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Whose uncertainty? Learning disability research in a time of COVID-19

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ABSTRACT
UK government responses to COVID-19 have intensified experiences of uncertainty for people with learning disabilities. The pandemic has eroded the support people receive, previously weakened by austerity measures. In research, COVID-19 related uncertainty has led to some reworking of methods and intensive contingency planning. This was to fulfil funding requirements and was underpinned by research teams' commitment to continuing research with people with learning disabilities not despite, but because of the pandemic. This is in a context where people with learning disabilities have been systemically excluded from research participation. Here, we reflect on these processes in relation to a project exploring how to improve the support for older people with learning disabilities. We consider the distribution of uncertainty in relation to conducting research during this time and ask whose uncertainty is attended to in these mid- and post-pandemic methodological debates and why. We suggest pandemic 'disruption' has created space for critical reflection allowing methodological creativity and consideration of in between strategies of trust, intuition, and emotion. We caution against the re-constraining of this space, instead arguing for continuing flexibility and creativity, where uncertainties are shared rather than used as a tool of control or dismissal of claims to support.

KEYWORDS
Learning disability; COVID19; ethnography; support; growing older

Introduction

In this paper, we consider how uncertainty and risk have been produced and negotiated in research with people with learning disabilities during the COVID-19 pandemic. There is no doubt that uncertainties experienced by people with learning disabilities have intensified under these conditions, with further eroding of the support received which, in places like the UK, was already systematically weakened by austerity (Flynn & Hatton, 2021). Furthermore, UK government responses to the pandemic in terms of the allocation of healthcare and temporary 'easement' of the Care Act have disproportionately impacted people with learning disabilities (Dunn et al., 2020). In research, COVID-19 related uncertainty has led to some reworking of methods and intensive contingency planning (Mikulak, Ryan, Russell, et al., 2022). This was, in part, to fulfil funding requirements, but was also underpinned by a commitment to continuing research with people with learning disabilities not despite, but also *because* of the pandemic. This is in a context where people with learning disabilities have been systematically excluded from research participation (Lester & Nusbaum, 2018; Spaul et al., 2020). Here, we reflect on these processes in relation to a project exploring how to improve the support for people with learning disabilities as they grow older. We

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consider the distribution of uncertainty in relation to conducting research during this time and ask whose uncertainty is attended to in these mid- and post-pandemic methodological debates and why.

Background

The COVID-19 pandemic has created unprecedented levels of uncertainty and generated new risks. It has further revealed and reinforced social and cultural divisions, laying bare inequalities, anxieties, and discrimination internationally (Comas-Herrera et al., 0000; Crowther, 2022; Leach et al., 2020; Lunsky et al., 2022; Office for National Statistics, 2022; Pieri, 2022; Taggart et al., 2022). The consequences of the virus have had an impact on health and social care delivery with effects disproportionately felt by marginalised groups (Armstrong et al., 2022; Richardson et al., 2020; Shakespeare et al., 2022). Disabled people in the UK (Broadbent, 2020; Dunn et al., 2020; Office for National Statistics, 2022; Shakespeare et al., 2022), across the European Union (Crowther, 2022) and internationally (Comas-Herrera et al., 0000) have consistently experienced the withdrawal of education, health, and social care support, struggles to be prioritised for a COVID-19 vaccine, discrimination in access to healthcare for COVID-19, and policy responses that result in long-term isolation. Disabled people in the UK are also more likely to say that their life will never return to normal (Office for National Statistics, 2022).

Similar findings have been reported in the UK (Flynn et al., 2022; Flynn, Hayden, et al., 2021; Scherer et al., 2022) and internationally for people with learning disabilities (Lunsky et al., 2022; Taggart et al., 2022). This group experienced intensified uncertainties (Courtenay & Cooper, 2021; Hughes & Anderson, 2022; Kavanagh et al., 2022) as networks of support, systematically weakened by austerity (Flynn et al., 2022) were further eroded. By mid-2021, over a quarter of adults with learning disabilities across the UK were not sure *when* or *if* their lives would ever go back to normal (Flynn, Hayden, et al., 2021). The overall impact was thus that of unprecedented levels of uncertainty and further marginalisation, which echoed and reinforced the systemic inequalities that people with learning disabilities face. The pandemic also generated new deadly discourses (Abrams & Abbott, 2020; Pieri, 2022) by centring ‘pre-existing’ and ‘underlying health conditions’, alongside ‘frailty’ and ‘vulnerability’ in healthcare allocation, with discriminatory consequences for people with learning disabilities (Baksh et al., 2021; Courtenay & Cooper, 2021; Hatton & Cooper, 2021). This reproduced deep-rooted prejudices against people who are valued less than their non-disabled peers.

That the living consequences of the management of the pandemic are disproportionately felt by people with learning disabilities as they are folded into and compound a sector-wide crisis does not come as a surprise. People with learning disabilities and mental ill health were at greater risk of dying from COVID-19, and from non-COVID related causes, than the general population, before, during and after the first peak of the pandemic (Das-Munshi et al., 2021; Henderson et al., 2022; Office for National Statistics, 2021). Access to health and social care services was reduced or removed for this group from March 2020 (Flynn et al., 2022) at the same time inspections by the UK regulatory body, the Care Quality Commission was suspended. Furthermore, social isolation, changes in routine, the loss of support and decreased health have been identified as key concerns in the UK (Flynn, Hayden, et al., 2021) and reported internationally (Lunsky et al., 2022; Taggart et al., 2022). In this already dire situation, people with learning disabilities experienced additional levels of uncertainty in research, as the rapid move to online research complicated access and created new pockets of exclusion.

Literature around the management of uncertainty tends to distinguish between objective, rational knowledge, and irrational strategies such as belief, hope, and ideology (Zinn, 2008). This distinction has been criticised for presenting scientific expertise as superior to lay knowledge, negating emotions or the gut instincts researchers may draw on, and ignoring the limitations of scientific work (Nyquist, 2014). As too much knowledge can be a hindrance in particular situations

(Gigerenzer, 2007), people develop short cuts or heuristics to identify salient information, drawing on experiential knowledge and the *in between* strategies of trust, intuition, and emotion (Zinn, 2008). While there has been a resurgence in consideration of the irrational alongside rational responses to uncertainty in recent pre-pandemic research (Alaszewski, 2015; Desmond, 2015; Zinn, 2016) it is clear that in between strategies gain more traction in times of uncertainty, where there is a deficit of trust.

The move to online research

COVID-19 clearly became a catalyst for researchers to develop strategies of adaptation to uncertainty, which has included questioning basic assumptions about research practices (Howlett, 2022; Shankar, 2020). Furthermore, the pandemic has intensified our online lives and accelerated the digital revolution (Hantrais et al., 2021). This is not to ignore considerable engagement with digital methods across two previous decades (see, for example, Hine, 2000; Ito, 1996). The dispersal of ethnographic sites across virtual and physical localities and consequent dilemmas is well documented (Deakin & Wakefield, 2014; Johnson et al., 2021; Kaur□gill & Dutta, 2017). This literature extends to ethnographer confessionals around ‘methodological failures, disciplinary posturing, and ethical dilemmas’ (Abidin & de Seta, 2020, p. 1).

The almost wholesale move to online research methods during lockdown periods (Barroga & Matanguihan, 2020) is already well documented. This includes the use of technology, recruitment, ethics, peer review, benefits, and barriers (Kara & Khoo, 2020), as well as acknowledgement there is little engagement with training for online qualitative research methods (Howlett, 2022). There are inevitable contradictions within this corpus. While projects ongoing or about to start were forced to re-evaluate methods and revise research designs (Mikulak, Ryan, Russell, et al., 2022), evidence suggests the research community avoided radically changing research designs in attempts to make research happen (Nind et al., 2021).

The move to online formats is not without consequences as people need access to and skills, or relevant support to take part in research online. This is in the context where people with learning disabilities experience higher rates of digital exclusion than the general public (Mikulak, Ryan, Russell, et al., 2022). The pandemic has had an uneven impact on digital inclusion of people with learning disabilities in and beyond research. Some studies report increased inclusion; (McCausland et al., 2021) while Chadwick et al. (2022, p. 1) observe that ‘COVID-19 has not provided the impetus to eradicate digital poverty for people with intellectual disability’.

There is also evidence of project teams using opportunities created by the move to online fieldwork to democratise research processes (Mikulak, Ryan, Russell, et al., 2022). Online methods and reallocation of unused travel and accommodation budgets have allowed more diverse sampling and wider social and geographical involvement than originally planned (Kessa Roberts et al., 2021; Valdez & Gubrium, 2020). Such flexible use of budgets might benefit research in unexpected ways, a point we revisit below.

Growing older, planning ahead

In this paper, we draw on an NIHR funded project Growing Older, Planning Ahead, which explores how older people with learning disabilities and so-called behaviours that challenge others, and their family carers, can be better supported in later life. The project proposal emerged from work author Ryan was doing with family carers for a user-led organisation supporting families. A family carer and employee involved in that work is co-applicant and coordinator of our project advisory group. An increase in the life expectancy of people with learning disabilities, reductions in the availability of services (Malli et al., 2018), and reluctance by older parent carers to forward plan for alternative living arrangements can lead to an increased risk in crisis placements (Bibby, 2013; Grey et al., 2020). This is particularly so for people whose behaviour is seen to be challenging to others. Such behaviours, attributed to 20% of the people with learning disabilities (Bowring et al., 2017), are best understood as resulting from distress or unmet needs, which might be physical, emotional, or social.

The first two parts of the project involved scene setting: two reviews of existing literature (Part 1) and a qualitative study to identify exemplars of supported living services for older people across England (Part 2). The latter identified four types of support: independent supported living; residential services; family/home-based support and daytime activities; and Shared Lives and a shortlist of exemplary providers. Part 3 involves an ethnographic study exploring how exemplary and innovative support services are commissioned and delivered in eight sites selected from the shortlist. The research has a strong co-production element, with people with learning disabilities and family carers involved in various public engagement and research roles: as co-applicants on the project, advisory panel members, co-researchers, and co-producers of ethnography training (Mikulak, Ryan, Bebbington, et al., 2022). Here, we focus on the research processes involved in the ethnographic study, related online activities, and interviews.

Methods

The Growing Older, Planning Ahead study is ongoing with planned completion February 2023. In this paper, we reflect on the process of the ethnography involving independent supported living providers (3 providers) and with family/home-based support and daytime activities and services (1 provider across 2 services). Providers are geographically spread across the South-West, Midlands and North of England. We consider these providers to be atypical as they have been identified as exemplary in a social care sector in which the support for people with learning disabilities continues to be poor (Forrester-Jones et al., 2021). Eighteen people with learning disabilities have been recruited as participants: 12 live in independent supported living settings and 6 live at home and access daytime services. All participants were aged 40 and over and white British. We predominantly relied on providers recruiting participants so had little control over the diversity of our sample beyond age and explicit focus on 'behaviours that challenge others'. It is, however, worth noting that this ethnic homogeneity was not reflective of our research sites.

The offline ethnography consists of 31 research visits conducted between September 2021 and April 2022 by author Mikulak. One of a small team of researchers with learning disabilities accompanied Mikulak on around 30% of the visits. The visits lasted between 2 and 6 hours. Shifting lockdown restrictions meant we adopted a hybrid approach with ethnographic work taking place in person when it was possible and safe to do so. Online interviews and short informal Zoom meetings (15–30 min, 3–5 times) with participants with learning disabilities were conducted during periods of heightened restrictions. These meetings involved chatting about everyday life and getting to know each other. Some participants did not communicate with words or have enough support to facilitate online participation. A total of 24 online meetings with people with learning disabilities took place before and between the ethnographic visits. To date, 32 interviews have been conducted online (via Microsoft Teams) or over the phone with people with learning disabilities ($n = 6$), managers, support staff, and commissioners ($n = 20$) as well as with family carers/members ($n = 6$).

Data analysis has been happening simultaneously to data collection with the research team starting to code interview transcripts and read and comment on fieldwork notes. Because COVID-19 disrupted scheduling meetings, we kept a log of communications with gatekeepers. This has created a rich data corpus, with commentary on the processes of doing the research embedded in the data sets. In this paper, we focus on the ways uncertainty has played out in our research process, drawing on these data sets, and discussions as a research team. Our approach here is not a systematic data analysis but one that sits within the in between strategies of trust, intuition, and emotion as we pull together 'situated occurrences and happenstance moments' cherry picked out of hundreds of fieldnotes, meeting notes and interviews 'about everyday life encounters' – to borrow de Seta's (2020, p. 83) phrase – and the negotiations around these.

Reinforcing inequalities

There is no doubt the pandemic generated new uncertainties and risks, and these were not universally distributed. The initial sentiment 'we are all in this together' quickly gave way under evidence of how the crisis reproduced and reinforced inequalities. Our research shows that people with learning disabilities who might display so-called behaviours that challenge others have experienced additional pressures and uncertainties under lockdown conditions. Their support workers and wider staff have also experienced an increased sense of burden, which has involved combining and mobilising strategies to continue to support people under extreme conditions. These circumstances have had a significant impact on the research process and below we discuss how uncertainties have featured in these processes for the research team and participants.

Uneven and ongoing consequences

Our research highlights that the distribution and burden of uncertainties are uneven and ongoing – linking back to the sense that things might never return to normal (Office for National Statistics, 2022) – and that they tend to be individualised. This follows the wider trend towards the individualisation of responsibility, choice, and autonomy within UK welfare delivery (Lloyd, 2010) which has increased uncertainties for people with learning disabilities in part, due to the rigidity of health and social care systems (Ramsey et al., 2022). Our research demonstrates this is multifaceted, as some pandemic-generated uncertainties in research can and have been shared and at times absorbed and managed by researchers and providers. For example, sharing a negative Lateral Flow Result before every in-person visit (including those conducted in 2022, after lifting of national restrictions) was expected practice by providers; researchers and staff were also expected to wear PPE, whilst participants with learning disabilities, could opt out of wearing a face mask. Yet other risks and uncertainties are shared with and shifted onto participants in ways that reproduce inequalities they experience as people with learning disabilities, both in research and more widely.

For people with learning disabilities, including our participants, the pandemic unsettled and at times damaged fragile ecosystems of support that have been put in place meticulously, sometimes across years. This, in turn, generated further challenges for conducting research as there were less resources available to facilitate participation. Conducting the ethnography on and offline involved considerable work for researchers and was reliant on staff goodwill and commitment to facilitating visits and online meetings. Due to COVID-related pressures, there was some resistance to scheduling times and meetings were often postponed. The constant rescheduling was typically around staff schedules and generated uncertainty for the researcher and participants. This extract from the researcher's fieldnotes demonstrates how much engagement was necessary to arrange one 15–30-min online meeting:

2/6

I was scheduled to meet the first participant today at 10 am. At 10:05 nobody has joined the Zoom meeting, so I sent a follow up email to the support worker who was supposed to be there and assist Z [the participant]. Got a reply at 10:08: 'Apologies I had forgotten about this meeting unfortunately Z is unable to attend the meeting today as she is not feeling 100% would I be able to postpone this until next week. Again im sorry for the short notice.'

I suggested we meet next week at the same time. The support worker was happy with that: 'Yes that is not a problem sorry for the inconvenience.' I am left unsure what was the deciding factor: the fact that the participant was not feeling '100%', or that the support worker forgot about the meeting and could not be bothered to sort it out.

21/7

Had a scheduled meeting with Ch [participant] and J [staff], but J's laptop did not work. After few tries, she asked to reschedule the meeting. She will let me know when works for her and Ch (. . .)

2/8 Meeting with Ch and J

After many rounds of rescheduling, we finally managed to meet online again.

Furthermore, online visits needed preparation in terms of devices to join the meeting and space to talk and this was not always done. Participants and researchers could be put on the spot by a lack of preparation. The burden of uncertainty often was passed onto participants as they did not know if they would meet the researcher. These contingencies extended into the field as daily testing and negative tests did not always lead to access, and at times, the researcher had to take a leap of faith and book travel and accommodation without a guarantee of being able to meet with participants.

The impact of COVID-19 also influenced the willingness of some providers to take part in the study. One provider chose not to take part as they felt unable to provide the standard of support they were known for because of staff shortages. Another provider withdrew temporarily because they felt unable to cope with the additional demands of the project. Whilst this is understandable, it had the impact of further limiting the opportunities people with learning disabilities had for social interaction, purpose, and enjoyment during this period. It also created further uncertainty around the research process, progress and quality of data produced and additional labour of monitoring the situation and encouraging providers to re-engage.

The backdrop of adaptations and innovations

We note that staff, with everyday life in disarray, draw on sources of tacit knowledge, going over what is conventionally expected of them in ways that reflected our approach to the research. Different strategies including well-informed guesswork and experience-based intuition (Zinn, 2016) were combined and evaluated. Following van der Molen and Brown's (2021) study of how Dutch medics dealt with pandemic-related uncertainties, we found a shifting in core preoccupations and foci over time as staff collectively implemented immediate actions then further developed, tested, and combined new strategies to support people. Our research was happening against this backdrop of innovations and adaptations and was at times enabled by them. Provider A, for example, described a response which initially involved phoning the people they provide outreach activities for, to sending out activity packs, supporting people to join Zoom sessions and considering whether it was possible to resume some face-to-face activities:

> And then as things changed slightly, we looked at if we could support some people out for a walk. So some people who had more complex needs, who weren't able to go out in the community on their own, we were like 'Actually we can support you out for a walk, because without that support, you're not going to be able to leave the house.' So we looked at options when we could, so we did that with a few individuals. And then as things developed even further, before we opened our buildings, we were doing one-to-one walks with anybody that wanted them then.

This dynamic response to changing rules and uncertainty was further extended to creating an impromptu 'meals on wheels' service drawing on the skills and expertise of staff:

> And also at [activity hub] they did a meal service, where they cooked. . . they've got some really good staff that cook really well and they've got a commercial kitchen there, and they cooked meals, really good ready-meals essentially. And they went out to certain individuals and certain houses, but including some of our Day Opps people as well, who maybe live a bit more independently, who were struggling. And that was really really helpful actually.

This was a piecemeal and creative response to pandemic conditions, which resonates with the concept of in-between strategies. Staff were dealing with familiar protocol-driven bureaucracy while feeling their way through the unprecedented constraints of national lockdown, demands of government regulations, PPE equipment shortages, confusion around what was permitted and the needs of the people they supported. At the same time, some participants dealt better with the restrictions than staff or family members anticipated. The pandemic generated disruption, described as a 'natural example' of Garfinkel's breaching experiment (van der Molen & Brown, 2021), created space for people to demonstrate strength and understanding. This breaching of normative expectations is evidenced by the ways in which people were able to engage with the pandemic-related constraints:

> Whereas some people with a learning disability, and some challenging behaviour, just saying 'oh, it's because of Covid-19, you can't go horse-riding today', doesn't quite wash. You know, [the person] doesn't quite understand it. But actually, the reality is, he [the participant] coped very, very well with it. And managed the support through it. And managed to get a bit of an understanding as to what was going on really. So yeah. So it's worked quite well really.

This is also reflected in how people were able to take part in our research despite the constraints outlined above. We would not have considered initial virtual meetings without the conditions imposed on us and, indeed, it is likely our participants and co-researchers would not have had access to devices, and the knowledge to use this pre-pandemic. An email exchange between the researcher and provider around whether a participant could take part in a Zoom meeting revealed how this participant had recently become comfortable with supported online calls for 30 min. This was common across providers, with clear efforts made to introduce new, digital leisure activities into people's lives creating familiarity with the online format.

Our research also found examples of less good practice and a sense that COVID could be used as an excuse to do less, echoing the sense of ongoing pandemic-related uncertainty for people with learning disabilities. In April 2022, it was not unusual for the researcher to hear that 'things are beginning to go back to normal' and people are 'starting' to go out more despite most restrictions lifted in February. At times providers seemed sluggish to support people in returning to activities or, where activities were not reinstated, seeking out new opportunities to socialise and/or develop new interests. This suggests that some people with learning disabilities were experiencing – and continue to experience – a form of informal lockdown for longer than the general population. Notes from an ethnography visit that included a short walk outside point to this issue as well as demonstrating how it is folded into wider problems with staff shortages in the sector:

> The riverside is busy, with people, kids, dogs, all enjoying the sunny weather. K [co-researcher] asks if they come to this place often 'not really' T says. R then adds that they are 'starting to get out more again'. . . [later, back at the house] I ask Tn [different support worker] how things have been in the house and K says it seems that the guys [participants] are 'out and about more' but Tn says 'not really' and says they don't have enough staff and drivers.

The pandemic had a negative impact on services and leisure activities for everyone, but here again, people with learning disabilities were further disadvantaged due to fewer options available to them before the pandemic. This points to systemic issues of lack of opportunities, undervaluing of the importance of leisure and other activities for people with learning disabilities as well as ongoing segregation of this group from mainstream services. The resultant uncertainty experienced by the people affected is additional to the uncertainties of the COVID-19 crisis.

Pandemic disruption allowing methodological creativity

On the oversight side of research, ethics committees recognised the additional pressures and uncertainties and drew on proportionality in granting approval and amendment. The NHS Health Research Authority, for example, issued guidance around fast-track ethical review for medical research proposals and existing projects, which needed revised research design (NHS HRA, 2020). This easing allowed flexibility, adaptability, and responsiveness which, in turn, created opportunities for relationship building, connectedness, and more ethically grounded approaches. For the research team, emotions such as commitment to the study and the desire to continue to work with people with learning disabilities as the crisis was unfolding were key to the research process. Emotions were thus central to research under pandemic conditions and far from expunged from research (see Shankar, 2020). The online engagement necessitated by the lockdowns facilitated establishment and continuity of relationships with participants at times of restrictions, as well as offering a new sense of reciprocity, as online meetings gave participants insights into the lives of researchers. Researcher notes from a Zoom meeting read:

> I asked Ch [the participant] if she had any questions for me, she asked 'where are you now?' I said I was in my flat, in the office and that I now work from home because of the pandemic. Ch said 'you can't have pets in a flat, can you?' I said I have a cat she seemed surprised and said 'really?' I asked her if she wanted to see it she said 'yes, please'. I got Mackerel, it took me a while to locate her under a pile of clean laundry, as she was having her nap. Ch seemed very happy to see the cat.

The window into the participant and researcher's homes evened the one-sidedness of conventional ethnography where researchers enter the spaces of those being researched, allowing the development of more 'symmetrical relationships' (Fujii, 2018). It challenged the false dichotomy between 'the field' and 'home' raised by Till (2001) as a construction by the academy, as research and personal lives were visibly interwoven (Howlett, 2022). At a practical level, it facilitated rapport building by bringing in everyday objects or pets as illustrated above. Opportunities were created to develop positive practices in response to unforeseen issues. At times, because of the online format, researchers got to 'accompany' participants to places where conventional fieldwork would not have taken them. In one instance, a participant brought her tablet on holiday:

14/9. 4th meeting with Z [the participant].

Z is on holiday. When she connected to the Zoom meeting she was in an elegant looking pub with old pictures on the walls and wooden panelling. She and her support worker, B, were having a cup of tea before going to see a castle. I thought it was brilliant and said it's the first time ever I had a Zoom meeting with someone who was in a pub. We joked about what they were having 'the only place open where you can get a cup of tea' said the support worker and pointed the camera at the table, with cups of tea on it. I thanked them for taking the time to meet me and bringing the ipad to the pub, on a day when they were having fun and had plans.

There was an added benefit of participants getting to know the researchers *and* having an extended opportunity to familiarise themselves with the study and its aims. This is evidenced by a series of notes from online meetings with JF: *28/6 2nd meeting with JF*

(. . .) I asked JF if he remembered why we were meeting. He looked unsure, I asked if he wanted me to remind him, he said yes. I recapped what the study was about and why we were doing it. JF nodded and seemed to recall some of the things (. . .).

26/7. 3rd meeting with JF

(. . .) I asked if JF remembered why we are meeting he said 'not really, darling'. I said that's okay and reminded him about the study and the plan to come and spend some time with him in autumn.

8/9. 4th meeting with JF

I asked JF about the place they were going [that afternoon]. He said there is a café and they serve black pudding. I said I'm vegetarian. . . JF asked 'what else do you like then?' I said all veg and fruit. JF got up and walked out to the garden, he returned a moment later with two pears. He said 'there is a pear tree'. We talked about fruit and veg and everyone had something to add, 'pineapple with cheese' was something J's support worker loves.

I asked J if he remembers why we are meeting, 'the study' he said. I said 'yes' and asked if he remembered what it was about. 'Getting older'. 'That's right', I said.

This is key and demonstrates that online meetings, in themselves a result of researchers' intuition to engage with participants despite the restrictions in place, became an important space for development of trust, which in turn also fostered greater understanding of the project for the participants.

Further, following Kessa Roberts et al. (2021) we were able to repurpose project resources enabling us to strengthen the research. Surplus funding from meeting expenses, travel, and accommodation budgets was used to increase the involvement of people with learning disabilities in advisory roles, cover the unforeseen costs of cancelled visits due to COVID-19 outbreaks and the wider costs of negotiating uncertainty. For example, covering taxi costs for co-researchers with reduced mobility to travel to sites; at times, these costs were substantial and would be difficult to accommodate without extra savings from moving activities online. While some methodological creativity was not relevant to participants who could not engage virtually, overall, the easing of administrative and financial burdens during that period was beneficial and should not be reversed.

Discussion

Support workers and providers have undertaken considerable work to help the people they support navigate their way through the pandemic. This work with its component parts of trust, intuition, knowledge, emotion, and creativity, is not typically recognised and yet central and necessary. Lupton (2013) asserts that risk judgements and emotions are fluid, shared, and collective. Staff were reliant on relationships with people they support and their commitment to reducing uncertainties by creating alternative everyday lives with participants. It is against this backdrop that our research took place, at times inadvertently adding to these uncertainties for participants, and their support staff, as the burden of uncertainty around facilitating their participation in the study during a crisis was shifted onto them in efforts to protect already stretched staff schedules.

At the same time, while people's level of comfort with risk and uncertainty tends to determine outcomes, delimiting what is possible in people's lives, the natural breaching experiment created by the pandemic unexpectedly created spaces in which participants were able to surprise staff, family members and researchers with their responses to these new uncertainties. These examples of unexpected competency and understanding should not be dismissed as exclusive to the pandemic but should instead lead to more trust being put in people's ability to exercise agency and independence. In a post-pandemic world, these affirming experiences and skills need to be further strengthened, harnessed, and celebrated.

The commitment of the research team to making the research happen despite the changed social conditions also speaks to fluid, shared, and collective risk judgements and emotions. We did not seek an extension to the project timetable, instead working with our participants and their staff to find ways around the obstacles generated by lockdown and the wider pandemic. In research terms, as in the practice and support examples presented above, this involved constant discussion, reflection, hesitation, and anxiety. It required new levels of flexibility and openness to trying things out.

This was facilitated by the loosening of the power that funders and ethics committees exercise at a time of uncertainty. Research teams have been trusted more to explore new ways of working to get the job done alongside an easing of administrative and funding-related burdens. The pandemic created a fracture in normative and well-rehearsed research practices and researchers have responded creatively as they continued to work through the crisis. While this has happened without necessarily radically changing research designs (Nind et al., 2021), it has led to reflection around the methodological and epistemological questions raised by uncertainties and associated conditions (Howlett, 2022). For our study, working together with people with learning disabilities, family carers, support workers and providers, introducing and testing tweaks to the research design, taking a leap of faith by forging ahead with uncertain plans and being forced to think 'outside the box' has created collective strengths in our research activity and capacity. The move to a hybrid fieldwork model also allowed participants time to get to know the researchers and better understand the purpose of the study before meeting in person. This additional layer of consideration is possibly unnoticed in conventional ethnographic research with people with learning disabilities.

It is, however, also important to consider the underlying epistemological and organisational power funders and ethics committees have in introducing flexibility and potentially removing it post-pandemic, defaulting to often rigid and cumbersome processes. It is crucial this loosening is not transient, and gains made during the pandemic are not reversed. We, as a research community, need to ensure this does not happen. We caution against the post-pandemic re-constraining of this space, instead arguing for continuing flexibility and creativity, where uncertainties are shared rather than used as tool of control or dismissal of claims to support.

Related to this, uncertainties on an unprecedented scale have allowed us to reflect on some of the limitations embedded in our conventional research designs (such as costly and time inefficient face-to-face meetings or qualitative methods that necessitate face-to-face engagement). The introduction of a hybrid model offered advantages to the fieldwork including a democratising of the process and method of developing relationships. However, it also highlighted the continuous digital exclusion that many people with learning disabilities face and the resultant added uncertainty they might experience when taking part in research online. At the other end of this process, there is the emotional labour and uncertainty of postponements and cancellations involved in managing relationships with staff that researchers perform to enable participation. The relative ease of online interactions makes them also easier to deprioritise, which has consequences for research, those who conduct it and take part in it.

While our study design meant that the ethnographic research relates to providers identified as exemplary, we also found examples of less good practice and the enforcement for some participants of an informal lockdown beyond the restrictions experienced by the mainstream British public. The concerns raised by Hughes and Anderson (2022) earlier about the long road back from social isolation were apparent. The concern that people with learning disabilities will face a magnified and ongoing sense of uncertainty constitutes a real challenge and deserves attention, as we consider how uncertainty is managed over time and differentially for, by, or on behalf of various groups of people. For research, similarly, new questions emerge around liminal times and spaces of the pandemic crisis and what autonomy limiting choices might become further legitimised in the name of managing uncertainty.

Finally, redesigning or tweaking already funded research allowed the repurposing of funding which in turn allowed us to involve more people with learning disabilities and family carers in our research. Having to rethink the research design, led us to recognise how there was much more value in the meaningful involvement of people with learning disabilities and family carers than reflected and acknowledged in the initial funding. The unexpected savings allowed us to redirect some funding towards what really mattered and worked. There are important lessons here about making sure that adequate costings are written into future research applications for this collaborative and democratising work.

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