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ORIGINAL PAPER

Breaking out of the box: increasing the representation of disability within archive science

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Abstract
This article explores the value of archives in increasing the representation of disabled people in social policy, and research narratives, as well as building an identity of the Disabled People's Movement beyond traditional activism, and the inclusion of young people and marginalised groups within archives. To achieve this, it is vital that archival studies and archival science engage with the conceptual understanding of disability and the different needs of disabled people, beyond the traditional focus on the medical model, to an understanding of the Social and Rights Models. This understanding will help to unify approaches to disability within the archive from both an archival science and humanities perspective to make sure that polices and approaches facilitate the participation and recognition of the wide experiences of disability. This will require re-evaluation of approaches to policy issues such as safeguarding and vulnerability, social media use and whose voice is worthy of preservation. Engagement with the broader field of disability studies in theory and practice offers a way for the field of archive science to address these issues.

Keywords Access · Art · Disability · Ethics · Non-traditional submissions · Social media

Introduction

This paper is the result of a 2020 research scoping event funded by the Keele University Institute for Social Inclusion (KISI), in the UK. The event, titled, 'The Perspective Collective, Opening a Window onto Rights and Reality: Hearing and

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Recording Experiences of Disability Rights to Shape Future Responses' was held to enable a group of academics from the fields of disability studies and disability law to come together to address how the voices of those with disabilities not identifying or participating in traditional activism may be heard by policy makers. The intended outcome of the event was to consider whether a participatory online interactive archive might be the way to achieve this. The trajectory of the project was interrupted and altered by the COVID-19 pandemic and the fact that it was no longer safe or practicable to bring together participants with disabilities and health conditions to expand on the scoping exercise to be able to build a grant application.

The message of this article is that currently, archival science and archive studies do not fully understand disability and, until they do, they will not be representative of disabled people, nor will they be accessible to disabled people. Achieving this requires both archivists and researchers to engage more fulsomely with law and policy around disability. These are fundamental aspects to the framing, understanding and creation of the lived experiences of disabled people in the United Kingdom and throughout the world. These laws and policies can have either an inclusive or exclusive impact and their intersections with archival practice, particularly in the contexts of safeguarding and data management, are important to acknowledge to ensure that practice does not perpetuate paternalistic and exclusionary approaches.

The papers forming the basis of this article include: 'Disability and the archive' by Miro Griffiths; 'A view from the outside' by Abigail Pearson; 'Interdisciplinarity, intersectionality, and internationality' by Burgandi Raskoska; 'Social media as an online disability archive space' by Christian Harrison; 'Online spaces for disabled children: a voice of experience' by Karian Schuitema; and 'On the margins: law and mental capacity' by Ezgi Taşcıoğlu. Though the substantive content of these contributions is reproduced in this article, the editor has opted to present each as a series of interwoven discussion points to better facilitate the overriding argument that archive studies needs to move beyond traditional and arbitrarily restrictive conceptions of disability and archives based on disability activism if it hopes to be truly inclusive and representative of disabled people. Therefore, the article is divided into the questions that were raised at the event. Abigail Pearson answers the questions 'What do we mean when we say archive?' and 'What has the field tried to increase accessibility and inclusion?', then along with Miro Griffiths, she explores the understanding of disability that needs to gain traction within archive science and archive studies to build inclusive archives. Then, Burgandi Raskoska answers the question 'Whose voices are included in the archive?', while contributions from Christian Harrison and Karian Schuitema focus on how archive science and archive studies might use online platforms such as social media and specialist websites to increase the representation of disabled children and young people specifically. This ties back to Miro Griffiths discussion about the potential of archives to respond to the changing needs and makeup of the disabled people's movement, to ensure that a new generation of activists feel included. Finally, Ezgi Taşcıoğlu explores how archive science as a field and individual administrators might navigate the concepts of vulnerability and safeguarding to ensure inclusivity over paternalism.

Firstly, as academics from outside of the field, we outline our understanding of archive and how we believe that this can increase the representation of disabled people in various discussions around policy and social discourse. Then, we orient readers as to the concept of 'disability' beyond restrictive narratives of sickness, charity, and activism, which are the dominant themes in contemporary archive research. This discussion is drawn principally from Griffiths and Pearson's contributions, in which they evaluate conceptions of disability as pathologised through a combination of medicalisation, ableist assumptions and orthodox views of activism and activists. The latter presents a special concern for archive studies as—for a variety of reasons—disabled people may be reluctant or unable to participate in traditional activism. Reasons may include physical and logistical barriers to access, alternatively, they may be attitudinal and ideological barriers to inclusion, or some combination thereof, such as capacity, age and technological literacy. Representation and inclusion of disabled children and young adults, including those who count themselves as activists, is essential to creating a responsive and representative resource. The potential of archives as a method of achieving inclusion for young people is considered Schuitema's discussion of their experience of gathering, organising and disseminating a collection of artworks by disabled children. Harrison provides a discussion on social media and technology as a route to participation, which also needs to be considered in relation to the barriers to cataloguing and presenting social media posts as artefacts within the archive. Griffith adds to this discussion by highlighting the ways in which traditional approaches in the Disabled Peoples' Movement have excluded young people to contextualise the call for a new approach and the value of archives.

To properly include disability in an archive, we need to understand what is meant by disability. Currently, archives seem to have a one-dimensional view of disability. Such examples include the Beyond Boxes Scheme (2019) and the Manchester Coalition on Disability Activism, Disabled People's Archive (n.d), where to be seen, disabled people are required to identify as activists. The archive webpage also states: 'The archive is testimonial to their attempts to be included and become an inclusive member during their lifetime; it will also help young disabled people to realise not to give up', and 'Younger disabled people can learn from past successes and mistakes and incorporate our own experiences into a wider fight for equality and feel part of a powerful movement', which is indicative of the marginalisation of younger disabled people within the movement, highlighted by Griffiths (2022).

A social human rights approach to disability requires that the barriers to participation are recognised within the sector along with an understanding that failure to address these is a human rights issue. Another key problem is that of access to archives, when disabled people are either physically hindered from participation or excluded as a matter of policy. The article's central theme is in addressing how archives understand disability and how this multifaceted understanding could and should impact archival practices. To achieve this aim, it is presented as a series of discussion points: firstly, it will explore the concept of disability and its relationship to the archive, to identify and address weaknesses in the current approach. Secondly, it will explore why archives have the potential to play a significant role in increasing the representation of those who do not identify as 'disability activists' and why this is important. Thirdly, the article will explain why it is important for archives to address the needs of underrepresented groups, intersectional experiences, the voices of young people, and those who's perceived of a lack of capacity may have traditionally excluded them from consideration. Fourthly, the article will consider policy issues such as General Data Protection Regulation (GDPR) and the safeguarding of young people and those with disabilities, particularly around management of health information within the archive and how these issues might be addressed in practice.

What do we mean when we say 'Archive'?

The importance of both archive and archiving are recognised in supranational and European Union law. The Universal Declaration on Archives (ICA 2011) states:

> Archives record decisions, actions, and memories. Archives are a unique and irreplaceable heritage passed from one generation to another. Archives are managed from creation to preserve their value and meaning. They are authoritative sources of information underpinning accountable and transparent administrative actions. They play an essential role in the development of societies by safeguarding and contributing to individual and community memory. Open access to archives enriches our knowledge of human society, promotes democracy, protects citizens' rights, and enhances the quality of life.

To begin talking about archives and archival science it is necessary to specify what aspects this article intends to cover. Caswell (2016) makes the distinction between a humanities understanding of archives and archival science. The humanities understand archives as the repository of records or artefacts which are waiting to be uncovered and analysed in their social historical and humanistic provenance, whereas archival science sees the archive as the housing, storing, cataloguing, accessing, creation and funding of archives. The present article will be dealing with both understandings of archive as the nature of disability is such that for a truly representative, useful, and participatory archive to exist, it is necessary to consider both the content of the archive, through the lens of the humanities, and also the processes of archival science which may present physical and procedural barriers for disabled people, in terms of access, repository, and retrieval to both to physical sites and records therein.

What do we mean when we talk about disability in the archive?

Having specified our definition of archive, we will now explore the academic conceptions of disability which are necessary to ensuring that archives, in both senses of the term, are accessible and inclusive of disabled people. Disability is a contested term in both academic and non-academic literature, often entangled in narratives of tragedy and pity, alongside the prioritisation of medical interventions to 'fix', 'cure', or 'rehabilitate' individuals; the 'medical model' as it is known (Oliver and Barnes 2012). Disabled people's resistance practices have challenged this view, which led to a reorientation of disability as a description of the injustices, exclusions, and disadvantages imposed upon them as a community. The 'social model' of disability is considered a central tenant of disability activism and politics, providing a distinction between impairment, health conditions, illnesses, as well as unnecessary restrictions imposed by societal structures (Shakespeare 2006; UPIAS 1975). These arrangements (political, economic, social, cultural, technological, and so on) reproduce the social injustices encountered by disabled people. Recognising disability as socially produced creates new spaces for identifying the material and discursive conditions required to produce an accessible and inclusive society. An emphasis has been placed on the rights-based approach, to deliver the legislative infrastructure for protecting the fundamental freedoms of disabled people's while increasing their participation in the community. Lawson and Beckett (2020) provide a comprehensive account of the importance surrounding the 'human rights' model of disability, which considers lack of access not only as discrimination but as a violation of human rights. In this way it complements and expands on the social model.

Archives have an instrumental role in the progress of disability activism, politics, and policy development. Griffiths's (2020) empirical research in disabled activism, in the UK, illustrates how the archiving of the historical activities and key debates in the community, can impact the sustainability and effectiveness of disability activism as well as disability as a social movement. Archive material can be levied to test levels of knowledge and familiarity amongst members of such movements. Similarly, materials can be inaccessible if the host sites are part of the academy. To that end, it is critical that the processes of archive do not undermine the participation of newcomers in their attempts to participate and influence the agendas and strategies of activism. Research has explored the accessibility and inclusivity of archives (Bailey et al. 2008), and innovations within new technologies have placed emphasis on creating open, transparent, flexible mechanisms to capture and protect materials (Pugh and Theimer 2011). Nevertheless, there is a considerable lack of research and commentary on disabled people as curators and producers of archives and data collection strategies.

Recent developments in the literature of archive practice recognise the importance of opening up participation to hitherto unheard or underrepresented voices (Flinn 2010, Newman 2012, Caswell 2015, Welland 2015, Tilton and Hale 2017, Benoit and Eveleigh 2019, UNC n.d.). This has led to concerns over the narrow focus of what is worthy of inclusion in the archive and who counts as an archivist, the broad remedy for which is the ongoing and increased inclusion and representation of marginalised voices. Such concerns have provoked additional questions about the utility of archive, both to communities in general and those actively engaged in the politics of deciding who or what to include.

The role of the internet in the archival process is also an important consideration. Popple et al. (2020) consider the relationship between archive and those constructing and included in them; they argue that a community shift in recent decades has led to archives becoming more *sous*veillant, as opposed to surveillant, that is, more individuated and crowdsourced rather than relying on the traditional top-down parameters and methods of state institutions and private enterprise. These grassroots information streams are facilitated by advances in information technology and social media and represent a push towards emancipatory collaborative practice, allowing for a proliferation of inclusive storytelling in the archive, away from the custodial narratives of the past (Popple et al. 2020). They acknowledge some attendant difficulties that accompany this shift, such as the need to accept the transience of content, the struggle for power, in terms of who is in charge of these new archives, and the prospect that such endeavours may lead to 'dead ends'. They nevertheless remain optimistic that 'this is no reason *not* to persevere and embrace the process, learning, negotiating, and feeling a constant sense of pleasure at the liberated knowledge that is the consequence of new collaborative practices' (our emphasis). Collins (2020) highlights the importance of ensuring that online spaces are sufficiently served with the relevant data-capacity and domain security to prevent community archivists feeling as though their efforts are unduly interfered with by large corporations and to ensure that their repositories and holdings are not lost due to online obsolescence. They also emphasise that community archives can, and often do, share values, and mission statements with their perceived professional counterparts, demonstrating a commonality between the two. They advocate for a collaborative approach between communities and mainstream institutions, not only as a means of knowledge sharing around archival practices but also to ensure that 'we fully realise the possibilities that the internet offers us all for creating and sustaining genuine participatory archives […] infused with memory-making, affective discussions and rich personal materials that enhance our understanding […]'. Prescott (2020) highlights the importance of viewing the internet as an ecosystem and that online archives can only be useful if this ecosystem is respected and improved through a community of archivists and members, creating positive values and rationales around their archive's purpose, focusing on accountability and accessibility, as well as ensuring that the voices of their community are heard and managed in a positive way.

In this line, Sheffield (2020 pp. 3–13) highlights the importance of questioning the concept of community by considering issues of both *community resource* and *identity* in creating and maintaining momentum through time, in the context of changing expectations and participation rates. She also highlights the importance of interrogating the central role of community within this process, to identify who is considered inside and outside of the community and, as such, whose identity is considered 'worthy' of representation in the community archive space. The present article deals with all these issues, and it is particularly critical of the way in which relationships and the concept of community have regulated and constructed current approaches to disability in the community archive space. It examines intersections of law and policy in the UK and the role of archive in advancing the voices of disabled peoples. This piece is offered to the archival science community as a means of beginning the formal research collaboration between members of a community and more traditional stakeholders within the conversation.

What has the field tried to increase accessibility and inclusion?

In addressing access and inclusion within the archive space, the Mass Observation Project created the buddy scheme with the Blind Veterans UK, to facilitate access to archives both in terms of deposit and retrieval (Beyond Boxes Scheme 2019). Though well intentioned, this project is problematic on three fronts: First, in instituting a 'buddy' system it continues to mediate the right to access archives, in both senses of the term, through an extra layer of bureaucratic intervention that does not obtain for their able-bodied counterparts. Here, we need to recognise the difference between *accessibility* as matter of accommodation and *retroactive measures* as a matter of adjustment. Accommodation is anticipatory whereas adjustment is retroactive. The latter is indicative of an absence or lack of consideration for disabled people in the planning and creation of processes and facilities. Second, the language of a 'buddy' is inherently problematic within the context of disability. As a label, 'buddy' has historically been used as a patronising—and overfamiliar—diminutive for disabled people, often employed by the able-bodied to assert their dominance over the relationship, either overtly or subconsciously. Third, the concept of 'buddy' schemes is principally drawn from a charitable conceit, where the broken and inadequate disabled person is paired off with a well-meaning, able-bodied, volunteer, who selflessly gives up their time to assist in doing things the poor, unfortunate disabled person had every right to do anyway. Such an approach emphasises the paternalistic charity model of disability over the social or human rights models that all social institutions should be working towards.

The closest existing model for what we would like to achieve in a domestic project, is exemplified by Alice Wong (2022), in the United States; The Disability Visibility Project in America, facilitated by Storycorp, offers great for future collaboration. The project accepted recorded video and audio submissions via online platforms such as YouTube which are more readily available for disabled people and can be created from home and at minimal cost. This was especially useful for those seeking help from a sign language interpreter or facilitator. There are, however, increasing concerns about information gathered in the context of disability, and how it might be abused as a kind of surveillance. As an American project, the Disability Visibility Project is subject to US legislation around of data protection and state surveillance, and all recordings and submissions ultimately stored at the US Library of Congress (Wong 2022). In the UK, protests around benefit reform, fuelled a similar concern around state surveillance. It was discovered that the Department for Work and Pensions (DWP) could request information from the police about claimant protestors, whose attendance at demonstrations was taken as proof of physical ability thus jeopardising their claims (Pring 2019) The politicised nature of data protection and management and the potential for state surveillance, is thus, a particular concern for the disabled community and their prospective archives, both nationally and internationally. Considering recent the changes to welfare and other policies in the UK, archive researchers would need to consider how access might be managed regarding politically charged projects of disability activism, to ensure both security and participation. Beyond these considerations, the coordinators at the Disability Visibility Project also acknowledge that their current submission strategy presents specific accessibility issues for those who cannot produce oral recordings. Though alternatives are offered, such as subtitled *YouTube* videos or written submissions, these are quite complicated to produce and require a significant amount of technical skill.

Whose voices are included in the archive?

Beyond the difficulties of accessing archives, as spaces in which to discover records about anything related to disability or not, and without mediation by an able-bodied and/or able-minded person, the presence of disability within archived materials is still limited either by the presumption of the medical model which focuses on responses to disability rather than lived experiences. There is a need to discuss the particulars of what constitutes the lived experiences of disability, such as differences in temporal relationships, due to the length of time it takes to carry out certain tasks and how factors such as fatigue can influence whether certain events even take place. Such factors, by their very nature, may not be recorded, because they do not figure in the lifeworld of the non-disabled researcher. Such omission can impact contemporary interactions with representations in and the utility of archival material concerning disability. The inaccessibility to both archival records and the spaces in which they are stored can lead disabled people to feel removed from their personal histories, making it vital that archival practice literature includes discussion on how barriers and bottlenecks to access of archival spaces actively prejudices archival content. The Living Archives Project, focusing on the lived experience of those who underwent sterilisation in the context of Canadian eugenics policy found that the ability of participants to share their stories and to create and edit the records was an empowering experience (Duff et al. 2019). This literature emphasises the importance of accessibility at all points of the archival experience.

Creating an accessible and representative archive requires a plethora of foresight; not least the necessary acknowledgment by creators of the parameters of inclusion and exclusion (Manoff 2004). This gatekeeping process must be handled delicately if the archive is not to perpetuate a cycle of publishing only the community's most prominent authors, while underrepresenting others (Shaw 2012; Ignatow and Robinson 2017). Any new archive must therefore be intersectional, interdisciplinary, and international.

Disabled people are not a homogenous group (Vernon 1999), they face privileges and oppressions related to their 'race, gender, trans/national location, age, sexuality, religion, class' (Goodley 2016, p. 44). Disability studies has been criticised for essentialising the implication that all disabled people experience the same disabling barriers, the same opinion on how those barriers should be removed, and the same general voice (Erevelles 2011; Goethals et al. 2015). To prevent this implication, an archive featuring disabled voices, and dealing with disabling barriers, must first acknowledge intersectionality, 'that people's identities and social positions are shaped by multiple factors' (Christoffersen 2017 p 1), and that these unique factors cause everyone to have different identities, lived experiences, and perspectives. Furthermore, the archive should encourage readers to become reflexive, 'acknowledging [their] own positionalities, experiences, roles, and political and theoretical frameworks' as they engage with other people's perspectives on such topics (Goethals et al. 2015, p 82). Acknowledging and practicing intersectionality requires, secondly, a commitment to an archive that is interdisciplinary.

The term 'interdisciplinary' is best defined as a 'division of intellectual labour, collaborative studies, [and] increased borrowing across disciplines' (Klein 1990, p 11). Notably, the process of being interdisciplinary creates essential tensions between convergent and divergent thinking (Kuhn 1977; Turner et al. 2015). Those navigating the interdisciplinary waters must ask themselves at what point do ideas meld together into one (convergence) and at what point do topics diverge into their own innovative categories (divergence)? As there is no concrete answer to this issue (Turner et al. 2015), interdisciplinary disability studies incorporate both materialist and non-materialist lenses across a variety of different topics, creating more opportunities for unique perspectives (Cheyne 2009). To combat this narrow focus, any new archive must include outreach to sources from different international perspectives. This need for connectivity between sources and institutions and an understanding of context to fully represent disability in the archive has been recognised in American Archival Science literature (Malley 2021). It calls for documentation strategies that focus on the creation of networks between archives and greater training for archivists to ensure that such representation is meaningful.

How can archives give voice to 'new generations' of the disabled people's movement?

In addition to considering representation of disability as a group of lived experiences in the archive, the KISI event explored the importance of archive in creating a sense of belonging and inclusion for new generations of the Disabled People's Movement in the UK. Among other disability specific archive projects, the ALLFIE (2023) has the inclusive education archive, but this is quite dated with the majority of contributors being from pre-1990s. The Greater Manchester Coalition of Disabled People's archive is highly focused on activism and gathering artefacts, rather than opinions on current issues. These contributions are more educative than problem-solving, and engagement with them may be contingent upon comfort around a certain model of disability identity, an identity that may not be broadly applicable to others and which leads to the 'other' being unheard and unrepresented in the debate space.

Griffiths's (2022) extensive work on disability youth activism has highlighted feelings of exclusion and difference that young disabled people feel when engaging with traditional activist groups, often due to a lack of familiarity or politics of the movement and feeling that their experiences are invalidated because they have not lived through the traditional struggle accomplished by the movement. Online spaces were highlighted as key aspect in enabling young people to participate in the movement (Griffiths 2022, p 10).

Social media is used by disabled people for community building, identity development, and activism (Shpigelman and Gill 2014; Cavalcante 2016; Miller 2017), it is also favoured by young people as an archival resource (Zhao et al. 2013). Social media has clearly allowed for an increase of self-expression and connection across the world, but this also places its own limits on archivists; the rest of this section will discuss ways in which social media both enables and inhibits the presence of disabled youth online through platform infrastructure and user interaction.

Social media enables disabled youth presence as it creates a common space for self-expression, documentation of current events, and connection to others (Velte 2018), combined with the availability of different forms of expression (audio, text, video). Ease of profile creation allows many users to personally archive their experiences and share them with others (Zhao et al. 2013). There are, however, limitations to social media's usability for community archives, such as a lack of searchability and consistent keywords for finding relevant information (Velte 2018). For archivists, there is an issue of legal access, as platforms often control the use of data and often only allow access to specific users (Velte 2018). Disabled people are often excluded from social media due to technical problems, including disorganised layouts and the inaccessibility of websites (Asuncion et al. 2012). Social media is also a space where personal biases can be reinforced, sometimes through hate speech and harassment (Bhatia 2020).

It would be beneficial for disabled people to craft their online archives in the following ways. First, such a space should allow for the centralised hosting of information that is searchable, organised, and allows for anonymous posting in a way that is not possible on social media (Velte 2018). This would allow the users to record their experiences without fear of harassment; the anonymity of contributors also assists archivists in mitigating the risk to the disabled community, specifically to activists who may face police violence if identified (Velte 2018). For this to occur, protocols need to be created to accommodate the archiving of intersectional experiences as well as ethical issues, such as the use of data (Velte 2018), by contributing both analogue and digital resources for archivists to encode and transfer into the digital space. An online archive could provide open and free access allowing for disabled people who are not connected to activism to share their experience and contribute to discussion.

Despite these positives, there is concern around the limited reach and exposure of a digital archive, which is where social media could work to broaden the visibility and reach of such projects. Bountouri and Giannakopoulos (2014) note how archives have found success in utilising social media to increase awareness and connections amongst communities and contributors. However, the place of social media data within the Archive space, both as an artefact and as means of accessing archive spaces, poses difficulties for archivists in terms of categorisation, preservation and access and this is relatively under explored and as such risks losing a rich seam of artefacts; therefore, it is vital that the sector works with stakeholders to ensure that institutions have polices and training in place to enable both archivists, archives, and contributors to make use of third-party platforms to increase representation (Acker and Kreisberg 2019, pp 106–107, 110).

The potential of online platforms more broadly for sharing experiences and engaging with policy makers in the context of disability is also underexplored in the UK. Liddiard et al. (2018) highlight the utility of the flexibility of the internet and digital methods to enable flexible participation amongst disabled young people. Others focus on non-language and traditionally non-academic means of expression, including the arts, which produce valuable methodologies and insights (Schuitema 2016; Liddiard et al. 2018), but these have been underutilised in social science and socio-legal research. Existing projects have focused on specific groups of disabled people as creators and partners in research, for example, the ‘Living Life to the Fullest’ focused on the experiences and voices of those with life-limiting or life-threatening impairments, with the researchers and participants all categorised as young adults (Liddiard et al. 2018).

Karian Schuitema has direct experience of setting up an online space showcasing the artwork of disabled children as part of her Leverhulme fellowship.

Arts Council England (ACE 2018) recognises the underrepresentation of disabled people and that this virtual exclusion produces a vicious cycle, with disabled people having little opportunity to take an active role in producing, creating and accessing cultural products, and representing themselves in mainstream media and culture, which in turn discourages others, specifically disabled children and young people, from participating in these sectors. The multifaceted means of expression within the arts and cultural sectors have the potential to assist disabled children and young people in communicating, making this lack of access even more perverse. Moreover, the cultural presence of disabled people can help to counter marginalisation and advocate for disability rights as well as offering a route to policy engagement.

There is a lack of research that actively includes the lived experience of disabled children on this topic. To respond to this, *Art* Research Together (ART! 2016) was established as an initiative that invites children to practice their right to expression and to share their views and opinions. In 2016, ART! ran a three-year project funded by the Leverhulme Trust to address underrepresentation in the cultural sector of the UK. Inviting children attending special schools to collaborate with artists and academics as well as their parents, carers, teaching staff, we aimed to understand how the child can be offered better cultural participation. As practice-based research the main aim was to develop knowledge by creating art that, in turn, aimed to add to the representation of disabled youth experiences.

In addition, semi-structured interviews were held with parents and teachers to contextualise the research. From these interviews two main themes came to the fore; parents and teachers mentioned that they often felt that cultural activities and spaces were inaccessible because there was not enough support and information to make them feel welcome and confident about suitability. The second theme was that parents and carers felt that it was important that children saw themselves represented in cultural products and spaces. Children were also invited to share their ideas about the creative activities they engaged with and asked what else they may like to do. Here we found that children mainly asked for more opportunities to participate in a range of different art forms; they also often expressed a desire to share their work with others online, on television, and as street performers.

To share the children's work, we created a website that aimed to be accessible for the children and the adults who collaborated in the project (ART! 2016). At the same time, to attract other people, young and old, who may be interested in seeing the art created or learning from the creative process. Building the website had many challenges: for example, it aimed to be accessible and of interest for all ages and include non-verbal contributions. It achieved this by layering the content in the sense that minimal text with images comes first and the text written for adults appears later. The site features paintings, music, films, puppetry and children's drawings, and the text for children can be heard by clicking a button in the shape of an ear. Without a large budget to develop this content, many hours were invested in finding creative ways of improving accessibility.

The biggest challenge however was not related to the creation of content, rather it was the difficulty in ensuring that children could access and contribute to the site when their internet use was mediated by adults, and in the competition of the artistic content with online sources, such as games and popular videos. We found that the promotion of the site, as well as the development of new content and engagement with new audiences, was essential to the aim of contributing to disability representation. To break the cycle of underrepresentation, highlighting stories from disabled people is not enough. Ensuring that these stories, views, and experiences are listened to and taken seriously is also paramount. For online platforms to develop the potential to advocate for children's rights, a close and continuous engagement with targeted audiences should be considered. Whether these target audiences are children, their parents/carers, teachers, health professionals, therapists, academics, politicians, or policy makers, it is important that their active involvement is invited and that their collective knowledge is used.

How do we balance conceptions of vulnerability while avoiding paternalism to champion representation?

Archives preserving and archivists handling sensitive data need to have an awareness of their duties and responsibilities in the context the legal threshold around disclosure of personal and private information required by the General Data Protection Regulation (GDPR) as implemented by the Data Protection Act 2018, in the UK. Archivists should receive training in safeguarding to assist them in identifying material which may qualify for disclosure in the context of vulnerable adults and children and be versed in the referral making process. The safeguarding element should also be clearly explained in documents and policies relating to deposit and retrieval of data so that both subjects and researchers are aware of their responsibilities when accessing and giving data. Care should be taken in the drafting of these policies so that these guidelines do not deter people from depositing or using data. Archival Science and archival studies should avoid an overly cautious or paternalistic approach to safeguarding, as this may lead to the inadvertent exclusion of the experiences of those who have historically been assumed to lack capacity and have been subject to both social and legal oppression, namely intellectually disabled people. Historically, they have been considered to lack the ability to make decisions about their own lives; decisions have been made by others on their behalf. the Convention on the Rights of People with Disabilities has prompted an impetus for a shift in such socio-legal approaches to intellectual disability (CRPD 2021), by detaching 'mental capacity' (decision-making skills of a person) from 'legal capacity' (the formal ability to hold and to exercise rights and duties), Article 12 of the CRPD invites us to recognise the legal capacity of intellectually disabled people 'on an equal basis with others in all aspects of life', moving away from substituted decision-making regimes towards providing them 'the support they may require in exercising their legal capacity'.

The notion of universal legal capacity, as embedded in the CRPD, has highlighted the need to address the gaps and tensions between the CRPD and domestic legal regulations (Dhanda 2006–7; Flynn and Arstein-Kerslake 2014). However, research in this area does not traditionally engage with the lived experience of intellectually disabled people (Harding and Taşcıoğlu 2018; Flynn et al. 2019). Consequently, we know little about the everyday experiences of intellectually disabled people, and the effect that capacity laws have on their lives. A digital disability archive could lie in this intersection of legal regulation and social life, as co-constituting each other (Ewick and Silbey 1998). Rather than starting with paternalistic assumptions that might limit intellectually disabled people's participation and access to archives, we must ask: 'What are the socio-legal barriers that prevent intellectually disabled people from engaging with archives and how might they be supported?' and 'What are the challenges and possibilities of archives for intellectually disabled people and the realisation of their human rights?'.

In England and Wales, the limits of legally recognised decision-making by intellectually disabled people are drawn by the Mental Capacity Act (MCA 2005). The MCA includes a safeguarding element in research participation of legally incapacitated adults, s. 30–34. In two recent judgments (England and Wales Court of Protection Decisions 2 2019; England and Wales Court of Protection Decisions 3 2019), the Court of Protection detailed the MCA's application for decisions made on internet use by, and with, intellectually disabled people. In the case of A, who was found by the Court to lack the capacity to decide on internet and social media use, an 'internet access and safety' plan was devised as a 'best interests' decision to provide for A's use of a device with internet access for a limited period each day, and under a degree of supervision by care staff.

Such decisions could exclude intellectually disabled people from engaging with an online digital archive space, thus supporting Harrison's assertion that there is a need to consider multiformat engagement and participation. How can we open up a space under the current legal frameworks, to which people on the margins of capacity can contribute to on an equal basis with others? The potential of a digital disability archive lies in the alternative that it represents to formal 'institutional' archives, by providing a corrective to intellectually disabled people's marginalisation, opening up a space for conversations that are embedded in the real lives of intellectually disabled people, rather than in the formal avenues of law, to mobilise new expressions and understandings of intellectual disability. A digital archive based on challenging rather than reproducing the invisibility of intellectually disabled people in law and society, can help us build a regulatory framework that ensures their equal enjoyment of rights, elucidating the moments and spaces of their lived experience in its ordinariness and potentials, removing the medicalised and translated narratives of literatures past.

Consequently, it is vital that archivists and researchers have a full understanding of the purpose and limits of safeguarding policy. In terms of guidance around the deposit around information, policy documents and procedures should accommodate the exercise of supported rather than proxy decision-making. Therefore, these documents should be drafted in such a way that allows for supported decision-making processes to be followed and recorded. Additionally, documents should also provide space for the role of any support workers in data retrieval or submission to be acknowledged. Regarding the use of data by researchers, particularly in the context of exhibition or publication, policy documents should inform both data subjects and data users about their responsibilities around sensitive or medical information. Though these procedures are well established in the field this article seeks to underline that the specific nature of disability means that engagement with these issues goes beyond standard legal and policy approaches to embrace a social and human rights understanding of disability which requires knowledge and awareness of the needs of data subjects and researchers with disabilities when drafting and implementing policies.

Design elements should be kept to a minimum to stop them detracting from the information. These aims can be achieved by taking additional care terms of disclosure in terms of exhibition, reproduction, and publication of archival material for research purposes. Policies should specifically consider the needs of people with intellectual disabilities and the information around these policies should be written in clear plain language. Easy Read formats should also be made available to contributors for archival materials with disabilities.

This aims need to be supported by accessible data gathering and maintenance policies need to sit alongside strategies and policies which move beyond the focus on accessibility within both the archive as repository and records to focusing on how to increase the engagement of disabled people in contributing to materials archived and raising awareness of these materials for researchers and appraisal by archivists.

Conclusion

We hope that by giving insight into the Perspective Collective scoping event and the questions raised, that readers will appreciate that archives both sources of research and as repositories of experience can play a significant role in the liberation and inclusion of disabled people beyond traditional images of illness, frailty, and dependence, to the full participants in social and policy discourse, as per the human rights construction of disability. This is crucial in ensuring that the disability rights movement continues to raise awareness of the barriers facing disabled people. To achieve this, the evolution of the priorities of the movement needs to be recognised and valued and archives play a role in legitimising new voices by deeming their input worthy of preservation. To do this, however, the sector must have a full understanding of how policies and practices can either include or exclude disabled people and how they might address these issues. Though the literature is emerging it is patchy in coverage in terms of individual projects or cultural approaches. The literature also needs to move from understanding disability in relation to archives, to an understanding of disability as a concept and a community, to ensure that archival representations and management policies reflect the multifaceted needs of various disabled people in terms of contributing to and accessing archives to ensure full representation and inclusion. We hope that we, as disability scholars, have helped to make these issues clearer and to suggest changes to future practice.

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