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Antonia's story: Bringing the past into the future

Owen Barden[1] | Steven J. Walden[2] | Nicole Bird[3] | Stella Cairns[4] |
Rhiannon Currie[3] | Lynne Evans[3] | Stephen Jackson[4] | Emily Oldnall[4] |
Sarah Oldnall[4] | Dawn Price[3] | Tricia Robinson[3] | Amber Tahir[4] |
Christine Wright[4] | Claire Wright[4]

[1]School of Social Sciences, Liverpool Hope University, Liverpool, UK

[2]University of South Wales, Pontypridd, UK

[3]TRAC

[4]The Brain Charity

Correspondence
Owen Barden, School of Social Sciences, Liverpool Hope University, Hope Park, Liverpool L16 9JD, UK.
Email: bardeno@hope.ac.uk

Abstract

Background: This paper reports on a participatory project on the history of learning disability. The paper makes contributions to discourses on using participatory research methods with people labelled with learning disabilities, on the nature of research impact in participatory research, and on the lived experience of learning disability today.

Methods: We used a two-step methodology. The first step involved searching for and selecting archive material relating to the history of learning disability. The second step involved a series of participatory workshops. We worked collectively to systematically analyse the case history of Antonia Grandoni. Then we responded to it in a variety of creative ways. In doing so, we made connections between Antonia's life and our own.

Findings: Many of Antonia's experiences seem very similar to what people labelled with learning disabilities often encounter today. These include discrimination, segregation and dehumanisation. Despite this, we very much enjoyed doing the research. As well as finding out about the history, some of us learned new skills, some of us grew in confidence, and we also made new friends.

Conclusions: Participatory methods are an effective way of making digital archive material more accessible to people labelled with learning disabilities. In this project, using participatory methods revealed a lot of parallels between how we think somebody experienced learning disability in the mid-19th century, and how it is experienced today. They also resulted in significant impact on the people doing the research.

KEYWORDS
disability politics, history of learning disability, learning (intellectual) disabilities, research

Accessible summary

- This is a paper about how we researched learning disability history together.
- We used material in a digital archive as well as creative methods to do our research.
- Working this way helped us learn about ourselves, and each other's experiences of learning disability, whilst we learned about the history.

- This is important because people with learning disabilities have not often been able to do historical research.
- Research like this matters because doing it teaches us useful skills and can be empowering.

1 | INTRODUCTION

This is a paper about how we researched the history of learning disability together. "We" are two teams of researchers who worked on a project called "Inside the History of Learning Disability". One team was based at The Brain Charity, in Liverpool. The other team came from the Teaching and Research Advisory Committee (TRAC) at the University of South Wales. The teams were made up of people with learning disabilities, their families and advocates, and academics. One academic worked with the Liverpool team (Owen), and one with the TRAC team (Steve). We used material from a digital archive to examine the history of institutionalisation of people labelled with learning disabilities. We focused on the life history of one person. She was called Antonia Grandoni, and lived between 1830 and 1872. She spent a lot of her life in an institution because she was diagnosed as an "idiot". We used creative methods as well as talking a lot about what we found to express what we felt about Antonia, her life, and the way she was treated. This helped us make sense of our own experiences of learning disability, and to learn about each other's experiences. One of us—DY[1]—summed this up very neatly: *bringing the past into the future*.

This project is important because people with learning disabilities have not often been able to do research about the history of learning disability. Historical research has tended to be done by historians and other academics like sociologists. Research about learning disability has tended to be done by doctors and other people in the medical professions, like psychologists. This means that people with learning disabilities have been excluded from learning disability history research in three ways. First, because they are not involved in producing research, they are excluded from writing about history. Their stories are not valued or listened to. Second, prejudice going back centuries means that disabled people—especially those we would now call people with learning disabilities—are often absent from official historical records. They are simply missed out because other people thought they weren't important (Brownlee-Chapman et al., 2018). Third, archives tend to be difficult to access. There are usually many barriers. For example, many historical records are still only available in their original paper physical form. This means travelling to where they are kept to see them, which can be difficult. Confidentiality rules can also prevent access to things like hospital and asylum patient records. Old-fashioned language and handwriting can make historical material difficult to understand. Archivists and other guardians of historical

materials can also be very protective of them. This is understandable, because they can often be sensitive, rare and fragile, but it does present a barrier to accessing the material. However, the recent trend towards digitising archive materials is helping to remove some of these barriers. The article begins by outlining recent improvements to archive access before describing our method, presenting our analysis of the archive material and considering the nature of the project's impact.

2 | IMPROVING ARCHIVE ACCESS

From the 1980s, there was a shift in museums towards realising that the context of a cultural artefact was more important than the artefact itself (Styliani et al., 2009). That is to say that understanding where and when an object comes from, why it was made and what purpose it served, is more important than the object itself. How an object is displayed in relation to this context also influences what sense the audience makes of it. Since this realisation, there has been increasing emphasis in the heritage sector on making known the context of artefacts and collections, to make their significance and relevance to audiences more obvious. In addition, changes in society, including moves towards embracing or at least acknowledging social inclusion agendas, alongside legislation—most notably the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), Disability Discrimination Act (Disability Discrimination Act, 1995) and Equality Act (2010) in the United Kingdom—have encouraged the cultural and heritage sectors to re-evaluate their relationships with, and responsibilities towards, disabled people (Waddington, 2004). As a result, some archivists have started to think more seriously about improving access to archives. Some academics have lamented the widening of access and democratisation of archival research, and in doing so revealed ableist prejudices (Mortimer, 2002). Similarly, professional attitudes can also present barriers to access. The Research Centre for Museums and Galleries (RCMG, 2004) argue that despite the burgeoning popularity of archives in recent decades, the archive domain presents particular challenges to developing capacity in relation to access and learning. They put forward a number of reasons for this, including:

- archivists' lack of understanding of the nature of learning;
- archivists' lack of understanding of the role of archives role in peoples' learning experiences;
- archivists not valuing accessible learning; seeing it as a threat to workloads and the traditional functions of archives (preservation and supporting scholarly research);

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[1]Initials are used to preserve anonymity.

- archives not operating in line with modern policy objectives such as social inclusion, cultural diversity and lifelong learning.

It appears that disabled people have been treated as "justifiably excludable" by archives (Titchkosky, 2011 p. 78). However, RCMG go on to argue that a contemporary vision for archives must be developed—one which is focused on providing accessible learning to diverse users (2004, p. 23):

> ...just as for museums and galleries, the collection function is never complete...archives must develop strategic responses in which the requirements to preserve the historical record must be balanced with the overwhelming benefits of increased access.

Happily, some archivists do recognise that diverse interpretations can add relevance and richness to that which is exhibited, and be a catalyst for community-led action and change (Gee, 2002; Graham, 2016, 2019). In addition to these shifts in attitude, the digitisation of archive material is also improving access. Digitisation involves processes like taking very high-quality photographs of artefacts. In the case of printed archive material, these photographs can have Optical Character Recognition,[2] meaning computers can recognise what has been written. This is important because it enables at least two other things to happen, both of which improve accessibility. First, printed material can be reliably translated into another format. For example, from a book to a word-processed document whose properties can be changed to make it more accessible. Second, the material can be automatically tagged by computer programmes so it can be sorted, classified, cross-referenced and so searched for more easily. This makes it easier for researchers to find what they want. Such technology also opens up a third possibility, which has potential but does not seem to have been widely adopted yet: collaborative cataloguing and tagging of archive material (Newman, 2012). This means that rather than archivists making all the decisions about what to catalogue and how to categorise it, different interested parties can contribute to the process of contextualising the artefacts and records. For example, people with learning disabilities could help to contextualise material about the history of learning disability. This is not just about doing research inclusively; it fits with the broader trend towards acknowledging the importance of the context of objects, and so is about creating better histories.

3 | METHOD

This project sought to use the digitised UK Medical Heritage Library Corpus (UKMHL) to generate new knowledge about the history of learning disability in the United Kingdom. Using the UKMHL archive

was a condition of the grant which funded the project. The questions we addressed were:

1. What does material in the UKMHL reveal about the construction of "Learning Difficulties" in the 19th Century?
2. What can perspectives of learning-disabled people bring to our understanding of material in UKMHL archive relating to learning disability?
3. How can appreciation of a variety of perspectives on the archive material enrich our understanding of the lived experience of learning disability today?

We used a two-step methodology. The first step was only done by one of the academics, Owen. This was because it involved working with archive material which, despite being digitised, had very limited accessibility. The second step involved everybody, working in the two teams with archive material. We now outline each step. A full account of the methodology can be found in another paper (Barden, 2021). This section finishes by considering how this approach relates to "impact." By "impact," we mean the changes research produces in the real world.

3.1 | Step 1: Archival research

The UKMHL is a huge collection of over 66,000 19th-Century history-of-medicine texts. It has full colour images, pdf downloads, and Optical Character Recognition. It is the result of a collaboration between Jisc, the Internet Archive, the Wellcome Library and nine other medical and university libraries. It is a very important historical resource. However, it is not particularly accessible, even for skilled researchers. First, the sheer number of available texts can be overwhelming. Second, the resource has been set up with medical historians in mind, and is organised accordingly. For instance, when entering the archive you are invited to search either by Body Parts or Medical Conditions. Third, much of the language is both old fashioned and very technical. Using modern search terms such as "learning disability" does not yield very helpful results, instead generating a huge list of texts mentioning the word "learning." It is better to use the old diagnostic labels like "idiot" or "imbecile", but even after extensive filtering a researcher is still faced with thousands of texts to choose from. Owen therefore used his research skills and knowledge of learning disability terminology to find and select a text. The book chosen was *On Idiocy and Imbecility*, written by Dr William Ireland and published in 1877 (Ireland, 1877). At the time, Ireland was Medical Superintendent of the Scottish National Institution for the Education of Imbecile Children at Larbert, Stirlingshire. He had already published a number of books on history, psychology and idiocy, and was sufficiently well-regarded to have an obituary in *The Lancet*. The copy of *On Idiocy and Imbecility* in the archive came from the collection of Professor George M. Robinson, who introduced asylums to Scotland in the 1890s and went on to become Medical Superintendent at Larbert in 1904. He was also 1922 President of the Medico-Psychological Association, a forerunner of the Royal College of Psychiatrists. The book can thus been seen to be

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[2]Hand-written documents still present a significant challenge for OCR, although a platform for these is being trialled by the National Archives: https://blog.nationalarchives.gov.uk/machines-reading-the-archive-handwritten-text-recognition-software/
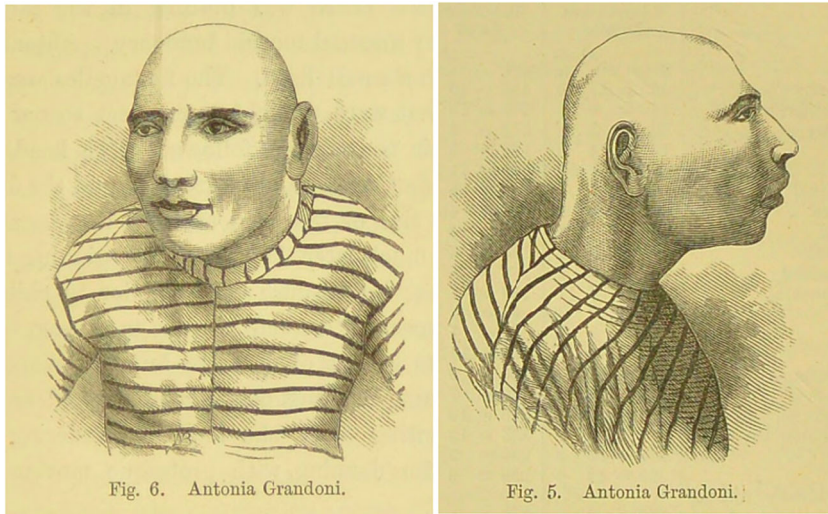
FIGURE 1 Portraits of Antonia Grandoni from Ireland's (1877) "On Idiocy and Imbecility" [Color figure can be viewed at wileyonlinelibrary.com]

written for gentlemen-scholars of the time. It contains Antonia Grandoni's case history. There is a descriptive account, two pencil portraits (Figure 1), and tables of her anatomical measurements. The history has been pieced together from the reports of doctors from Milan, where she lived with her family before being institutionalised in a hospital for an undisclosed period up until her death from septicaemia in 1872, at the age of 42. Antonia was diagnosed as being a "microcephalic idiot," and appears in a chapter dedicated to that topic. *Microcephaly* refers to having an exceptionally small head. Apart from this diagnosis, the justification for her institutionalisation appears to relate to notions of risk and control (Barden & Walden, 2021):

> For many years she led a wandering life, an object of curiosity, of pity, or of ridicule to all. At last she was removed to the hospital where she died (Ireland, 1877, p. 106).

The various elements of her case history made it ripe for analysis, yet Antonia's perspective and voice are missing, as are many details of her life. This is why it was chosen for the second, participatory step, which would aim to rediscover and re-interpret Antonia's story for the present day (Hayward, 2017).

3.2 | Step 2: Participatory workshops

The Liverpool team and the TRAC team each ran a series of four 2-hour participatory workshops. Ten to twelve people attended each workshop. There was a mixture of people with learning disabilities and their advocates and support workers, plus one academic per group. The aim of these workshops was to analyse Antonia's story, with a view to understanding attitudes towards learning disability in her own lifetime, and to relate her life to the lived experience of learning disability today. In the early workshops, the teams focused on analysing and interpreting Antonia's case history. We used an easy-read version of Dr Ireland's account, and the two portraits.

Working systematically, paragraph-by-paragraph, we used three prompts to guide the analysis and interpretation:

1. How is Antonia described?
2. What does the description make her sound like?
3. How does it make you feel?

These simple prompts were enough to generate many filled pages of flip-chart paper and many hours of discussion. We made audio recordings of these discussions for subsequent analysis. After analysing Antonia's story, we moved to more creative methods to respond to her story and make connections to the lived experience of disability today. Both teams were facilitated in this by graphic illustrators. The Liverpool team used collaging (Figure 2).

The TRAC team worked with Rhondda Cynon Taf People First's professional illustrator Stacey Harding, who illustrated their ideas in poster form in a dialogue with them. The use of creative methods like these has been recognised as a good way of doing research inclusively by a number of researchers (Atkins & Duckworth, 2018; Grove, 2017; Hayward, 2017; Marshall, 2017; Masters et al., 2018; Stubbs, 2017). For example, Clarke (2019) argues that arts-based methods within participatory approaches enable research to be made accessible and emotional, prompting thinking about complex issues, opening up new ways of seeing, broadening understanding and highlighting issues of social injustice. Similarly, Burch (2021) used artistic methods in participatory research as a way of supporting explorations and shared understandings of disability hate crime. In our project, the production of these artworks prompted a good deal more discussion (again, recorded), adding extra layers to the interpretation of Antonia's story, as well as acting as a catalyst for discussions about our own experiences of learning disability. In this way, we learnt a lot about ourselves and about each other. In fact, these discussions resulted in some of the most significant project impacts.
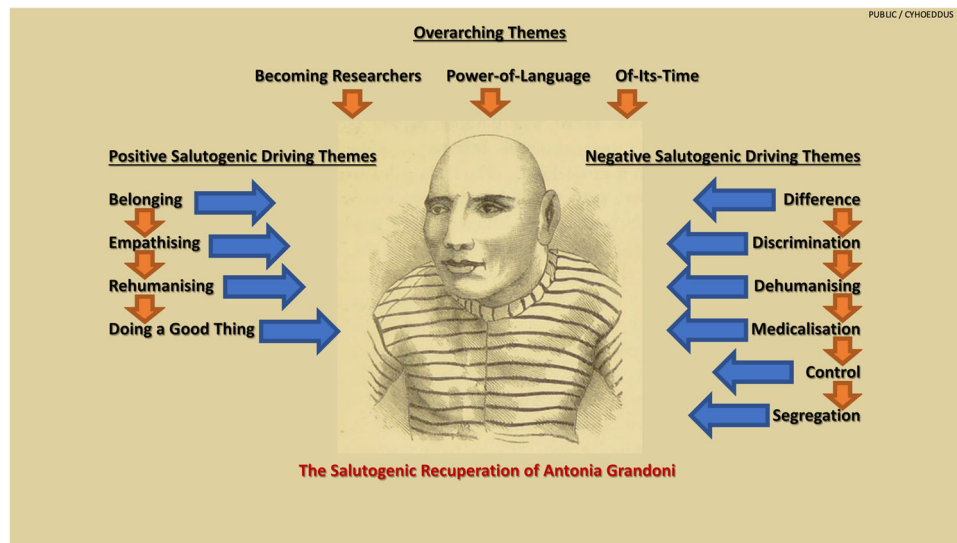
FIGURE 2 Collage by members of The Brain Charity Team [Color figure can be viewed at wileyonlinelibrary.com]

3.3 | Data analysis method

We then undertook a five-step analysis of our data. Owen and Steve conducted the technical analysis in the first four steps, and the fifth step involved everybody discussing and feeding back on that analysis. Firstly, an inductive thematic analysis was conducted on the transcripts of the sessions, as well as the artworks produced during them, using NVivo 12. Thematic analysis is a method for identifying, analysing and reporting patterns—often themes or concepts—within data (Braun & Clarke, 2006). It allows researchers to efficiently organise their data set and to describe it in detail, through ongoing reflexive interaction with the data. At this point we got feedback from our teams via Zoom meetings, and they agreed that the themes were appropriate. Our second step was framework synthesis, whereby the data is brought together in a framework according to commonalities and differences. This helps develop descriptions and explanations of the themes constructed from the data (Carroll et al., 2011; Houghton et al., 2017; Ward et al., 2013). Our framework was built by allowing participants' experiential knowledge of the topics discussed to guide and structure the synthesis. As additional concepts emerged during synthesis that did not initially match our existing themes, thematic synthesis was

undertaken as the third step to build on to the existing framework so that all the data was accounted for in the analysis. In the fourth step, C- and K- means cluster analyses were conducted using NCSS software to establish statistical relationships between different elements of the data set. This helped us confirm how the themes related to each other, and also where similarities and differences existed in the two teams' interpretations of Antonia's story. Finally, we all met on Zoom to talk about how we had analysed the data, what that analysis seemed to say, and how to write about it in this paper.

3.4 | Pathways to impact

By impact, we mean the real-world changes that result from our research. Different people think impact is important for different reasons. Unfortunately, in the UK context in which we work, research evaluators, funders, and the government—who have a great deal of influence—have tended to take quite a narrow view of what counts as impact, emphasising things like economic benefits derived from research. For example, the development of new products. Assessment of impact has focused on what can easily be measured, such as income generated or public audience reached. This narrow view has been problematic for participatory research, where the impacts are unlikely to be economic or far-reaching. Instead, the impact is likely to be directly on the people doing the research, and happen whilst they are doing it—for example, developing new skills, learning, and growing in confidence. In participatory research, impact is part of the research process itself, rather than something that comes afterwards. In this way, impact is something that is co-produced, rather than something academic researchers "have" on other people; academic researchers' intellectual endeavours are also positively impacted as they encounter insider knowledges and perspectives (Pain et al., 2016). Thankfully, the UK Research Excellence Framework does now go some way to recognising more diverse forms impact such as capacity-building and enhancing individuals' learning, participation or quality of life. Knowledge-exchange—such as that facilitated between ourselves, Jisc and other professional bodies in this project—is also being recognised as a kind of impact. Both "reach" and "significance" are aspects of impact. *Reach* refers to the number and range of people impacted; *significance* refers to the importance or depth of that impact. Participatory projects like this one may therefore have very modest reach but major significance for participants. The nature and extent of the impact on team members is explored more fully below in the next two sections of this article. Our methods—recorded conversations and making artworks—helped us capture much of this impact.

4 | FINDINGS

Our analysis revealed that although there were variations, there was a considerable degree of consistency between the two teams. They responded to Antonia's story in very similar ways, and they had had

FIGURE 3 Themes relating to the salutogenic need to recuperate Antonia [Color figure can be viewed at wileyonlinelibrary.com]

similar experiences to each other in their own lives. This is significant because the two teams worked completely independently: neither knew what the other was doing or saying. So, the high degree of similarity between them lends credence to our thematic analysis (Kuo et al., 2018; Prevett et al., 2020). Thirteen themes were identified in the data set. They can be organised into Overarching themes, Positive Salutogenic Driving Themes and Negative Salutogenic Driving Themes (Figure 3). By *salutogenic* we mean things which influence the well-being of people labelled with learning disabilities. Positive drivers enhance well-being; negative drivers are detrimental. *Salutogenic* thus refers to the way our research participants had an empathic desire to do something good for Antonia, or prevent something bad from happening to her if it had been in their power to do so, and this desire was driven by their own similar lived experiences of having a learning disability.

4.1 | Overarching themes

The first theme to emerge was that of *Becoming Researchers*. This theme was about the process of becoming researchers; harnessing curiosity and an inquisitive disposition; learning about and doing processes and methods (some of which might be considered somewhat unorthodox), and, perhaps most importantly, making change happen. This change was felt internally through a developing sense of learning and ability to change things, and expressed externally through recognising Antonia's dehumanising experiences and then working salutogenically and creatively to address our collective need to rehumanise her. This need was expressed through visual arts, poetry and declarations of love and affection, our website, social media, conference papers and conversations with each other, friends and family. The process of becoming researchers foregrounded recognition that Antonia's

representation and treatment by others was of its time, and yet unsatisfactory and warranting intervention to make her more whole and human. The recognition resonated with participants' own lived experiences of learning disability.

We called the second theme, which pervaded almost all of the discussions, *Power of Language*. This theme recognises that choice of words matters: a word that might be right in one context might well not be right in another, and ultimately that treating people with respect includes being careful about how we talk about them. Diagnostic terms that were commonly used in Antonia's time such as *idiot* or *imbecile* are today regarded as terms of abuse that many of us had encountered, so discussing them engendered varying degrees of discomfort. These derogatory connotations of the term "idiot" came to prominence in the 19th century (Jarrett, 2020)—that is, during Antonia's lifetime. The key discourse that arose related to this theme pertained to labelling. Labels are widely regarded as problematic: they may be necessary to access support, but do not foreground the bearer's strengths and capabilities (Rix, 2006; Strnadová & Walmsley, 2018). The point was raised in our discussions that there is a case for moving beyond such labels and indeed social constructs, to the point where a person is recognised for their capabilities and given support when needed without judgement by society (Klotz, 2004).

The final overarching theme *Of Its Time* was about recognising the socio-historical-cultural nature of Antonia's representation and treatment (Barden & Walden, 2021). There were aspects of Antonia's life, particularly discrimination, social isolation, and institutionalisation that could be argued to belong to her epoch. Parmenter (2001) explains how the institutions of Europe built to "other" and contain people with learning disabilities grew from the wards of similar institutions housing people living with mental health disorders. People with intellectual disabilities were segregated within the *back wards* of sprawling, gothically-styled hospitals of the period; hence the origin of the derogatory term *backwards* (Ferguson, 2014). It was only

toward the end of the nineteenth century in Italy, where Antonia lived, that a more benevolent, if still patriarchal and certainly clinically positivist, attitudinal shift became apparent, largely due to the seminal, humanistic influence of French physician Edouard Seguin across Europe and America.

To segue to the present day, the current neoliberal context continues to foreground risk as an overarching principle informing social responses to people with learning disabilities. A paradox is evident in dependency on commercial services which claim to promote choice yet in many ways limit the choices available (Dowse et al., 2009). The overt segregation that Antonia was subjected to is thus replaced by a more nebulous, covert segregation for her modern-day counterparts predicated on disability as commodity (Brown et al., 2017; Care Quality Commission, 2020). In short, not as much has changed in 180 years as we might have hoped; many of the facets of Antonia's life resonated with our lives, and continue to be part of them. Here is AA, who has a diagnosis of Asperger's syndrome and a visual impairment, discussing his understanding of research in the first Brain Charity workshop. The quote encapsulates much of these overarching themes:

> Yeah, it's all based about comparative stuff, so you would have to look at what was perceived as the norm at that time to actually compare why are certain people being measured and examined, like you've said, like lab rats, and I guess the other thing is we are doing a project about the history of learning disability, so I guess you start looking at things critically and start, you tend to make that assumption that a lot of the things that we are going to be looking at over the next four sessions probably do have a learning disability, so we have, we've come equipped with that knowledge, so I think it's hard to kind of unlearn what's been said [about learning disability].

In the discussion on project impact that finishes this section, we explore the consequences of this process of becoming researchers through engaging with archive material about learning disability.

4.2 | Positive salutogenic drivers

Rehumanising arose as a theme, with participants recognising and appreciating Antonia as a person, as a woman, as someone who could love and should be loved. A distinction emerged which rendered this theme in stark relief (Gallagher, 2002; Ilyes, 2020; Walmsley & Jarrett, 2019). Several older team members had, like Antonia, had been denied intimate relationships. Younger members had not experienced institutionalisation and had rightly normalised their experiences of being in long term relationships. Rehumanisation became not just about amending Antonia's representation in the archive; it was about addressing a salutogenic desire to bring her back to life, welcome her into the group, make her one of us and part of

our lives, and give her opportunities to do the things she loved. For example, both groups independently expressed a desire to go out dancing with Antonia, as this excerpt from the second TRAC workshop illustrates:

> SW: [Reading Antonia's case history] "She was fond of learning amorous poetry." Now what amorous means is she was fond of learning poetry about love. So there might be some of you who like watching Love Island...
>
> <Group either love or hate this show, and mention other TV shows>
>
> SW: So we could maybe talk about that when we talk about this paragraph... and she showed erotic tendencies.
>
> JJ: What does that mean?
>
> SW: Erotic tendencies means she was aware of her sex and sexuality.
>
> JJ: What, men?
>
> LL: She might've wanted a kiss and a cuddle. She might've wanted a boyfriend. She might've wanted a girlfriend.
>
> JJ: The boys picked on her and so did the girls, so a bit of a problem then
>
> SW: Maybe, we'll have to see how we go with a bit more of the paragraph. We'll have to discuss the possibility.... on getting older she took to wandering about and she might be seen dancing grotesque movements to her own singing.
>
> JJ: What does grotesque mean?
>
> SW: Strange, different. So there might be something we need to think about there.
>
> JJ: I like dancing down to the bus stop
>
> [...]
>
> JJ: Who says her movements were grotesque?
>
> SW: The doctors. That's what we need to look at.[...] So how many of you enjoy dancing?
>
> RR & KK: Yes
>
> BB, LL: When I'm out for a few drinks, yeah
>
> SW: Any more of you?

Several: Yes; yes, I do; yes

WW: No

SW: So, you all like dancing, some of you like dancing a bit more when you've had a couple?

KK: Especially DW

<group laughs>

SW: Is this something you've all got in common with Antonia, you've all enjoyed dancing at one point or another? You enjoy dancing don't you RR, when we get tighter you take your wheel up?

RR: "Yeah"

This linked closely to the theme of *Belonging*. Both the Brain Charity and TRAC teams expressed a feeling of belonging to the research group, to family, to the Brain Charity or TRAC and to the learning disabilities community more broadly. This theme acknowledged the researchers' need to see Antonia as "one of us," linking it closely to Rehumanisation theme and other salutogenic drivers born of mirrored experiences, empathy and members' own need to belong (Hall, 2010; Lindström & Eriksson, 2010). Unlike Segregation and Discrimination, *Belonging* was perceived by both groups as always good. The theme of *Doing A Good Thing* bridged *Rehumanising* and *Empathising*. It encompassed recognising and supporting need because that was the right thing to do, and was exemplified by an example given by one coresearcher who described a bus driver who stopped to help her friend when she had a seizure. The theme of *Empathising* is derived from the same desire for a better life for Antonia, drawn from learning-disabled researchers' appreciation of the significance of her experiences and their resonance with lived experiences of prejudicial attitudes, low expectations, fewer opportunities and direct discrimination. The phrase "you can't, because…" was commonly encountered by both the Brain Charity and TRAC teams in various aspects of their daily lives where they were denied inclusivity, belonging, and in some instances, their legal rights because of assumptions made by others. These forms of othering would have been just as familiar to Antonia (Ali et al., 2012; Jahoda & Markova, 2004).

4.3 | Negative salutogenic drivers

Our analysis also produced a set of themes with more negative connotations for people with learning disabilities. We called these negative salutogenic drivers. The first of these is *Difference*. This theme concerns the ways Antonia was made to be or seem different, and about the ways differences associated with learning disabilities are experienced and perceived. The convivial encounters of the research sessions promoted camaraderie through shared identity and belonging,

yet were couched in terms of resilience toward shared experiences of othering in wider society (Gappmayer, 2020). Many learning-disabled team members had been subjected to name-calling and other forms of overt bullying alongside more covert othering, masked by supposedly good intentions that still manifested as experiences of being patronised, infantilised, and devalued. This theme is closely linked to *Medicalisation*. Medicalisation as a phenomenon emerged in Antonia's lifetime, and she was represented in some sections of Ireland's book as a synthesis of her diagnoses (Carter, 2017; Vehmas, 1999). Learning-disabled team members shared stories of being viewed similarly: of needing to have a diagnostic label to access services, instead of being seen as a person deserving of help just for being human; and of being over-medicated and even sedated, instead of being communicated with and having underlying emotional and physiological needs supported from a more holistic and humanistic frame of reference. This brings us to the theme of *Control*. When younger, Antonia seemed to have been controlled through her family's adherence to Catholicism, with piety also demanded by the institutions of the medico-legal patriarchy that claimed her as an inmate in her later life. She was viewed as less than fully human, and thus denied sexual identity, intimacy and agency. This was a theme that resonated strongly with many team members, who had experienced similar contemporary encounters. SA likened these institutional representatives to sharks who encircle and threaten Antonia and people with learning disabilities, and vultures wanting to pick them off for purposes of normalisation or career advancement (Figure 4). One of the key positive salutogenic drivers to the desire to recuperate Antonia was a resistance to such dehumanisation through self-advocacy.

The theme of *Dehumanisation* was born from the multiple ways Antonia was dehumanised in her lifetime and subsequent representation in Ireland's book (and therefore the archive). It was also about the ways people with learning are still dehumanised, particularly by the medical professions who attend to the label/diagnosis more so than the person, and through ongoing institutionalisation and coercive control. Such experiences ranged from being allocated a number instead of being allowed to label one's school clothes with a name, to supposedly having freedom of choice in staffed adult group accommodation yet having to conform to set bedtimes and regimented activities (see Barden & Walden (2021) for a detailed exploration of this issue). The theme of dehumanisation is beautifully illustrated by Figure 5, from the TRAC group.

Dehumanisation brings us to the theme linked most closely to it, *Discrimination*. This theme reflected Antonia's lack of voice. Both teams noted that in Ireland's book there was scant evidence of anyone talking to Antonia, other than to administer tests or instruction. This was an experience that resonated acutely with many of the co-researchers; if you have a learning disability, you often go unheard, even as we approach the end of the first quarter of the 21st century. The brings us to the second facet of this theme: that attitudes and practices have not really changed, even though we supposedly live in more enlightened times (Pelleboer-Gunnink et al., 2017). Voice, identity, autonomy, and selfhood

FIGURE 4 A detail from a Brain Charity collage about Antonia, showing the "sharks" surrounding her [Color figure can be viewed at wileyonlinelibrary.com]

FIGURE 5 The dehumanisation of Antonia Grandoni (Courtesy of Stacey Harding Illustrations) [Color figure can be viewed at wileyonlinelibrary.com]

continue to be denied to people with learning disabilities, squashed by the rules and regulations of the benevolent dictatorship of support provision that claims to promote choice, but only within extremely restrictive constraints. It is here that discrimination entwines with the theme of *Segregation*. Support still engenders a separateness, an othering, shackled to social expectations and a lack of awareness of the learning disability experience (McManus et al., 2011; Parmenter, 2001). Although the warehouse-type institutions where Antonia spent the latter part of her life are less prevalent in the United Kingdom that they once were, supported living, with groups of people with learning disabilities living together as communities within communities, still propagates segregation (Jones et al., 2008; Milner & Kelly, 2009; Thorn et al., 2009). These themes came together as key salutogenic drivers for Antonia's recuperation, imagining the better life we would have given Antonia we could, as alluded to earlier. Learning-disabled researchers unanimously expressed they wanted to give Antonia choice, a home, and a future where she would have more than her own thoughts and unheard voice for company.

4.4 | Project impact

This project had substantial public impact through public engagement activities including building a website (https://www.thebraincharity.org.uk/antonia), and showcasing our work at the national Being Human Festival in November 2019. Attendees who completed the feedback questionnaire unanimously rated the experience as either Good or Excellent, because it helped them think about both learning disability history and research methods in new ways. Our event was featured in the organiser's Twitter Festival Highlights and blog. There were also very significant impacts on the researchers themselves. After the main workshop series was complete, we held further Zoom sessions to explore how the project had affected the people involved. They were asked to give one word which summed up their experience of the project. The words they gave included: Enlightening, Powerful, Very interesting, Truthful, Inspiring, Joyful, Fascinating,

FIGURE 6 The Marginalisation of our Researchers (Courtesy of Stacey Harding Illustrations) [Color figure can be viewed at wileyonlinelibrary.com]

Fun, Challenging, Transformative, Amazing, & Very moving. When asked what they had learned from the project, several people said that they had learned how research could be done inclusively. Others emphasised learning about similarities and differences between attitudes towards learning disability between 1870 and now. A third category of learning was related to people's own stories of living with learning disability; people felt privileged to have the opportunity to tell their own stories, be listened to and understood, and to listen to others' stories. Many people spoke about how they had grown in confidence and were more willing to try new things and to express their ideas and opinions. For example, one person said he was terrified before the first workshop and almost went home without getting out of the taxi, but now thinks it's one of the best things he's ever done. Several TRAC researchers felt able to participate in another study about the impact of Covid-19. Others spoke about how the research methods used tapped into creativity they didn't know they possessed. We all—academics, learning-disabled researchers, family members and volunteers—learnt a lot about each other and the lived experience of learning disabilities today.

5 | CONCLUSIONS

We conclude that participatory methods can be an effective and enjoyable way of doing historical research with researchers who are labelled with learning disabilities. Such research can reach and influence public and academic audiences; it can also have major significance for those who do it. As such, historians, archivists, as well as professionals and scholars working in related fields, may wish to consider participatory approaches similar to the one described here.

Our collective thematic analysis of the themes revealed that although choices and personal freedoms have increased to some extent for people with learning disabilities compared with the documented and inferred experiences of Antonia Grandoni, there are also stark parallels that may still be drawn, some 180 years later (Figure 6). The analysis foregrounds the continued perpetuation of deeper sociocultural tensions and ascription of negative, paternalistic tropes which sustain the marginalisation of people with learning disabilities as an outgroup (Goodey, 2016). This points to considerable effort still being needed in Western society to actualise social inclusion—beyond tokenism—for people with learning disabilities.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID
Owen Barden https://orcid.org/0000-0002-3175-0037

REFERENCES
Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities, 33*(6), 2122–2140.

Atkins, L., & Duckworth, V. (2018). *Research methods for social justice and equity in education.* Bloomsbury.

Barden, O. (2021). Getting inside histories of learning disabilities. *Educational Action Research, 29*(4), 619–635. https://doi.org/10.1080/09650792.2021.1899952

Barden, O., & Walden, S. J. (2021). The metanarrative of learning disability. In D. Bolt (Ed.), *Metanarratives of disability* (pp. 77–93). Routledge.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101.

Brown, M., James, E., & Hatton, C. (2017). *A trade in people: The inpatient healthcare economy for people with learning disabilities and/or Autism Spectrum Disorder* (CeDR Briefing Paper). University of Lancaster. Retrieved June 22, 21, from http://wp.lancs.ac.uk/cedr/files/2017/06/A-Trade-in-People-CeDR-2017-1.pdf

Brownlee-Chapman, C., Chapman, Eardley, C., Forster, S., Green, V., Graham, H., Harkness, E., Headon, K., Humphreys, P., Ingham, N., Ledger, S., May, V., Minnion, A., Richards, R., Tilley, L., & Townson, L. (2018). Between speaking out in public and being person-centred: Collaboratively designing an inclusive archive of learning disability history. *International Journal of Heritage Studies, 24*(8), 889–903. https://doi.org/10.1080/13527258.2017.1378901

Burch, L. (2021). 'We shouldn't be told to shut up, we should be told we can speak out': Reflections on using arts-based methods to research disability hate crime. *Qualitative Social Work, 19,* 147332502110028. https://doi.org/10.1177/14733250211002888

Care Quality Commission. (2020). *A review of restraint, seclusion and segregation for autistic people, and people with a learning disability and/or mental health condition* (pp. 20–41).

Carroll, C., Booth, A., & Cooper, K. (2011). A worked example of "best fit" framework synthesis: A systematic review of views concerning the taking of some potential chemopreventive agents. *BioMed Central Medical Research Methodology, 11,* 29.

Carter, S. M. (2017). Overdiagnosis: An important issue that demands rigour and precision: Comment on "Medicalisation and overdiagnosis: What society does to medicine". *International Journal of Health Policy and Management*, 6(10), 611–613.

Clarke, C. L. (2019, November 22). *Hearing eye to eye—Authority, power and voice in participatory research: Secondary data analysis*. Paper presented to the UK Participatory Research Network, Edinburgh.

Disability Discrimination Act. (1995). *HMSO*. Retrieved January 7, 2016, from http://www.legislation.gov.uk/ukpga/1995/50/introduction

Dowse, L., Baldry, E., & Snoyman, P. (2009). Disabling criminology: Conceptualising the intersections of critical disability studies and critical criminology for people with mental health and cognitive disabilities in the criminal justice system. *Australian Journal of Human Rights*, 15(1), 29–46.

Ferguson, P. M. (2014). *Disability incarcerated*. Palgrave Macmillan.

Gallagher, E. (2002). Fundamentals of theory and practice revisited: Adult clients with mild 'intellectual disability': Rethinking our assumptions. *Australian and New Zealand Journal of Family Therapy*, 23(4), 202–210.

Gappmayer, G. (2020). Disentangling disablism and ableism: The social norm of being able and its influence on social interactions with people with intellectual disabilities. *Journal of Occupational Science*, 1–12.

Gee, S. (2002). A Standard Service for All? The case for a flexible attitude. *Journal of the Society of Archivists*, 23(2), 233–238. https://doi.org/10.1080/0037981022000006417

Goodey, C. F. (2016). *Learning disability and inclusion phobia. Past, present and future*. Routledge.

Graham, H. (2019). How the exhibition became co-produced: Attunement and participatory ontologies for museums. In P. Bjerregaard (Ed.), *Exhibitions as research: Experimental methods in museums* (pp. 181–194). Routledge.

Graham, H. C. (2016). The 'co' in co-production: Museums, community participation and Science and Technology Studies. *Science Museum Group Journal*, 5. https://doi.org/10.15180/160502

Grove, N. (2017, July 20). *Working together to find things out: The fortunes of Fanny Fust*. Paper presented at the Social History of Learning Disability Conference, The Open University.

Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 54, 48–57.

Hayward, S. (2017, July 20). *The problem with Lucy': A story from the Normansfield Archives*. Paper presented at the Social History of Learning Disability Conference, The Open University.

Houghton, C., Murphy, K., Meehan, B., Thomas, J., Brooker, D., & Casey, D. (2017). From screening to synthesis: using nvivo to enhance transparency in qualitative evidence synthesis. *Journal of Clinical Nursing*, 26(5-6), 873–881.

Ilyes, E. (2020). Psychology's eugenic history and the invention of intellectual disability. *Social and Personality Psychology Compass*, 14(7), e12537.

Ireland, W. W. (1877). *On idiocy and imbecility*. J.A. Churchill. Retrieved November 13, 2018, from https://data.ukmhl.historicaltexts.jisc.ac.uk/view?pubId=ukmhl-b21951342%26;terms=ireland%20idiocy%20imbecility%26;pageTerms=ireland%20idiocy%20imbecility%26;pageId=ukmhl-b21951342-1

Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research*, 48(8), 719–729.

Jarrett, S., (2020). *Those They called idiots: The idea of the disabled mind from 1700 to the present day*. Reaktion Books.

Jones, J., Ouellette-Kuntz, H., Vilela, T., & Brown, H. (2008). Attitudes of community developmental services agency staff toward issues of inclusion for individuals with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 5(4), 219–226.

Klotz, J. (2004). Sociocultural study of intellectual disability: Moving beyond labelling and social constructionist perspectives. *British Journal of Learning Disabilities*, 32(2), 93–104.

Kuo, R. J., Lin, T. C., Zulvia, F. E., & Tsai, C. Y. (2018). A hybrid metaheuristic and kernel intuitionistic fuzzy c-means algorithm for cluster analysis. *Applied Soft Computing*. Jun, 1(67), 299–308.

Legislation.gov.uk. (2010). *Equality Act 2010*. Retrieved January 11, 2021 <http://www.legislation.gov.uk/ukpga/2010/15/contents

Lindström, B., & Eriksson, M. (2010). A salutogenic approach to tackling health inequalities. *Health Assets in a Global Context*, 36, 17–39.

Marshall, K. (2017, July 20). *The ART of gathering and presenting stories with and without words*. Paper presented at the Social History of Learning Disability Conference, The Open University.

Masters, A. S., McNair, L. D., & Riley, D. (2018). *Liberatory methodologies: Participatory action research strategies for discovering inclusive maker space practices*. 2018 IEEE Frontiers in Education Conference (FIE), pp. 1–5.

McManus, J. L., Feyes, K. J., & Saucier, D. A. (2011). Contact and knowledge as predictors of attitudes toward individuals with intellectual disabilities. *Journal of Social and Personal Relationships*, 28(5), 579–590.

Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society*, 24(1), 47–62.

Mortimer, I. (2002). Discriminating Between Readers: The case for a policy of flexibility. *Journal of the Society of Archivists*, 23(1), 59–67. https://doi.org/10.1080/00379810220120564

Newman, J. (2012). Revisiting archive collections: Developing models for participatory cataloguing. *Journal of the Society of Archivists*, 33(1), 57–73. https://doi.org/10.1080/00379816.2012.666404

Pain, R., Askins, K., Banks, S., Cook, T., Crawford, G., Crookes, L., Darby, S., Heslop, J., Holden, A., Houston, M., Jeffes, J., Lambert, Z., McGlen, L., McGlynn, C., Ozga, J., Raynor, R., Robinson, Y., Shaw, S., Stewart, C., & Vanderhoven, D. (2016). *Mapping alternative impact: Alternative approaches to impact from co-produced Research*. Centre for Social Justice and Community Action, Durham University.

Parmenter, T. R. (2001). Intellectual disabilities-quo vadis. In G. L. Albrecht, K. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 267–296). SAGE Publications, Inc.

Pelleboer-Gunnink, H. A., Van Oorsouw, W. M. W. J., Van Weeghel, J., & Embregts, P. J. C. M. (2017). Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: A systematic review. *Journal of Intellectual Disability Research*, 61(5), 411–434.

Prevett, P. S., Black, L., Hernandez-Martinez, P., Pampaka, M., & Williams, J. (2020). Integrating thematic analysis with cluster analysis of unstructured interview datasets: An evaluative case study of an inquiry into values and approaches to learning mathematics. *International Journal of Research & Method in Education*, 1–15.

RCMG. (2004) *Engaging archives with Inspiring Learning for All*. MLA North West. Retrieved June 12, 2019, from https://le.ac.uk/%7E;/media/uol/docs/rcmg/publications/mla-nw-archives-report.pdf?la=en

Rix, J. (2006). Does it matter what we call them? Labelling people on the basis of notions of intellect. *Ethical Space: The International Journal of Communication Ethics*, 3(4), 22–28.

Strnadová, I., & Walmsley, J. (2018). Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities*, 31(1), 132–141.

Stubbs, C. (2017, July 20). *Capturing fragile histories: A cut & stick methodology*. Paper presented at the Social History of Learning Disability Conference, The Open University.

Styliani, S., Fotis, L., Kostas, K., & Petros, P. (2009). Virtual museums, a survey and some issues for consideration. *Journal of Cultural Heritage*, *10*(4), 520–528.

Thorn, S. H., Pittman, A., Myers, R. E., & Slaughter, C. (2009). Increasing community integration and inclusion for people with intellectual disabilities. *Research in Developmental Disabilities*, *30*(5), 891–901.

Titchkosky, T. (2011). *The question of access: Disability, space, meaning*. University of Toronto Press.

United Nations. (2006). *Convention on the rights of persons with disabilities and optional protocol*. United Nations General Assembly.

Vehmas, S. (1999). Discriminative assumptions of utilitarian bioethics regarding individuals with intellectual disabilities. *Disability & Society*, *14*(1), 37–52.

Waddington, N. (2004). The employment of people with disabilities as archivists, records managers, conservators and assistants. *Journal of the Society of Archivists*, *25*(2), 173–188. https://doi.org/10.1080/0037981042000271493

Walmsley, J., & Jarrett, S. (Eds.). (2019). *Intellectual disability in the Twentieth Century: Transnational perspectives on people, policy, and practice*. Policy Press.

Ward, D. J., Furber, C., Tierney, S., & Swallow, V. (2013). Using framework analysis in nursing research: A worked example. *Journal of Advanced Nursing*, *69*, 2423–2431.