectual disability resulting in delayed diagnosis and treatment, increasing health

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inequalities (Javaid et al., 2019). A person's inability to effectively communicate their health concerns or to understand why treatment is necessary has also been highlighted as a key issue in this population (Cooper et al., 2015; Ninnoni, 2019).

In the United Kingdom, people with intellectual disabilities were not initially prioritised in COVID-19 vaccination roll-out, although evidence later emerged that the risk of hospitalisation and death from COVID-19 was proportionally higher for people with intellectual disabilities (Ninnoni, 2019), particularly for people with Down's syndrome (NICE, 2018). Evidence using General Practitioner (GP) data, from over 17 million people and 90,307 people with intellectual disabilities shows that people with intellectual disabilities were five times more likely to be admitted to hospital from COVID-19 infection (Williamson et al., 2021). Recent data has shown that excess deaths in people with intellectual disabilities was more than double that of the general population and the leading cause of death of people with intellectual disabilities in 2021 (LeDeR, 2022), and those who were unvaccinated were eight times more likely to die from COVID-19 than any other cause compared to the general population.

People with intellectual disabilities should have equal access to the COVID vaccination programme to those in the general population along with all other clinical care and services (NHS England, 2015; United Nations, 2022). Accommodating cognitive differences and communication preferences aim to reduce the barriers to people with intellectual disabilities accessing services through empowered self-advocacy and decision making (NHS England, 2015; NICE, 2018). Producing accessible public health information about these services in a variety of formats (pictorial, easy read, video) to support people in their decision making about their health is a recognised reasonable adjustment to accessing care (Great, 2005; The Equalities Act, 2010; United Nations, 2022), and underpins mandatory standards in England (NHS England, 2017).

'Easy read' refers to constructing and presenting information that makes it easier for a reader to understand and can extend beyond simplifying language and grammar to encompass the use of illustrations or photographs, colour and the layout of text and pictures on a page (Sutherland & Isherwood, 2016). Processing information and health literacy is challenging for some people with intellectual disabilities (Geukes et al., 2019; Riess & Kraft-Todd, 2014; Tuffrey-Wijne et al., 2013, 2014). It has been postulated that when written words and pictures occur together in an 'easy read' document there is an increased demand on the working short-term memory to process both simultaneously which can lead to sensory overload (Hurtado et al., 2014; Mayer et al., 2001). Presenting pictures alone could therefore reduce sensory input, lessen anxiety and improve interaction with a conversation partner in those with an intellectual disability (Mander, 2016). Additionally decoding solely pictorial information can be easier for some who have communication needs in verbal reasoning (Murphy & Cameron, 2008), allowing them to explore their own narratives using 'meaningful literacy' (Deagle & D'Amico, 2016) enabling access to information. There is evidence that this individually tailored public health information has more impact with those with intellectual disabilities and to those in the wider general population (Chinn & Homeyard, 2017). However, the effectiveness of accessible information on health behaviours has been difficult to establish (Chinn &

Homeyard, 2017). Wordless information (visual pictorial resources) for people with intellectual disabilities have been produced, evaluated (Mengoni et al., 2016) and the subject of literature review (Hollins et al., 2017), and compared with integrated literacy combining words and pictures (Alberto & Fredrick, 2011). Efforts to present health information in an accessible pictorial format may however boost the uptake of services and improve the health of those with intellectual disabilities.

With concerns that those with intellectual disabilities maybe hesitant to receive the Covid-19 vaccine due to the high rate of needle phobia in this population (NICE, 2018), a draft visual storybook resource was co-designed with people with intellectual disabilities to maximise accessibility with the charity 'Beyond Words' (BW) and their 'Books Beyond Words' series. The resource was entitled 'Having a Vaccine for Coronavirus' (Hollins, 2021) and used the key principles that underpin BW values, and ChangePeople's guidance (ChangePeople, 2022; Hollins et al., 2017) in working with people with intellectual disabilities. The resource aim was to explore the feelings around having the COVID-19 vaccine with someone with intellectual disabilities, through the personal story of two people.

The aim of this research was to develop, and then evaluate the usefulness and impact of this resource, in collaboration with people with intellectual disabilities. Our objective was to gather opinions on the draft content, how and when the resource was received and used. We also wanted to know if it enhanced awareness of the COVID-19 vaccine programme for adults with intellectual disabilities and to show the process of having the injections and how this conferred protection against the virus.

2 | METHODS

2.1 | Design

The research design was mixed methods evaluation, underpinned by a participatory and inclusive approach that strived to co-develop meaningful outputs for people with intellectual disabilities (Bergold, 2012; Bigby et al., 2014; Cocks & Cockram, 1995). We adopted a *qual-quant* design, with greater emphasis on the qualitative element (Creswell & Plano Clark, 2007), across two work packages. Work package 1 comprised of semi-structured interviews to gauge understanding of the resource purpose and a national survey to establish reach and utility of the resource. Work package 2: resource mapping (including vaccination uptake) and the infrastructure to support both vaccine and resource roll-out in the locality covered by a mental health NHS organisation and local authority in the East of England. In this article, we report on the findings from work package 1. Work package 2 will be reported elsewhere.

2.2 | Ethics

NHS Research Ethics approval was granted (Leicester Central Rec, 21/EM/0089) and Health Research Authority (HRA) (Ref: 296159). All research activities with people with intellectual disabilities adhered to

the ethical principles relating to research quality standards (NHS Health Research Authority, *n.d.*; ICH Harmonised Tripartite, 2001), and good practice principles for research with people with intellectual disabilities (Di Lorito et al., 2018; Nind, 2008).

2.3 | Patient and public involvement in the research

Meaningful co-production and participatory methods are integral to the research design (Chinn & Homeyard, 2017). We sought inclusive patient and public involvement (PPI) on all research processes from people with intellectual disabilities, who helped develop study resources, interview schedules and sense-checked study data. We designed the initial draft resource (tested in the study) with people with intellectual disabilities, drawing on imagery from an existing resource 'Love in Lockdown', (Hollins & Hollins, 2021) which had previously undergone internal Books Beyond Words review processes with people with intellectual disabilities.

The PPI for the research was input through two key mechanisms. Firstly, working with an organised group of people with intellectual disabilities in Hertfordshire who support delivery of health messages through creative arts from Hertfordshire County Council (HCC). This group contributed to early design discussions (outlined below), alongside reviewing study documentation and ethics approval processes by choosing wording/images. The research team also included an expert by experience (EbE), a person with intellectual disabilities, employed as a visiting lecturer at the University, who reviewed the ethics documentation, interview guide and survey questions.

2.4 | Initial design of the draft resource

The research team met with the group of people with intellectual disabilities at HCC online in the early part of 2020 to review images for the draft resource about the COVID-19 vaccine. Amendments to imagery were made following these discussions for example seasonal images were added to convey time passing between vaccinations.

2.5 | Recruitment and sampling

2.5.1 | Interviews

Inclusion criteria for the interviews were adults (aged over 18) with mild to moderate intellectual disabilities who were able to provide supported consent using visual 'easy read' information sheets and consent forms and were in receipt of care under HCC Health Liaison Team or Hertfordshire Partnership NHS Foundation Trust (HPFT). We wanted to obtain the views of the person with intellectual disabilities directly who could communicate those views to a researcher and so sought individuals who had mental capacity rather than seeking consent through a third-party (NHS Health Research Authority, *n.d.*).

Formal (paid) and informal carers (>18 years) of people with intellectual disabilities and health professionals able to provide informed consent were also approached to participate. Purposive recruitment was undertaken through convenience sampling of known individuals who accessed health support through either the mental health team or social care team (health liaison team) during the recruitment stage of the study to gather rich qualitative contextualised data about the resource and how it influenced health decisions around the COVID-19 vaccine uptake (Coyne, 1997; Palinkas et al., 2015). Staff referring on potential participants also gave an indication about their likely ability in expressing their views in relation to the research and the book (and whether they had capacity to consent with professional support). We planned to recruit 35 participants to gain a broad picture, rich data and likely data saturation (Guest et al., 2006).

Ethical approval permitted both face-to-face and remote research participation. However, given the ongoing risk of COVID-19 infection during the research, participants were recruited and interviewed remotely using the Microsoft Teams™ platform or by telephone. Some interviewed needed support from a carer to access the link for the online interview on the computer and help to rephrase questions from the interviewer. Furthermore, one participant needed a British Sign Language Interpreter intermediary so that their views could be relayed during the interview. Participants were given an electronic (and/or hard) copy of the draft resource following consent if they had no personal copy.

Participants with intellectual disabilities were given the opportunity to have someone present with them throughout the interview for support and assistance in understanding the interview questions only, not to influence their opinions. Carers who wished to provide their own views did so in separate interviews. Dyadic interviews with people with intellectual disabilities and carers were also offered whereby interviews with the carer followed after those undertaken with the person with a learning disability.

2.5.2 | Survey

A short on-line survey was co-developed with our EbE member of the team to understand the opinions on, and the impact of, the draft resource use of other resources and the perceived need for such a book. SurveyMonkey® (Momentive Inc. software) was used to circulate the survey widely through relevant networks (including social media) via forums including RADiANT (a clinical and research network hosted by HPFT, www.radiant.org.uk) and other Intellectual disabilities networks totalling approximately 6000 individuals on those lists (as reported by list hosts). The URL link to the online survey was emailed to potential participants (distributed between October 2021 to mid-November 2021 and again in Jan 2022) and ran in parallel with the interviews.

Study information and consent prefaced the survey and respondents could withdraw prior to submission. Questions were asked about the respondent's type and scope of caring roles, opinions on the resource, whether/how it had been used and open questions

on the need for such a resource. No names or contact information were gathered to ensure anonymity.

2.6 | Data analysis

2.6.1 | Interviews

Interviews took place from September 2021 to January 2022, were audio-recorded and transcribed verbatim using a university approved supplier. The anonymised transcripts were uploaded onto NVivo© software (QSR International, version 13).

Explorative qualitative data analysis was adopted from a critical realist interpretative stance using 'reflexive' and 'flexible' Thematic Analysis (Braun & Clarke, 2012; Braun & Clarke, 2019) to draw out meaning and patterns in the data.

Each transcript was read while listening to the audio recording; checking for inaccuracies and for data familiarisation (Ashworth, 1997; Lincoln & Guba, 1985). Deductive and inductive descriptive nodes were generated, following the six-phase process of analysis allocating semantic (descriptive) and latent (conceptual meaning) nodes (Braun & Clarke, 2012). Initially, three master nodes were generated from the interview topic: 'The resource' 'Work role' 'Books Beyond Words'. Semantic nodes were then formed directly from the interviewees words for example 'they self-check' which related to people with intellectual disabilities monitoring their own safety to COVID-19 infection, demonstrating credibility.

Rigour was applied through member checking of the transcripts and dataset (credibility) and by reviewing of the analytical reflexive memo recorded in NVivo, to demonstrate transparency in decision-making (confirmability) (Lincoln & Guba, 1985; Speziale et al., 2011), by the wider study team. The data were then summarised in tabular format according to the main themes to identify the range of opinions and outliers (dependability). Findings were presented to a group of people with intellectual disabilities at HCC during a meeting in March 2022 for sense-checking and to further enhance credibility.

2.7 | Survey

2.7.1 | Data analysis

The survey comprised of open and closed questions. Qualitative data from free text sections of the survey was extracted from the Survey-Monkey® outputs via Microsoft Excel®. Codes were assigned to

facilitate grouping. Qualitative excerpts were then coded alongside the interview data in NVivo®.

Quantitative data was extracted into Excel and then into SPSS® (IBM Statistics, version 26) for descriptive statistical analyses (proportions). No other statistics were planned, since this was not powered to detect differences in effect size and we were not looking for associations.

Data integration took place to integrate the survey findings alongside the qualitative data and is reported on collectively as much as possible (Fetters et al., 2013).

3 | RESULTS

3.1 | Study sample

Thirty-five people participated in in-depth interviews (Table 1), with a broad sample of: people with a mild-moderate intellectual disability ($n = 11$); informal and formal carers ($n = 10$); health professionals ($n = 14$) from one region in the United Kingdom, as outlined above.

3.2 | Survey data

We received 55 responses to the survey data, and the key quantitative (from closed questions) items are outlined below in Table 2, the open-ended free-text qualitative data is integrated into the overall qualitative data below.

Forty-two Health professionals, seven informal carers, one formal carer, two people with intellectual disabilities and three 'others' including a speech and language therapy student and social care professional (unqualified) responded. In a separate article, we describe the processes and include some of this survey data, therefore are only reporting on the qualitative open-ended survey data here.

TABLE 2 Survey responder by caring role.

Number of people with learning disabilities cared for	Caring/professional role
1 person	7
2-5 people	3
6-10 people	5
11 or more people	28
Total	43 (12 people skipped question)

		Person with learning disabilities		Health professional	Other	Total
Interview	Mental health trust	8	9	10		27
	Local council	3	1	4		8
Survey		2	8	42	3	55

TABLE 1 Responder category by site.

3.3 | Exposure to and use of the resource

Everyone interviewed, except one carer, had reviewed and/or used the book previously. From the survey, however, only half had heard of the book ($n = 27$, 49%) and 8/55 (14%) people had used the resource. Only one health professional interviewed had used the resource directly (1/14). Reasons provided by health professionals for not using the resource included: perceived irrelevance to their roles, timing of the resource launch, circulation and awareness (lack of). One health professional who worked in needle desensitisation services with people with intellectual disabilities had not used it because of the depiction of the needles.

Thematic development (as outlined earlier) resulted in three key themes: Why? The importance of understanding; How and when it was used: Facilitating communication; Use of other resources.

Theme 1: Why? The importance of Understanding.

The purpose of the book was to relay the process and potential benefits of receiving the COVID-19 vaccine through the social story of two people, Stephan and Kali. In line with other BBW books, the pictorial storyline could be adapted and related to individual life-experiences with a suggested storyline written at the end of the book; the books could be used to have broad conversations around the subject. During the interview the interviewer asked questions such as 'what's happening in the story?' and 'what's your favourite page?' and 'why is that?' In this way, the interviewer used their personal judgement, based on the interview conversation, on whether they understood the intended story or had used the resource for an alternative purpose.

The majority of the interviewees (Creswell & Plano Clark, 2007) reported either they, or the people they were supporting, were able to use the book to generate conversations around having a vaccine. This included people in the book depicted in conversation about, and then having, a vaccine, and the resumption of their normal daily activities, such as being around friends and family. The two respondents who did not understand were a mother and son who stated that they struggled half-way through:

Yeah. The first picture was fine, the second, but then the middle we start losing it.

(Interview Carer32)

Some carers and health professionals did not understand certain visual elements in the book but indicated they had not read the storyline words supplied by 'Books Beyond Words' (located at the back of the resource), which were aimed to supplement the images and help provide clarity. These visual elements were the depiction of the two vaccinations. Two carers and three health professionals interviewed did not interpret it in this way suggesting visual or text ambiguity; this was reflected in open-ended data from two people in the survey (one informal and one formal carer). Confusion also surrounded the horse image as a usual activity returned to following full vaccination (three health professionals and one carer interviewed and two health professionals from the survey misunderstood this).

In addition, two carers (a mother and a care home manager) reported that the image of the virus on pages one and two did not, or would not, make sense to the people that they cared for (not interviewed):

No, it's definitely not clear enough, it's just not saying anything, it's just like to [son—not interviewed] it would be like a blob, a syringe and a tick, it's not saying anything.

(Interview Carer30)

These two carers thought that those they cared for would not be able to relate the pictures and storyline to their own lives and life experience. Two informal carers from the survey reported that the resource would not be useful, nor suitable for their sons. Instead, these carers talked to those they cared for in simple language they were confident would be understood, relying on the inbuilt trust in that relationship to relay this and any other important health messages.

Seven interviewees (three carers, two people with intellectual disabilities and two health professionals) and seven survey respondents (all health professionals) wanted to incorporate more about the reasons why the vaccine was needed, the serious nature of COVID-19 and social responsibility behind having the vaccine:

...it's about not what the act is, but what it's trying to achieve. So it's not about helping someone, no one is ever going to, who doesn't understand why, is ever going to say, I love having my arm stabbed with a needle.

(Interview Health Professional8)

The participants thought that although the resource would help people agree to have the vaccine (compliance), it did not necessarily explain why it was needed (including consent) and a missed opportunity to include this background:

I like the fact that people can have a discussion about words and that, but I think on a subject like this, as big as this and as important as this from their health perspective.

(Interview Carer9)

Five interviewed people with intellectual disabilities described not understanding elements of the storyline in terms of why the vaccine was needed. The majority of participants with intellectual disabilities who did explain the impetus to get vaccinated, largely focused on protecting their own or their family or friend's health and returning to normal activities, in line with the resource storyline.

Similarly, three health professionals and three people with intellectual disabilities interviewed wanted the depiction of more COVID-19 restrictions or up-to-date restrictions in the resource and thought that it sent mixed safety messages. This sentiment was mirrored in the survey with nine people expressing the same (two carers, one 'other' and six health professionals):

- Interviewer: Okay, all right and how did you feel about the story that they... at the end of the book when they're holding hands at a café, how did you find that part of the story?
- (Person with Intellectual Disability25): That I didn't think it appropriate because you're not allowed even to hold their hands. You have to be socially distanced and sitting at the table.
- Interviewer: Yes.
- (Person with Intellectual Disability25): Then you can.
- Interviewer: Okay.
- (Person with Intellectual Disability25): But if you're in a family unit you can do it as a family unit, so...
- Interviewer: Hmm. So still to stay safe?
- (Person with Intellectual Disability25): Yes.
- Interviewer: Even though they've had the vaccine?
- (Person with Intellectual Disability25): Yes.

It was recognised by the majority of respondents that a book cannot suit everyone. Conversations stimulated by the book, that interviewees reported, indicated varied understanding around the vaccine or its purpose. Furthermore, some carers thought that full understanding or even partial understanding was not always desirable. Two carers described 'filtering' (or they debated filtering) information about the severity of COVID-19 and the pandemic to 'shield' people with intellectual disabilities that they cared for:

And we didn't appreciate how shielded we'd managed to keep her from how serious COVID-19 was and it was only when we got round to going for the first vaccine that we suddenly realised, gosh, she hasn't actually worried or anything, she's had great fun.

(Interview Carer3)

Shielding information was reported as a mechanism of limiting stress, which would negatively impact on mental health, and potentially increase behaviours that communicate distress. Carers in the study decided which information could be shared (verbal or pictorial), tailored to those they cared for and their level of need/ability accordingly. One health professional who worked with a person with intellectual disabilities, who partially understood restrictions, described that this person would unnecessarily limit their social activity due to the fear of legal prosecution.

The ability of the resource to be 'understood' depended on the underlying purpose of the conversation. The resource could be used as traditional storybook as per the suggested storyline or as jumping off point to explore wider issues relating to the coronavirus pandemic. As a traditional storybook it did not meet the needs of some people who found the pictures story confusing. Some would have liked more

information on the severity of the pandemic and regulations aimed to minimise transmission of the virus whilst others preferred not to have a resource that contained that background level of information.

Theme 2: How and when it was used: Facilitating communication.

A larger proportion of carers interviewed had used the resource, compared to health professionals. However, two health professionals who planned to use the resource in the future described plans to pass the resource onto family members and carers to use it with a person with intellectual disabilities. Survey data indicated fewer people (less than half) had come across it or used it (Table 2). Of those interviewed, those who had used the resource, or similar 'Books Beyond Words' resources, expressed the importance of tailoring the storyline to the person with intellectual disabilities. This was recognised by five surveyed carers and health professionals as easier if the 'reader' could directly relate it to the life of the person, which required a degree of knowledge and understanding from an established relationship:

I liked it, I used it with patients in an inpatient setting to good effect. It minimised the fear and enabled a great deal of additional conversation about the virus, the story in pictures doesn't reflect the same setting I am in but it was easy to adapt.

(Survey HealthProfessional18)

Responding to the survey question of when this resource should be used, the most common suggestion (by 12 participants) was when the person with intellectual disabilities was calm and relaxed, receptive to new information and in quiet/familiar surroundings. The timing of using the resource was also stressed, as soon as it became available, revisiting it a few times before the vaccination appointment.

The adaptability of the resource storyline may not have been apparent to all who used it or know their conversation partner well enough to make this personalisation possible.

Theme 3: Use of other resources.

Carers and health professionals interviewed reported that they relied most heavily on unstructured one-to-one verbal communication to explain COVID and vaccinations to people with intellectual disabilities that they cared for:

Interviewer: So we talked about this resource, this Books Beyond Words one, did you use any other resources that were available at the time to talk to [her] with?

Interviewee: No not really, no, we just talked to her.

Carer12:

However, some people described using a mixture of resources at different timepoints, such as government produced media (three),

google searching (three) and 'Facebook' (Meta Platforms, Inc) groups (two), on aspects of the pandemic to fill knowledge gaps as needs and comprehension level warranted. Five health professionals even created their own resources; this was particularly common at the start of the pandemic when information tailored to those with intellectual disabilities was hard to find:

...the Government started to actually create these documents that we could then send out, but at the very beginning, it was quite difficult because we had to make this easy read stuff quite quickly. then things would suddenly change at the drop of a hat, so it was then rattling around trying to get that sorted and I think that was the main source of confusion for a lot of the service users and carers was when things were changing.

(Interview Health Professional26)

People with milder intellectual disabilities who had the ability and access to the internet sought information independently or with help and supervision of family.

No. I just Googled stuff. [name] is really good with his computer skills. Yes. I think, to be honest, because he's really, really good, I do leave him to his own devices.

(Interview Carer10)

One health professional told of a parent of someone with autism whose stress levels were so elevated, that she created her own COVID-19 newsletter to supply her son with appropriately levelled information on the pandemic. This echoed the survey data, which outlined that the majority (73%) of respondents had used other resources, such as videos, pictures or other written information.

Types of information about the COVID-19 pandemic used in discussion with people with intellectual disabilities therefore depended on their perceived needs, abilities and communication preferences.

3.4 | Suggested changes to the resource

Eight people interviewed (three people with intellectual disabilities, two carers and three health professionals) and 16 people from the survey thought no changes were necessary to the resource:

But to be...he's just saying I liked it all really, I did like it, I liked the whole thing, I liked it all. I liked it all, yeah, I liked it all, it was good.

(Interview [Interpreted] with person with intellectual disability)

Suggestions for modifications/improvements to the resource were linked to the images discussed above (first and second vaccines, horse, safety messages, science/purpose to vaccine). Additional suggestions included: clarifying the passage of time between the vaccines and later activities; depicting administration paperwork

at the vaccination appointment; using photos and not drawings; depicting positive emotions during and after the vaccine by both vaccine staff and the patient. Health professionals responding to the survey suggested there should be better depiction of support, and information about managing side-effects. The other mostly commonly requested suggestions from carers and people with intellectual disabilities were to include some easy-read words, or Makaton, on each page for those who were able to read them, to promote independence and/or avoid ambiguity and stress of potential misunderstanding.

From the interviews, three people with intellectual disabilities who were needle-phobic and seven health professionals working with needlephobia thought that the image of the needle on pages 1 and 2 was disproportionately large and/or should come into the story later in the book. This finding was mirrored in the survey with nine others expressing the same (two carers, one 'other' and six health professionals). Others were more pragmatic:

The reality is, that's the reality. It doesn't matter if it's on the front page or the back page, it's going to come.

(Interview Health Professional21)

One person with intellectual disabilities was so concerned by the pictures of the needles that she mistakenly thought that there was blood on the needle depicted where there was none:

I think the needle next to the arm, because I think they [could be] showing a little bit of blood, which is scary.

(Person with Intellectual Disability10)

In summary, a variety of suggestions were made to improve the clarity of the storyline or to minimise needlephobia.

4 | DISCUSSION

The purpose of the new resource was to improve accessibility of information about the benefits of the COVID-19 vaccination programme to individuals with intellectual disabilities with the hope that uptake of the vaccine would be improved, protecting their health and improving their health outcomes.

The resource was used in the setting of 'teachable moments' (Dowling et al., 2019), between carers or health professionals and people with intellectual disabilities, or used independently in naturalistic settings (Chinn & Homeyard, 2017). When resources can be used independently at an individual's convenience then evidence suggests that this approach can promote privacy and reduce confusion (Waight & Oldreive, 2022), while others argue that it can create fear and anxiety (Codling & Macdonald, 2008). The presentation of pictures and symbols can tip the balance in either direction, adding confusion or supporting greater understanding. Additionally, neo-liberal ideological discourses on disability have postulated that teachable moments with a conversation partner can result in power imbalances between a 'teacher' and a 'learner' with the misplaced assumption

that people with intellectual disabilities need educating thereby reducing choice and control (Pilnick et al., 2010). However, it is intended that Books Beyond Words stories can be personalised during discourse in mutual exploration, relating the pictures to an individual's life. The ethos of BBW is therefore more in line with Williams and Porter (2017) when they argue that people with intellectual disabilities need trusted relationships to make good decisions, and Dowling et al (2019) in believing that relational autonomy (at the interface between the environment/relationships and disability) is a more achievable goal than isolated independence.

The survey and interview data indicated local reach was better than national reach, with only half in the survey having come across the resource. Other resources of COVID-19 information were accessed by interviewees and survey respondents, in line with research by Flynn et al. (2021) where 76% of people with intellectual disabilities surveyed felt that information was easy to find.

As the data shows, opinions on the resource varied. As Mander (2016) states 'It is impossible to produce an accessible resource that will meet the needs of every person that requires accessible information' (p. 15) and individuals interviewed and surveyed had specific views and communication preferences which aligned with the resource or did not. This was similar to the findings of others (Chinn & Homeyard, 2017; Codling & Macdonald, 2008). To optimise clarity and increase appeal, we involved the views of people with intellectual disabilities in the design of the resource from an existing resource that had been through the Books Beyond Words rigorous review process. We also consulted people with intellectual disabilities during the project to further maximise accessibility. It is also possible that through the process of designing this resource and hearing seldom heard voices (Crook et al., 2016; Feldman et al., 2014) increased the social capital of those involved (Chinn & Homeyard, 2017).

Assessing the comprehension of the intended purpose of the resource is difficult (Mander, 2016) and the researcher and carers interviewed relied on personal judgement without supporting in-depth conversation analysis. Others using conversation analysis have used the method to reflect on decisions making processes in research teams with people with intellectual disabilities (Ellis, 2018) and during daily events (Dowling et al., 2019; Pilnick et al., 2010). These reflections on assumptions on understanding and power relationships within these settings were helpful to the researchers but shed no light on the understanding and perceptions of the people with intellectual disabilities themselves. To address this uncertainty, to provide additional data and enhance rigour, seven interviews were dyadic whereby carers were interviewed directly after those with an intellectual disability and could feedback to the researcher how the resource was used in discourse, easily and as intended or otherwise.

5 | FINDINGS IN CONTEXT

A meta-analysis of literature by Chinn and Homeyard (2017) raised the importance of avoiding ambiguity of easy-read information content for people with intellectual disabilities and our research demonstrates how important it is to optimise clarity. Where co-design does take place, it

is not infallible, dealing with conflicting suggestions and expectations (Aschhoff & Vogel, 2018; Oliver et al., 2019) requiring ongoing refinement. Importantly, the aim of these wordless books is to open and support conversations, rather than replacing these (Hollins et al., 2017). This research shows that care professionals also need to engage with such resources to relate information to support decision making for those in their care (Finlay et al., 2008). The key issue is for people with intellectual disabilities to receive information in the way that is accessible to them and in their preferred format (Thurman et al., 2005).

Current research in this area continues to be scant, with research centring on population-level health outcomes with respect to mortality (Williamson et al., 2021). Continued prioritisation for vaccination in this group was recommended as a result of the OpenSAFELY platform research by Williamson et al. (2021), however to our knowledge, there has not been published research on how professionals and carers encourage people with intellectual disabilities to engage in health conversations to receive COVID-19 vaccines.

It is clear from wider work that this underserved population still have unmet health needs in relation to COVID-19. Reasonable adjustments to facilitate vaccine uptake, as outlined in the Public Health England paper (Public Health England, 2020), require supported conversations and our research suggests a visual resource may be helpful here, alongside other resources.

An international survey of professionals supporting people with intellectual disabilities reported the wider impact of the COVID-19 pandemic, including isolation, distress and increased carer burden and differing impacts of telehealth on maintenance of health (Howkins et al., 2022). This resonates in further surveys examining family and carer experiences, all of which report adverse effects of the pandemic on engagement with health (Jeste et al., 2020; Rosencrans et al., 2021) as people try to navigate strained health care systems and telehealth (Linehan et al., 2022). This study demonstrates people with intellectual disabilities need to be supported in accessing health care, and that carers often take on this role.

There are policy implications from our research, specifically consideration for the infrastructure, support, time and resources required to administer COVID-19 vaccinations when planning vaccination programmes for people with intellectual disabilities, and the individualistic nature of information needs. From a public health perspective, providing such a resource for free, and embedding the access to these resources within existing health care system, such as online via GPs, who hold registers of people with intellectual disabilities, might be considered as a preventive measure to improve health outcomes. However, the clinical and cost effectiveness of such an intervention remains untested.

6 | STRENGTHS AND LIMITATIONS

While this was a small study primarily focused in one locality in the United Kingdom, it has identified several key issues with wider transferability beyond this study. This research yielded rich qualitative data from 35 participants, several of whom had intellectual disabilities, and including someone who was hearing impaired, emphasising the commitment to an inclusive approach to the research. Our research was

not intended to provide definitive answers as to whether the book worked in improving vaccination uptake, but instead to examine the usefulness of the resource in supporting conversations about the vaccination programme.

This research was conducted during a national pandemic, consequently recruitment and data collection were limited to remote online methods because of the need for social distancing. It is acknowledged that this may have limited engagement to those able to use these platforms, or carers to support them.

Despite repeated mail-outs the survey responses were lower than was expected given the prominence of the networks and estimated reach. In future studies, alternative approaches could be considered to enhance the reach of the survey, such as circulating through primary care networks and integrated care systems. It is unfortunate that due to the low response rate to the survey no statistical analyses were possible. However, insight was gained from beyond the locality which enriched the overall picture and emphasised the need for resources like this and a coordinated approach to sharing such resources widely through targeted campaigns. Our focus was necessarily narrow for this project, however with a broader scope we could have examined why some professionals, as elicited in the survey, chose not to engage with this or other resources and what other mechanisms they used to engage people with intellectual disabilities in health decisions.

Those who participated had mild to moderate intellectual disabilities, and those with significant severe or profound intellectual disability were precluded from participating, through the informed consent process. This means we may not have fully captured the views of those with more complex needs, and this is an important consideration for future work. Future research should also consider alternative multi-modal approaches, and evaluation, in complex health issues, like the COVID-19 vaccination in people with intellectual disabilities. Wider lessons can also be drawn across other health issues, such as supporting the influenza vaccination programme and managing needlephobia.

7 | CONCLUSION

This research has demonstrated the need for varied modes of information-giving around the COVID-19 vaccination in people with intellectual disabilities. Our research shows that a visual resource can be a useful resource, as part of a panoply of approaches, to support people with intellectual disabilities in having conversations about health decisions.

Co-production and inclusivity demonstrates good practice and provided insights around understanding that may otherwise have been missed, enriching the resource and the research.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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