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# "I was Excited by the Idea of a Project that Focuses on those Unasked Questions" Co-Producing Disability Research with Disabled Young People

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*In this article, we detail the politics and practicalities of co-produced disability research with disabled young people with life-limiting and life-threatening impairments. We centre an ESRC-funded arts-informed co-produced research project that has brought together a Co-Researcher Collective of disabled young people. Co-production is an established approach; however, our co-researchers have led us to develop inclusive research practices that engage with online social research methods in innovative ways. As we detail our experiences, we aim to encourage disability studies researchers and others to adopt virtual environments when researching with and for the lives of disabled people. © 2018 The Authors. Children & Society published by National Children's Bureau and John Wiley & Sons Ltd.*

**Keywords:** co-production, life-limiting, online, virtual, youth.

## Introduction

Designing research that involves children and young people has burgeoned across the social and educational sciences over the last 20 years (Bailey and others, 2014; Clavering and McLaughlin, 2010; Hallett and Prout, 2003; James and Prout, 1997). The politics of researching and consulting *with* children, both inside and outside of the Academy, has undergone methodological and political shifts through a prominent children's rights discourse that has promoted an acknowledgement of children and young people as subjects-with-voice (rather than objects of study and intervention) and experts in and of their own lives (see Fargas-Malet and others, 2010; Kay and Tisdall, 2017; United Nations Convention on the Rights of the Child, 1989). According to Nind and others (2012: 654), such shifts have emerged against the political and intellectual backdrops of the 'new sociology of childhood and moral and ethical standpoints about the importance of children's voices and children as social actors'. Likewise, in a disability research context, emancipatory and participatory approaches (Oliver, 1992), which have emerged alongside disabled people's claims for civil rights, have (re)positioned disabled people as social actors with rights, and research as a potentially democratising activity aligned to disability politics with ethical approaches rooted in social justice and equity (Zarb, 1992). Research is positioned as inherently political (Swain and others, 1998) and as such has the potential to empower and/or exploit those who are its subject. In short, the traditional power relations inherent to academic research must be destabilised for inquiry to be in the interests of disabled people's emancipation. Thus, there are many overlaps and tensions between emancipatory disability research and child-led inquiry that are worthy of attention (Kellett, 2005b). It is important to note here that our project predominantly focuses

on young disabled people, making it distinct from the contributions of researchers such as Kellett (2005b) who research with younger children.

More recently, emphasis has shifted towards the capacity of children and young people to act as researchers and partners in their own right who can contribute to inquiry in a number of ways (Bailey and others, 2014; Bucknall, 2010). Positioned as potential leaders of research that have ‘an alternative, legitimate expertise to that of academic researchers’ (Nind and others, 2012: 660), Bucknall (2010) suggests that such a shift is reactive to adult-centric histories of exploitative research upon children and young people. Thus, the notion of children as ‘active’ researchers in co-production contexts ‘has been influenced by the perceived lack of children’s own voices in research about their lives’ (see also Kellett, 2005a: np).

It is important to critically explore such shifts. While having good intentions, there is doubt as to the extent of democratisation of researching with children and young people, with critiques centred on tokenism; imbalances of power in child/adult collaborative research; and a denial of access to the full research process, with children only being considered to have the ‘capacity’ to lead certain aspects of a project (see Coad and Lewis, 2004). Thus, while the role of the child in research has shifted significantly, it is noticeably still adults who hold much of the control regarding participation and research leadership. According to Kay and Tisdall (2017: 68), co-production and the inclusion of children and young people can in fact be used to ‘control participation, to make service users complicit in experts’ agendas’. And Carter and Coyne (2018) stress that, to counter tokenism, being a participatory researcher means ‘a fundamental commitment to believing that children and young people can and will shape your research, construct and challenge your ideas and bring their own ideas and agendas to the table’.

Furthermore, discussion rests upon the specific roles of children and young people in the research process (Carter and Coyne, 2018). For example, some proponents of child-led inquiry argue that, inevitably, some aspects of the research process are better managed by adults (see Nind, 2008); for example, the writing up and publishing of research findings (Bailey and others, 2014; Nind, 2008). As Abell and others (2007) state, it is academics that have the access to computer technologies, experience of academic writing, and knowledge of peer review and publication. We want to be explicit here and state that this article has been co-authored with *Living Life to the Fullest* young co-researchers. Later in the article, we purposefully detail these methods of co-authorship (see Walmsley, 2004). Thus, our focus in this article was not to debate whether disabled young people should be included in research, but to show *how* (see Tuffrey-Wijne and others, 2008): what we have learned from our experiences so far and how these can helpfully inform other researchers.

In the last decade, public bodies — from non-governmental organisations (NGOs) to national charitable organisations — have begun to produce their own guidance as to how to research *with* children and young people. For example, the National Institute for Health Research (INVOLVE, 2016) developed guidance that stresses the importance of participation across the research process while being cautious of aspects of the research that might be ‘too challenging, sensitive or inappropriate for children and young people’ (INVOLVE, 2016, p. 3). Save the Children’s (2000, p. 3) *Young People as Researchers* further questions the resources necessary to enact research relationships meaningfully. This particular guidance builds upon the Joseph Rowntree Foundation’s *Involving Young Researchers: How to enable young people to design and conduct research* (Kirby, 2004), which argues for the early inclusion of young people into the process, alongside a political positionality that understands children and young people as vital contributors to health and social care research.

But where are the voices and expertise of disabled children and young people? Rabiee and others (2005, p. 385) argue that, in general, disabled children and young people have been

excluded from ‘consultations and involvement in decisions which affect them’ (see also Byrne and Kelly, 2015). This exclusion is echoed in research contexts, where disabled children and young people are less commonly involved in research than their non-disabled peers (Bailey and others, 2014). Thus, despite similar emphases in policy on the participation of disabled children and young people (Every Child Matters, 2003; Children’s Act 2004), the disabled child and/or young person remains conspicuously absent, or at best marginalised, across research contexts, as well as in much of the practical research guidance referenced above, although there are some exceptions (see Bailey and others, 2014; Beresford, 2012; Nind and others, 2012). Our preliminary read of such guidance reveals disability as present primarily only through concerns about safeguarding, accessibility and gatekeeping, and as that which demands extra time, resources, and planning on the part of the academic researcher (see Bailey and others, 2014). Seldom is there any explicit focus towards disability as a worthwhile life experience and valuable lived perspective from which to contribute — a positionality readily adopted in *Living Life to the Fullest*.

Interestingly, Bailey and others’ (2014: 512) systematic review of 22 research publications that claim to have included disabled children and young people as researchers found that, across all studies, ‘few details were given about involvement and limitations of involvement were not commonly evaluated’. Thus, little explicit information is often given in research write-ups as to what disabled co-researchers’ specific roles are, or how these are enabled, encouraged or supported (see Littlechild and others, 2015). This is one of our key contributions in this article: to be clear about how *Living Life to the Fullest* functions as a co-produced project; how it is empowering young disabled people to take control of the research agenda and methods; and, as Bailey and others (2014: 510) put it, to ‘define their own and others’ roles in the project’. Currently, all *Living Life to the Fullest* Co-Researchers are disabled young women. It’s important to note here that we have found very little literature that explicitly focuses on gender, co-production and research leadership (although there are quality exceptions — see Olsen and Carter, 2016), making our contributions in this article important towards thinking through the intersectional lives and identities of disabled co-researchers; how class, race, age, gender, sexuality and nation — as well as impairment and its effects (see Thomas, 1999) — impact participation, involvement and inclusion in contexts of co-production research.

Moving forward, then, it’s pertinent to state that this Othering is not new: disabled children’s childhoods have largely been omitted from progressive moves to develop participatory methods with and for researching with children and young people (Rabiee and others, 2005). Pluquailec (2018: 217) argues that the participatory research agenda has overlooked the value of disabled children and young people as worthy contributors to research, largely due to ‘an overly homogeneous conceptualisation of childhood agency’ and an ambiguity and lack of knowledge about how to mediate different types of impairment within the research process. Thus, participatory methods with children and young people are routinely steeped in ableist boundaries of what it means to have and give voice and enact agency and autonomy (see Pluquailec, 2018). Children and young people with life-limiting and life-threatening impairments (hereby LL/LTIs) — marginal lives at the centre of our project — have been further marginalised: as research participants and co-researchers (Gibson and others, 2014). Mitchell (2010) suggests that including children and young people with LL/LTIs raises acute and often unexpected challenges for researchers. Like Pluquailec (2018), Mitchell (2010) denotes ‘a ‘standard’ approach’ to research, where typical research tools are not diverse or accessible enough to enable disabled children and young people to lead or co-produce a project. Furthermore, Mitchell (2010: 1747) draws attention to a change in the pace of research where disabled children and young people are involved: that ‘listening to disabled children

can take time and negotiating access may involve a range of adults, not only parents/carers but also professionals'. Olsen and Carter (2016: 6), who carried out co-production research on rape and support with learning disabled women, noted that working in ethical ways with learning disabled women as co-researchers 'took more time than funders wanted'. They reported that each part of the project took several weeks because of the extra time women needed to process information (Olsen and Carter, 2016). Thus, while co-production research — inquiry that seeks to embody equity, partnership and meaningful collaboration — makes attempts to unsettle the problematic power dynamics inherent to academic research, Olsen and Carter's (2016) experiences show this can often be compromised by neoliberal academic and funding structures that restrict innovative and equitable ways of working with marginalised communities.

In this article, then, we detail some of the politics and practicalities of co-produced disability research with disabled young people with LL/LTIs as we are encountering them in our transdisciplinary ESRC-funded arts-informed co-produced research project, *Living Life to the Fullest*. Significantly, *Living Life to the Fullest* has established a Co-Researcher Collective of disabled young people — currently all young disabled women aged between 19 and 30 years who identify as living with LL/LTIs. Through virtual research environments, the Co-Researcher Collective is actively and meaningfully co-leading inquiry. To be clear (and to counter the poor reporting of young people's contributions in the literature detailed above), this has thus far involved: (i) supporting research design through discussion (planning both narrative and arts-informed approaches); (ii) co-writing interview schedules for young people and parent participants; (iii) recruiting participants for data collection and carrying out online interviews through email, Facebook Messenger and Skype; (iv) planning the project's impact strategy and building relationships with impact partner organisations; (v) working with our community research partner organisations; (vi) meeting regularly via the Research Management Team to co-manage the research process as a whole; (vii) writing blogs and making films that communicate and document our processes and preliminary findings; (viii) presenting at conferences and research festivals; (ix) undertaking various public engagement and knowledge translation activities (online and offline); and (x) co-authoring articles for publication (Aimes and others, unpublished data; Goodley and others, 2017). As stated earlier, together co-researchers and project academics have co-written this article for publication. Practically speaking, this involved online discussions about the article's content via Skype sessions, followed by each of us contributing to a Google document in order to co-write accessibly together. Furthermore, peer reviewers' comments were discussed over email and FaceTime, and worked on in collaboration in order to revise and resubmit for publication.

We begin, then, by outlining how *Living Life to the Fullest* embodies the politics of disabled children's childhood studies (Curran and Runswick-Cole, 2013; Runswick-Cole and others, 2018), enacting co-production from the outset, co-authoring our bid for funding in collaboration with disabled children and young people, their parents/allies and key representative NGOs. Notably, this early work preceded and later led to the establishment of the Co-Researcher Collective, borne out of a collective desire to position disabled children and young people as longer term contributors to the project as partners.

We then move on to critically discuss the Co-Researcher Collective and its use of virtual and online research environments. We centre such environments as highly beneficial to collaboration with Co-Researchers, suggesting that social research technologies offer meaningful opportunities for valuing the embodied knowledge and lived experiences of disabled young people with LL/LTIs. We also attend to the dominant concerns around the 'extra time' required of researchers to undertake research with disabled young people. Using Alison

Kafer's (2013) notion of 'Crip time', we think through ways to reframe these alternative temporalities of research (see also Koppers, 2014). Crip time is defined by Kafer (2013) as the recognition of (disabled) people's need for 'more time' — affirmation that diversity in embodiment and barriers in the social world means life can take place on a different time-scale. As we detail the politics and practicalities of our processes, this article aims to encourage critical disability studies researchers and others to take up virtual environments when researching with disabled people and undertaking empirical explorations of their lives.

### Co-producing knowledge from the outset

As a project that seeks to forge new understandings of the lives, hopes, desires, and contributions of disabled children and young people with LL/LTIs, *Living Life to the Fullest* embodies the ethical and political principles of disabled children's childhood studies (Curran and Runswick-Cole, 2013, 2014; Runswick-Cole and others, 2018). Disabled children's childhood studies actively positions the voices and experiences of disabled children and young people at the centre of inquiry. Or as Pluquailec (2018) suggests, as an approach to research it rightfully makes space to acknowledge disability as (positively) disruptive towards the typically ableist and exclusive boundaries of research theory and practice.

In the context of our project, we understand co-production as academics working together with a range of partners to produce research and outcomes not possible in isolation (Runswick-Cole and others, 2017). According to Durose and others (2012: 2), co-produced research 'aims to put principles of empowerment into practice, working "with" communities and offering communities greater control over the research process'. For Olsen and Carter (2016: 7) the co-production of knowledge 'can promote respectful integration of ideas'. By extension, then, for us research is not a process *about* or *for* disabled children and young people with LL/LTIs their families, but conducted *with* and *by* them (see Fudge and others, 2007). Moreover, the research questions, methods, strategies of analysis, and plans for impact and public engagement reflect the ambitions of disabled children and young people and their families and community stakeholders. Thus, co-production became a necessary part of shaping inquiry at the very early stages. As such, our bid for funding was co-authored in collaboration with disabled children and young people, their parents, carers and allies, and key representative NGOs. We wanted to contest the routinely dis/ableist and elitist ways in which research-funding bids are generated and how funding itself is allocated (Runswick-Cole and others, 2017). In this context, co-writing for us involved the discussion of ideas and research and impact planning through a number of writing workshops and meetings. We asked disabled children and young people many questions, such as: What should we be asking questions about in the research? Who should we be asking? What aspects of your life often go unnoticed that you would like to see explored in this project? What would enable you to participate in our research if you wanted to? How can we make it easier/appealing for you and other young disabled people to take part? What do we need to get right in our project? What could we get wrong? With permission, we posed these questions via a short accessible film posted to the Facebook pages of disabled young people's organisations and related charities. Disabled young people either 'commented' below our posts, or sent an email containing their thoughts.

Ultimately, our emphasis at this time was to work in ways that ensured the inception of the research process was both accessible and enacted a shared distribution of responsibility from the outset. Integral to this is our Research Management Team (<https://livinglifetothe fullest.org/researchers/>) — at that time made up of disabled and non-disabled academics (at a variety of career levels, from PhD to Professor); young people with LL/LTI; parents and family members; allies and campaigners; researchers, practitioners and representatives of our NGO and community research and impact partners,<sup>1</sup> many of whom occupy several of those

subject positions. They invited us to engage with their communities outside of the academic context. The Co-Researcher Collective — established later in the project (after funding had been awarded) — is now an integral part of the Research Management Team. Ultimately, we are critically engaging with a co-production methodology that provides space for partners to inform the running of the project, the kinds of findings that emerge, and ideas for impact and public engagement that are creative rather than prescriptive. Co-production can be a contested field, but we are purposefully making space for unknowing and uncertainty, letting research relationships with disabled young people and partner organisations lead, with the aim that partners take ownership of the research in ways unforeseeable at this juncture.

### The co-researcher collective: contesting power imbalances

Currently the Co-Researcher Collective consists of six disabled young people (all women) who live with LL/LTIs. In recruiting co-researchers, the only ‘criteria’ placed upon participation was a desire to explore young disabled people’s lives and contribute to the process through undertaking project-related activities of co-researchers’ choice. Initial groundwork to build the Collective began early in the process — after funding was awarded (following co-authoring the bid for funding) — and involved running an *Introduction to Research* project workshop in a residential special education school and college in the South of England, UK. Mediating gatekeepers and getting access to undertake the workshop took considerable time — far more than we had anticipated. Unfortunately, despite the enthusiasm of young people in the room (all, bar one, young disabled men), our workshop did not result in any people committing to become co-researchers. While initially disappointed, this eventuality encouraged us to rethink our approach and ‘go back a step’ to ask critical questions of how to build the necessary relationships with disabled young people for successful co-produced disability research; as well as reconsider disabled young people’s motivations for engaging in research about their lives (see Littlechild and others, 2015). In his co-produced research with older people, Buffel (2018: 53) comments that co-production research seldom reports, or understands, ‘why some do choose to act as a co-researcher’; thus understanding people’s motivations is critical towards recruiting co-researchers. Suffice to say, such a lack of interest affirmed to us not to make assumptions about disabled young people’s motivations, interest, time, or their keenness towards taking on the responsibility and accountability of being a full co-researcher. Despite many young people in the introductory session voicing the importance of what Kitchen (2000: 38) describes as ‘the opportunity to correct misrepresentations and influence the direction of the research’, the choice to not commit any further emphasised that, like other young people, disabled young people have likely got other things to do that are more important to them. In addition, situating this session within school (and school time) likely emphasised the project as another form of schoolwork. The students who came to the session were all post-16 and thus busy with the current demands of GCSEs, A-Levels and BTEC learning. It is probable that this positioning impacted young disabled attendees’ desire to commit to what was seen as yet more ‘work’. This session was followed up with letters and age-appropriate information packs, for young people, parents and teachers, unfortunately to no avail.

After meeting Lucy Watts MBE, a prolific young disabled campaigner who currently serves as an Ambassador for the national charity Together for Short Lives — and now Lead Co-Researcher in *Living Life to the Fullest* — we were advised as to the benefits of online spaces towards building meaningful relationships with disabled young people. Lucy explained how virtual environments are critical to her advocacy and activist work and, in short, we listened, and this conversation significantly shaped inquiry moving forward. From this, online advertising through the project website and social media led to prospective Co-Researchers making initial contact (typically through Facebook Messenger) and eventually joining the Collective,

enabling a radical revision of the didactic ways in which research into disabled young people's lives is typically carried out. However, despite recruitment stressing the desire for diversity amongst Co-Researchers — with specific attempts made to recruit co-researchers with the label of learning disability and/or disabled young people from Black, Asian and minority ethnic backgrounds — all Co-Researchers recruited are young disabled White women from middle class backgrounds (all but two have a university degree). This highlights co-production as a potentially exclusive research space that lacks diversity, even in the context of disability research.

However, we quickly found that the Co-Researchers we did recruit had a desire for social change and curiosity as to the potentials of social research:

As a young disabled person I answer a lot of surveys on my disability, my care and other similar topics. But I'm rarely asked about what it is really like to be 24 and disabled. No one has asked me whether I'm scared about my future or whether my life-limiting condition has impacted my life choices. These are not pleasant things to think about, but I can promise you, nearly every disabled person has thought about them. When I was asked whether I wanted to be a co-researcher for *Living Life to the Fullest*, I was excited by the idea of a project that focuses on those unasked questions. I wanted to help find out what our lives' are really like and how we really feel about them

Emma Vogelmann, Co-Researcher, *Living Life to the Fullest* (The Co-Researcher Collective, 2018)

The reason why I wanted to get involved in this project is because I feel that we have a duty to help young disabled people live their lives as they wish. To have experiences that, although are different and adapted from the experiences of our healthy counterparts, are just as rewarding — after all, we deserve that. Life is precious, let's live it to the fullest.

Sally Whitney, Co-Researcher, *Living Life to the Fullest* (The Co-Researcher Collective, 2018)

Importantly, in *Living Life to the Fullest* participation and leadership is shaped and adapted to fit around the needs and wants of Co-Researchers. As such, much of our communication with the Co-Researcher Collective takes place online — we connect daily through a closed Facebook group, Skype, FaceTime, email and Whatsapp. Far from embodying the tokenism that can plague research with disabled people (Liddiard, 2013), the Co-Researcher Collective has made important decisions and undertaken the majority of the fieldwork with young people thus far. This has ranged from designing interview schedules (which took place through a Facebook post to the group upon which Co-Researchers offered questions through 'commenting'); to recruiting participants for interview (young disabled people and parents); carrying out online semi-structured qualitative interviews via new social technologies; growing the Co-Researcher Collective through recruiting fellow Co-Researchers; writing articles and conference papers (see Aimes and others, unpublished data); promoting the project across social media platforms, and disseminating information via their own networks and organisations. At the time of writing this article, we are planning analysis workshops with the Co-Researcher Collective and our Community Research Partner, Purple Patch Arts, in order to participate in collaborative meaning-making of artistic data with one another in order to share our interpretations of data (see Koski and others, 2016).

### *Embodied knowledge — valuing lived experience*

Engelsrud (2005, p. 281) argues that the 'researcher's body can be understood as both access and limitation to the acquisition of knowledge'. In her research into disabled sex/ualities (Liddiard, 2013, 2018) identifies her disabled identity and material and physical embodiment of impairment as ever-present within the research context. As such, disabled people can offer



a unique 'insider perspective' (Kellett, 2010) that is critical towards furthering understandings of disability life and dis/ableism (ableism and disablism) (Goodley and others, 2015), particularly the emotional labours and affective politics of what it means to be disabled in such dehumanising austere times (Runswick-Cole and others, 2018). In much the same way, Co-Researchers' networks have enabled access to communities we may not otherwise have accessed, and their disabled identities and lived experiences of disability and dis/ableism have informed the research process in immeasurable ways. As an example, many of the questions generated through discussion and later adopted in the interview schedules emerged from a deep (lived) understanding of what it means to live with LL/LTIs as young people with short lives. As interlocutors and co-constructors of participants' stories, Co-Researcher identity, subjectivity and embodiment became integral to the dialogical process of storytelling. While we acknowledge that, at times, this requires ethical considerations — both for prospective participants and Co-Researchers (and non-disabled researchers — see Goodley and Tregaskis, 2006), such questions have generated valuable and rich data for analysis.

According to INVOLVE (2016: 8), 'the importance of saying thank you [...] should not be underestimated'. Thus, in order to not reproduce the exploitative relationships that characterise histories of research on disabled children — or invite the critiques of tokenism that some suggest may be inherent to research with children and young people (see Coad and Lewis, 2004; Kellett, 2005b) — we have established a budget to fund Co-Researchers to purchase technology of their choice as recognition of their commitment and labour within the project. We have also invited Co-Researchers to become members of the research centre the Institute for the Study of the Human (iHuman) at the University of Sheffield — in acknowledgement that as researchers they should have access to research communities — and are offering Co-Researchers university certificates and references as evidence of their contribution of expertise, skills and knowledge to the project. This is important towards supporting the educational and work-based aspirations of Co-Researchers with LL/LTIs, the majority of who face significant barriers to higher education and meaningful employment (Abbott and Carpenter, 2014).

### *Virtual spaces, disability research and young people*

The Co-Researcher Collective cannot have benefitted the research in the ways it has without access to virtual spaces and methods. The use of the Internet has been argued to be transformative within social and educational research (Hewson, 2014). This is often known more commonly as Internet-mediated research (Hewson and others, 2003), computer-mediated research or electronic research methods (Seymour, 2001). In an information age where new social technologies are rapidly (re)shaping human communication, online spaces can proffer new forms of inquiry: for example, netnography (Jong, 2017), web-based surveys (e.g. surveymonkey.com) and 'unobtrusive observation approaches' which 'gather data from existing online sources such as discussion group archives' (Hewson, 2014: np). As Seymour (2001: 147-148) argues, online and electronic research methods can 'substantially enhance the development of methodologies that relate more closely to the needs of research participants'.

To 'draw disability in', many disabled people are often more visible online — where new forms of citizenship are being claimed due to the Internet (or 'online spaces') providing more accessible avenues for participation, communication, education, entertainment and employment than in the 'real life (RL) world' where significant barriers to these areas of social life forcefully prevail (Seymour, 2001). Seymour (2001: 149) argues that information technology can serve to circumvent bodily function, 'enabling participation in previously inaccessible domains'. Others (Bennett and Segerberg, 2011; Pearson and Trevisan, 2015) have also suggested that online spaces (particularly new social technologies and social networking sites)

offer new opportunities for social and political participation: access to rights, equity, justice and citizenship through disability activism, community-building and solidarity (see Obst and Stafurik, 2010), as well as raising a consciousness that has been particularly important to Disabled People's Movements through the austerity politics of past and present UK governments. Such technologies have also been integral towards enabling new avenues through which to fight for justice in response to the routine institutional violence and avoidable deaths of disabled people (see Ryan, 2017). And Liddiard (2018) has identified the Internet as a key space wherein disabled people can claim sexual and intimate citizenship and facilitate engagements with sex workers (Liddiard, 2014; Liddiard, 2018).

The Internet is also a platform upon which to build an identity of choice (Burch, 2016; Huffaker & Calvert, 2005): Bowker and Tuffin (2002: 340 in Burch 2016: 8) suggest that this is because 'the power of the gaze becomes displaced by a textually oriented medium.' However, as in the 'RL world', ableism and disablism — key oppressions in the lives of disabled people — are ever-present. As, Seymour (2001: 148-149) reminds us, technology is far from neutral: 'old forms of social division underpin the new information age'. Thus, it's important to not homogenise the disability experience in relation to virtual technologies — digital exclusion remains a key form of oppression for many disabled people (Lane-Fox, 2010; Watling, 2011). Digital exclusion is exacerbated as more and more of our lives 'move' online in what Watling (2011: 491) calls 'visions of a digital future': banking, food shopping, community-building, activism, social communication, and finding friendship, love and intimacy and accessing sex (Liddiard, 2018). Adults with the label of learning disability, people with visual impairments and D/deaf people are routinely excluded and Othered in online and textual media — it is likely this has contributed to the lack of diversity in the Co-Researcher Collective. Furthermore, as conditions of dis/ableism have become more acute through the austerity agenda of multiple UK Governments, hate speech and crime, both online and offline, have worsened 'propagating a metanarrative of disability as the ultimate 'dustbin for disavowal' within a climate of austerity' (Burch, 2016: ii).

Despite this, disability researchers have demarcated online or virtual research environments as being of significant value to existing and emerging disability research methodologies (Bowker and Tuffin, 2004; Carr, 2010; Liddiard, 2013; Seymour, 2001; see Obst and Stafurik, 2010) — for myriad reasons. Firstly, they are often malleable to different embodiments, capabilities and bodily functions (although, as we suggest above, this has its exclusions). Secondly, virtual arenas can offer greater accessibility and privacy: new social technologies can provide the means for disabled people to participate in research without this becoming known to social workers, personal assistants, carers, partners and parents. Thus, for young disabled people with LL/LTIs, who face significant exclusion in multiple spaces of their lives (Abbott and Carpenter, 2014) — often aggravated by their need for complex medical and surgical care, support and interventions — online spaces can offer improved access to social, political and cultural worlds. As Co-Researcher Emma Vogelmann states in an article she wrote for Huffpost, and later reposted on our project website (<https://livinglifetothefullest.org/2018/04/19/co-researcher-voices-speaking-out/>):

I've written about the value of social media in regards to activism for disabled people; it is an extremely valuable tool given these barriers, so I support armchair activism. Having a social media presence is how I started my activism career. The day I wrote my first blog on the attitudes and discrimination I encountered as a disabled student, I posted on Facebook (it was more of a rant if I'm being honest). When I realised I could reach an even wider audience by having a larger presence, I jumped at the chance to make my voice as widely heard as possible. I created a professional Facebook page and paid for certain articles I wrote to reach a wider audience. It worked, one of my posts reached over 10,000 people.

Yet Seymour (2001: 159) argues that in the context of a disability research agenda, “giving a voice” means more than providing the researched [and, we would add, Co-Researchers] with an opportunity to speak: it involves creating the appropriate means and communication context’. Although, as Nind (2008) comments, ‘the idea of some people empowering others raises all kinds of questions’, making this positionality of giving/claiming space and voice a key tension in co-production. We suggest, however, that our online research relationships with one another as researchers in *Living Life to the Fullest* embody our egalitarian research politics as well as counter the routine dis/ableism inherent to the research process: we actively work towards generating a politicised space that welcomes and values the perspectives of young people with LL/LTIs. Markedly, this is facilitated through the ways in which the Internet ‘erases boundaries of time and distance’ (Eysenbach, 2001; pagination unknown) and blurs public/private divides, meaning that our relationships as colleagues are not restricted to neoliberal temporalities of ‘work’. Some disability theorists have called this ‘Crip time’ (Kuppers, 2014), defined by Kafer (2013) as the recognition of (disabled) people’s need for ‘more time’ and a political acknowledgement that contexts of ableism propagate timescales and temporalities that benefit non-impaired bodies and minds.

In relation to *Living Life to the Fullest*, then, online environments mean our project invites flexibility with regard to time. Through ‘the intricacies of crip time’ (Zola, 1998) new temporal frameworks of research embody alternative orientations in and to time. For example, co-researchers will often message us at all times of the day and night; we schedule meetings around the presence and time of care visits and support from personal assistants; Skype meetings involve breaks to adjust tracheostomy tubes or seat cushions; blog posts and tweets get written during the night; online interviews via Facebook Messenger are meticulously broken down into multiple sessions due to exhaustion on behalf of the interviewee and/or the co-researcher; contributions require regular breaks due to frequent hospitalisations, and planning a ‘physical get-together’ (e.g. to a conference) can take considerable time and labour due to the need to manage multiple barriers to access. We do not mention these here as negative impacts of impairment, but as vital moments to rethink and reconsider conventional temporalities of qualitative methods and research processes. Rather, once again we suggest that these embodied experiences shape the process to the benefits of our participants — young disabled people with LL/LTIs and their families — ensuring that the materialities of disabled body-minds are centred in inquiry, rather than written out and overlooked. In *Living Life to the Fullest*, impairment is more than an ‘unwelcome presence’ (Shildrick, 2009: 32), but serves to disrupt the embodied norms of inquiry, acknowledging the generative relations of alternative ways of being in the research process. In this way, our processes become more responsive to the real life worlds of disabled children and young people with LL/LTIs and their families.

### Drawing some conclusions

In this article, we have detailed our experiences thus far of some of the politics and practicalities of co-producing disability research with disabled young people. Centring our trans-disciplinary arts-informed co-produced research project, *Living Life to the Fullest* and disabled children’s childhood studies (Curran and Runswick-Cole, 2014; Runswick-Cole and others, 2018), we have made attempts to locate the disabled child and young person in ‘child-as-researcher’ discourses, movements and literatures, demarcating their routine exclusion and marginalisation — particularly in the context of life-limiting and life-threatening impairment. Our experiences articulated through this article highlight significant gaps in the literature here: that a focus on the disabled child-as-researcher does not offer enough towards thinking about the possible roles and leadership of disabled young people in and

across research contexts and its possibilities for their futures. Moreover, where disabled young people are positioned as researchers, far more practical and explicit information needs to be written into research studies in order for young people's contributions to be fully acknowledged, rather than merely the negative emphasis of the 'extra time and labour' facilitating their participation can take academic researchers.

As a means to show the value of disabled young people's participation and co-leadership of the research process, then, we have articulated the work of the Co-Researcher Collective. Through discussing our successes and failures, we have centred accessible virtual research environments and online spaces as that which, in the case of our project, has enabled us to welcome diverse embodiments, levels of skills and knowledge, and enable meaningful leadership on the part of disabled young women Co-Researchers — who are often shut out of leadership (Liddiard, 2018). We recommend, then, and encourage other critical disability researchers (and others) to embrace social research technologies. This is due to the very ways in which they can offer opportunities for valuing the embodied and unique 'insider' knowledge (see Kellett, 2010) and lived experiences of disabled people as researchers and participants, as well as incorporating the flexibility of Crip time to research processes that are typically dominated by normative neoliberal frameworks, temporalities and body-minds (Kafer, 2013; Kuppens, 2014). Thus, virtual spaces, we argue, are critical to the ethical development of collaborative disability research with young people, particularly those with LL/LTIs.

In sum, as our experiences detailed in this article reveal, what is required to democratise research with children and young people (disabled or not) is a shift in what constitutes research 'contribution', 'capability' and 'leadership' — the notion that enabling leadership and control of the research agenda by non-academics involves challenging the normative (and ableist) rubrics of research and its traditional methods to give better access to researchers with a wide range of skills, capabilities and knowledge. Lastly, as we have attempted in this article, we call for researchers who practice co-production to better map their empirical experiences of research as a key way to develop existing inclusive research methodologies towards the potential contributions and values of marginalised young people as contributors and research leaders.

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## Note

1 Community Research Partners: Purple Patch Arts; DMD Pathfinders; and Good Things Foundation.

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