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Surviving through story: Experiences of people with learning disabilities in the covid19 pandemic 2020–2021

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Abstract

Background: History starts from where we are now - it is not just things that happened a long time ago. The global pandemic began in 2019. It has changed the lives of people with learning disabilities. We began our project during the first lockdown in April 2020. We came together to set up a website to collect stories and support and learn from each other about how to survive and keep strong. Storytelling is very important because it helps us understand what is going on. It is also a way to capture the history of people with learning disabilities at a very difficult time. We know that thousands of people with learning disabilities became ill and died in the flu epidemic of 1918. But nobody recorded their stories in their own words. We want to make sure this does not happen again, so we created an archive to help us remember.

Methods: The project was managed with an advisory group of people with and without learning disabilities who met monthly to monitor the collection and analysis of stories on the site. A site audit was performed regularly to determine the themes in the stories and who had submitted. The article describes the progress of the project, the stories we have shared, and the challenges we have faced.

Conclusions: We discuss how people with learning disabilities have been presented in the media and our views about the way we are not heard, or always shown as vulnerable victims. We have found many sad stories, but also positive ones about people being creative and supportive. We look forward to the future and share our ideas about how society could be different and more inclusive. Being part of this project has given us confidence to know we are not alone, and shown us how we can help with the recovery.

KEYWORDS

bereavement, disability politics, empowerment issues, history of learning disability

Surviving through Story can be found at <https://www.survivingthroughstory.com>

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Accessible summary

- This article is about the lives of people with learning disabilities during the Covid-19 pandemic.
- It has only just happened, but it will be history for the next generation who will look at it and learn from it.
- In the article, we describe how our site, Surviving through Story, was set up.
- We share some of the stories and discuss the messages they have for us.
- How we wrote the article.

Nicola Grove, Liz Tilley and Sue Ledger wrote the introduction and the conclusion and found references.

We discussed the content between us. Individual sections were sent to Nicola to combine in the article.

Nicola and Pat Charlesworth wrote the discussion and the accessible summary.

1 | INTRODUCTION

History provides us with narratives that tell us who we are, where we came from and where we should be going. It defines a trajectory which helps construct the essence of a group's identity, how it relates to other groups, and ascertains what its options are for facing present challenges (Liu & Hilton, 2005, p. 2).

In this article we describe how the Surviving through Story site was set up and organised, followed by personal experience stories contributed by our six authors with learning disabilities, reflections on the changing situation in the summer of 2021, and a discussion of some key themes. Documenting the history of persons with learning disabilities in their own right, as Atkinson and Walmsley (2010) remind us, is a fairly recent phenomenon, dating in the UK to the rise of the self-advocacy movement in the 1970s and 1980s, and coinciding with a 'turn to the personal' in historical studies generally under the influence of post-colonial, feminist and psychoanalytical discourses (Summerfiel, 2019). Before this time, service perspectives predominated—whether medical, educational, social work or organisational. Atkinson and Walmsley use the term *lived experience history* to propose a rounded approach that takes account of the views and memories of people with learning disabilities, and those who live and work alongside them—families, friends, staff and volunteers. They regard oral and biographical accounts as critical to this discourse.

A 'turning point' in history is shorthand for describing events that trigger a radical change to what was the expected course. Oral and autobiographical accounts serve to put such events in context and to gain insights through understanding how they were experienced at the time by different populations, thus challenging dominant discourses (Liu & Hilton, 2005; Summerfiel, 2019). The pandemic can certainly claim to be such a turning point (Grey, 2020). In retrospect, it will probably be seen as one of the greatest international crises

since World War II, comparable in its effects to the 1918 flu epidemic. There have been many disasters in the first decades of the 21st century, but few have had the global impact of the coronavirus. It was recognised early on that those with disabilities would be disproportionately affected, and research indicates that this was indeed the case (APPG: All Party Parliamentary Group for Special Needs & Disabilities, 2021a). In 2010, Macdougall (2010), in her preface to a UN resource and toolkit for supporting the needs of disadvantaged minorities, makes the point that:

Disadvantaged minorities are commonly poorly represented in political structures and decision making bodies and consequently have little control over decisions that affect them. Lacking a voice in shaping their own circumstances, they are vulnerable to neglect. And when disasters strike, these communities are most likely to be at the back of the line for humanitarian assistance, if not totally forgotten.

Events were to prove that (as if we needed convincing), little has changed in the intervening 10 years—except perhaps for growing self-confidence and willingness to speak up and reach out to others by the communities of people with learning disabilities whose histories are documented in this 50th-anniversary edition of the *British Journal of Learning Disabilities*. In this article, we summarise some of the stories and the learning that have emerged through our project, Surviving through Story, a website set up jointly through the support of The Open University's Social History of Learning Disability Research Group, the charity Generate, and Three Ways School in Bath. The plan is that the stories gathered through this project, including extracts shared in this article, will become part of a permanent archive collection documenting the Covid-19 pandemic. This will enable the experiences and contributions of children and adults with learning disabilities to be documented and included as part of mainstream history. By contrast, the Spanish flu epidemic of

1918–19 killed between 50 and 100 million people worldwide: about 2%–5% of the global population (Spinney, 2018, p. 1296, cited in Walmsley et al., 2021). Yet there appear to be no accounts from people with learning disabilities surviving from that era.

1.1 | Setting up the site

Organisations that supported people with learning disabilities were quick to respond once the severity of the virus and its effects became clear. For example, Photosymbols,¹ with remarkable speed, and the active support of health and social service professionals developed sets of graphic images that clearly depicted the new concepts and practices with which we had to familiarise ourselves. *Books Beyond Words*² produced sets of social stories designed to document the varied trajectories of separation and isolation, illness and outcomes. Mencap,³ among other charities, produced guidelines that could be used by staff and families to communicate what needed to be done. However, what was missing was the personal dimension that was proving so necessary to maintaining our human connections and relationships, and making sense of what was happening. Anecdotal conversations or 'small stories' (Bamberg & Georgapoulou, 2008) are the way we recall and share experiences and are prominent in everyday interactions (Ochs & Capps, 2001). For example, the first time one of the authors (NG) went to do the weekly shop at the supermarket, she did not understand what was meant to happen and found herself inadvertently jumping the queue, only to be reprimanded publicly in a way that made her feel confused and guilty. It was only by sharing this tiny story and hearing her friends and family's reassurances that she started to feel less embarrassed. Where were the opportunities for people with learning disabilities to do this? There were isolated projects set up for people with learning disabilities, for example, The Rix Centre had a project called 'Stay Connected' which used an online secure social networking site where people with learning disabilities were able to stay connected with their friends, families and carers and share their stories privately (RIX Research and Media, 2020). Many services and organisations also worked hard to keep people in touch with each other. However, these opportunities were offered on a local basis to people who were already linked to services. Cronin et al. (2020) produced a powerful collection of pandemic experiences from international sources. There were national initiatives that tried to address the need for storytelling, for example, National Voices,⁴ who already had an established site advocating for people with disabilities, set up their Covid project, inviting people to submit their stories. But for many people with learning disabilities, the site was not easily accessible as the submission was via a typed form. Perhaps because of this, very few stories were posted by or about people with learning disabilities.

Katrina Arab and Flo Hopwood, teachers at Three Ways School working with Nicola Grove, started a Surviving through Story Facebook site in April 2020,⁵ with content that featured both the stories of young people with special educational needs and specially composed sensory stories that enabled teachers to share on zoom or in person stories about clapping for carers, rainbow paintings, weird cooking and exercise classes online (Arab et al., 2020; Grove, 2020).

At the same time, Craig Hart, co-chair of The Open University's Social History of Learning Disability Research Group, asked the question '*what happens to people with learning disabilities who have a partner or friend or a family member who dies?*' He felt that sharing stories of loss could help and support others and show how people with learning disabilities were coping with what were often very painful and difficult circumstances. And so the idea for a dedicated website was born, designed as a space where, during lockdown, people with learning disabilities and autism could share their experiences and support each other.

The site needed to be a space accessible to and directed by people with learning disabilities themselves, allowing content to grow organically in response to the contributions received, the evolving pandemic situation and new ideas.

One key issue which was critical to get right was to have robust consent procedures. We drew on ongoing research from The Inclusive Archive Project, which developed legally compliant consent processes and documentation for sharing stories online (Tilley et al., 2021). By July these consent procedures had been through the relevant ethical approval process,⁶ and we were ready to launch. We also sent out formal invitations to join an advisory group and were fortunate in gathering a team of dedicated and committed individuals, including nine self-advocates (see <https://www.survivingthroughstory.com/about>). Two advisors left during the year, due to other commitments. Susie Gentry was not formally a member of the advisory panel but following the death of her partner in April 2020 took a lead role in thinking about the possibility of story sharing to help others coping with loss. As Susie was unable to access online platforms, she instead worked with Sue Ledger, dictating, revising and editing her stories by phone.

1.2 | Stories on the site

The site was regularly audited and featured 127 stories at the time of writing, made up of images, videos and written stories. Figure 1 represents the distribution of these story types. Figure 2 shows authorship. One hundred and twenty have been contributed by people with learning disabilities themselves.

Figure 3 shows themes, using headings and categories that were discussed with the advisory group, and which stood out to us as the most logical. Other headings could of course have been used.

¹<https://www.photosymbols.com>

²<https://booksbeyondwords.co.uk>

³<https://www.mencap.org.uk>

⁴<https://www.nationalvoices.org.uk>

⁵<https://www.facebook.com/survivingthroughstory>

⁶The Open University HREC Reference 3606.

What kind of stories?

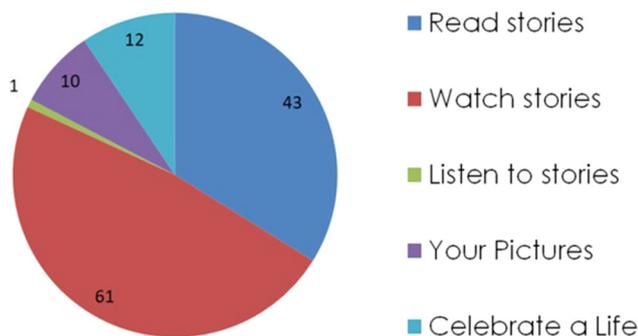


FIGURE 1 Types of stories on the site [Color figure can be viewed at wileyonlinelibrary.com]

Who are these stories by?

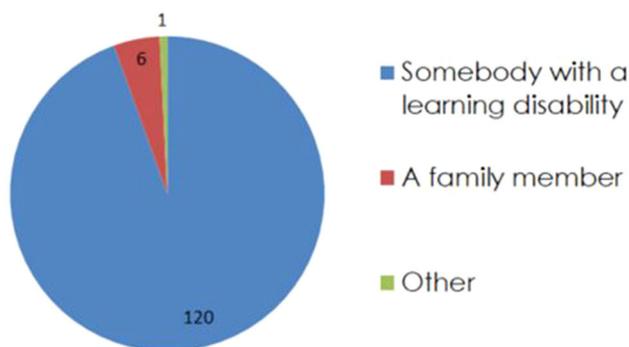


FIGURE 2 Authors of stories on the site [Color figure can be viewed at wileyonlinelibrary.com]

As the site developed and more stories were added, members of the advisory team worked together to challenge stigma and exclusion from the Covid-19 narratives in the media. Ideas for new collaborations were suggested and followed up. The team worked hard to ensure that the experiences and contributions of people with learning disabilities, including people from Black British, African, Caribbean and Asian heritage (Christian & Ledger, 2022; Christian, 2021), were shared.

2 | OUR STORIES

In the sections that follow, members of the Advisory Group tell some of their stories, first from the long months of the crisis and lockdown, then of emergence into the 'new normal' as experienced in the summer of 2021. The stories featured here from our authors provide a taster of the rich collection on the site. The authors themselves chose what to include. The final section, on getting back to normal, contains points made in conversation that the authors wanted to communicate.

2.1 | Pandemic stories

2.1.1 | First reactions

The powerful case for our need to share stories was made by Craig Hart in his first story on the site, transcribed by Nicola from his film. Craig independently filmed himself on his mobile talking directly to the camera, and sent four films to the site.

It's Wednesday 26th May 16.50. I'd like to share my stories of this lockdown and Virus 19. What my personal feeling about my story is—my life is—it feels like we are back in the war, second world war and that, and my feeling is, my confidence is... not really... it's ruined my life, it's not letting me go and do normal things. Also —it's not very nice talking about this—but what happens to people lost, in the middle of that Virus 19? People aren't doing anything, don't go and see their family and friends. It's not fair on them. But it's nice to share the feelings with people. And also, respect for people and also share their stories and what happened to them, and keep clear, and keep your distance and keep safe.

Craig continued his job working for the postal service all through the pandemic—an essential worker. But in November he was directly affected.

It's 5th November 2020. This is a new story. In Northampton, they're taking lockdown from today and might be till December, probably till December. I went to work on Monday. I been sent home straight after I got into work. I got into work and ...my manager told me I had to isolate for four days. And there you go! So just to remind you, keep safe and watch what the Government tells you.⁷

(from <https://www.survivingthroughstory.com/video-stories>)

2.1.2 | Being left out

Terry Bartlett was one of the first people to join the team. He dictated his thoughts to Kate Tokley.

Before Lockdown started, I filmed steam trains for a living and working with a steam locomotive called Clan Line. It was most enjoyable preparing the engine for special Raitours around Southern England with the

⁷<https://www.survivingthroughstory.com/video-stories>

What are the themes in the stories?

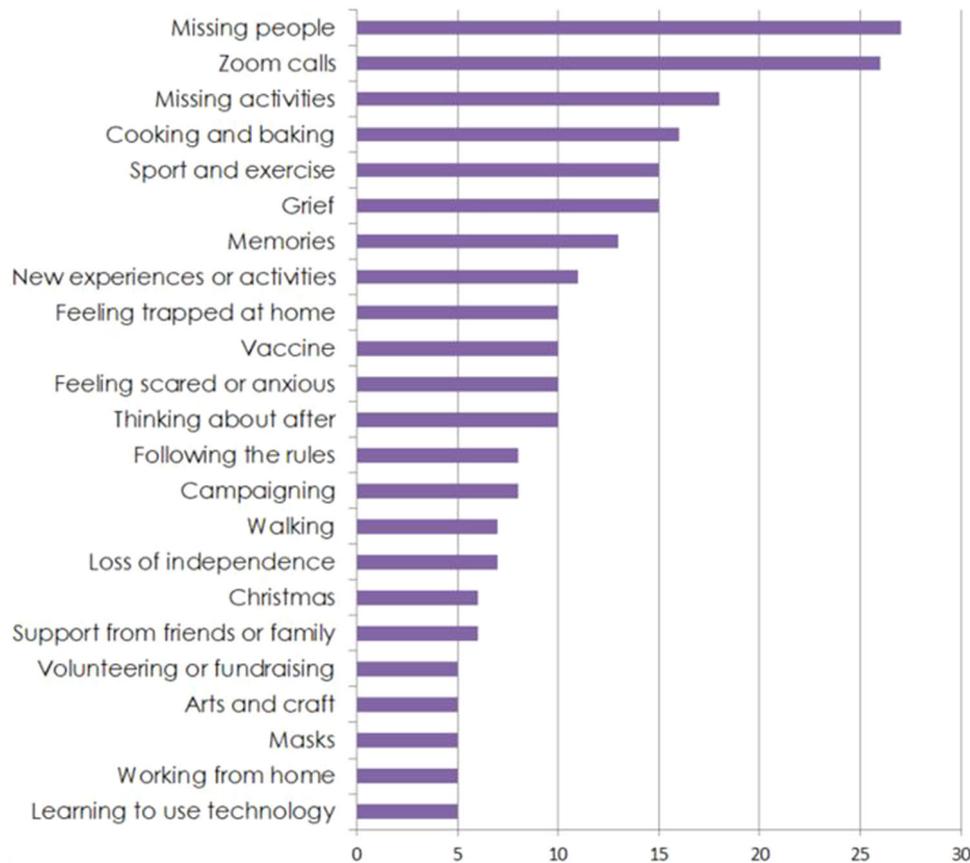


FIGURE 3 Story themes [Color figure can be viewed at wileyonlinelibrary.com]

Belmond British Pullman. Also working alongside Generate enjoying fun activities but unexpectedly the Covid-19 Pandemic hit the UK and a National Lockdown was imposed this meant I couldn't see steam trains or visit my family members in Eastbourne due to social distancing measures.

I was upset and frustrated at being confined to my home but thanks to technology I managed to play a PC Game called Train Simulator making YouTube videos for the time being. I kept on thinking why haven't the government thought about people with learning disabilities and autism or how do they know who has the virus and who does not. They keep on making empty promises saying we will go back to normal as soon as possible. As time went on thanks to Zoom I managed to take part in sessions also joined Surviving Through Story Advisory group to get as many stories as possible about how everyone with learning disabilities coped during Lockdown until the vaccine came into play. I expressed my frustrations towards the UK Government.

What really made me mad is when people with learning disabilities and autism were not prioritised for the vaccine...that's until Jo Wiley⁸ saved the day... if there was an inquest which will be soon, I would go to it.

He filmed and posted a video on the site, aimed at the popular breakfast news show Good Morning Britain.⁹

Hello there. I'm Terry Bartlett. I've been living with autism and learning disabilities all of my life. I'm one of your viewers, and I watch your programme a lot. I helped set up a project called Surviving Through Story. This is to help people with learning disabilities share their stories about Covid-19. Many people with learning disabilities are being left out during this pandemic. Many people like me are afraid to go out. They do not know the new rules. They miss their friends and families. We know about one

⁸Jo Wiley is a British TV and radio presenter whose sister has learning disabilities, and an active campaigner for disability rights.

⁹<https://www.itv.com/goodmorningbritain>

man in a care home who didn't recognise his family, cos he hasn't seen them all the time. This was awful

I'd like to ask you three questions. One, why can't someone like me ask a question to the Prime Minister during his press conference? Two, why aren't the media talking to people like me? Three, why are our voices being ignored? Please support us by giving people with learning disabilities a voice.¹⁰

It should be noted that nobody from the programme acknowledged this contribution.

2.1.3 | Bereavement

All the team agreed, with Craig Hart, that it was very important for the site to include a space where lives could be remembered and celebrated and where experiences of loss during the pandemic could be shared. Susie Gentry was one of the first contributors to respond to Craig's idea. Sadly Susie's husband Ron died in April 2020 at the start of the first lockdown. They had been together for over 40 years. Susie is supported in her own home by a team of carers. She chooses not to access technology independently and during lockdown preferred to dictate her stories and memories to Sue by phone, using the following process. Susie would talk to Sue about her story and then 'plan it out' before the next phone call when she would dictate. They would then revise the story together with Sue reading back each section until Susie was happy with it. When lockdown restrictions lifted, they were able to meet in person, and Susie selected photographs to accompany each story. Here she explains why she wanted to share her own story on the site:

I wanted to help other people. I wanted to tell them what had helped me. Because I had lost Ron I knew how they were feeling and how hard it can be. When I lost Ron I wanted to write about him, our wedding, holidays, our Christmas celebrations, Valentine's day, our friends. I thought out what I wanted to say in my story and told it to a member of the team on the phone. Later I chose photos to go with the stories. It has helped me to tell my stories. It has been hard to do as it is very sad as I want Ron to come back and things to be like they were. My stories give me hope and remind me that Ron is still in my heart.

The following contributions can all be found on the site.¹¹

This piece in memory of Ron was titled 'My husband Ron—I loved him very much and I still do':

Ron and I got married in 2005. The reason why I married Ron was because I fell in love with him and I still love him. I fell in love with him the first time I met him at Sandilands [a care home]. We had known each other for 25 years when we got married and moved into our flat. We would have been married for 15 years this year. We were very happy together. We had a good life together.

We went on holiday together, we went out together, we went to the pub together and we celebrated all our birthdays and Christmases together.

He was a good man and a good husband to me. He looked after me when I wasn't well and I looked after him when he wasn't well. I loved him very much and I still do. I miss Ron very much.

Each of Susie's pieces ends with her thoughts for others facing the loss of a loved one.

To help other people I would say that even though your husband has gone try to think of all the good memories and good times you had and the good life you had. Ron was the best husband in the world and I will always have that.

One very moving and courageous contribution from Susie tells the story of her husband's funeral (Figures 4 and 5).

Our favourite song 'Don't cry for me Argentina' was playing when the coffin went into the chapel. I was going to cry but when I heard our song I didn't as it reminded me of him and, although I was still very sad inside, I didn't cry. The song helped with that and I watched the coffin go in.

They called us in—the funeral director and we all went into the chapel room. The priest said nice things about



FIGURE 4 Susie Gentry looks at the website [Color figure can be viewed at wileyonlinelibrary.com]

¹⁰<https://www.survivingthroughstory.com/video-stories>.

¹¹<https://www.survivingthroughstory.com/celebrate-a-life>



FIGURE 5 Susie Gentry shares her Valentine's story [Color figure can be viewed at wileyonlinelibrary.com]

him—where he was born, he was born in Liverpool, he had two brothers—James and William and he had a family—a mum and dad [...]

As with all her other pieces in memory of Ron this ends with thought for others also struggling with loss.

I have Rudolf—a reindeer Ron used to carry at Christmas. I think to myself 'ah Ron used to carry that'. So to other people, if they have anything like photos or toys or memories, try to hold them and talk to them, it really does help. If you are on your own and feel sad—find your friends and talk to them. It's important to have people who know you and understand what has happened. I say to myself Ron would like me to live on and carry on with my life. This is for other people too—the person you have lost would like you to live on and carry with life even though it's hard sometimes.

Another person who suffered the death of her partner was Sharon Murphy, who joined the advisory group in January 2021, introduced by her long time friend Vicky Green. Sharon contributed this story in her own words of loss to an online conference, putting together a PowerPoint and film with photos and a tribute. It was extremely moving and powerful.¹²

I first met Paul through his stepmom and her friend when I worked in the hospital in Essex. On 12 March 2017 we meet up at the train station we went up London we went for a meal in a very nice restaurant by London bridge after we went on a boat ride on the Thames. After the boat ride we went to the O2 arena to have a look around and we got the train back to

Newbury Park station waiting for a bus he asked me to be his girlfriend. And Paul met my friends they all liked him they classed him as a friendly giant, and he had his own car. On 24 January 2018 me and Paul went to the awards at the O2 arena in London we saw all the celebrities from EastEnders, Ant and Dec, This Morning, Boy George and Billy Conley loads more. Before Covid 19 came to England me and Paul went London on our 3 year anniversary for the last time before lockdown. I last saw Paul on my birthday March 20 2020... 4 days later he went into hospital was put on a machine. I was going to tell Paul that I had Covid on the 31st of March but a day later Paul sadly passed away from Covid on 1st April 2020. He is badly missed by me his dad, stepmom and his friends.

You only have to look at the photos of Paul and Sharon together to see how close and loving their relationship was. We were all deeply affected by her experience and felt very privileged that she was prepared to talk so openly about it. The anniversary in April 2021 was particularly painful. Susie would like to meet with Sharon and is hoping to connect by Facetime so they can talk to each other. Susie told Sue that she loves Sharon's story and was very sad to hear that Paul had died so young. Susie said:

I mean my heart goes out to her because I know what she is going through. I can understand what she is feeling. And he is so young. It's sad but it helps me too to hear her story. I would like to meet Sharon one day and hope we can talk on the phone before that. Tell her that I love her story and that I say thank you for sharing it.

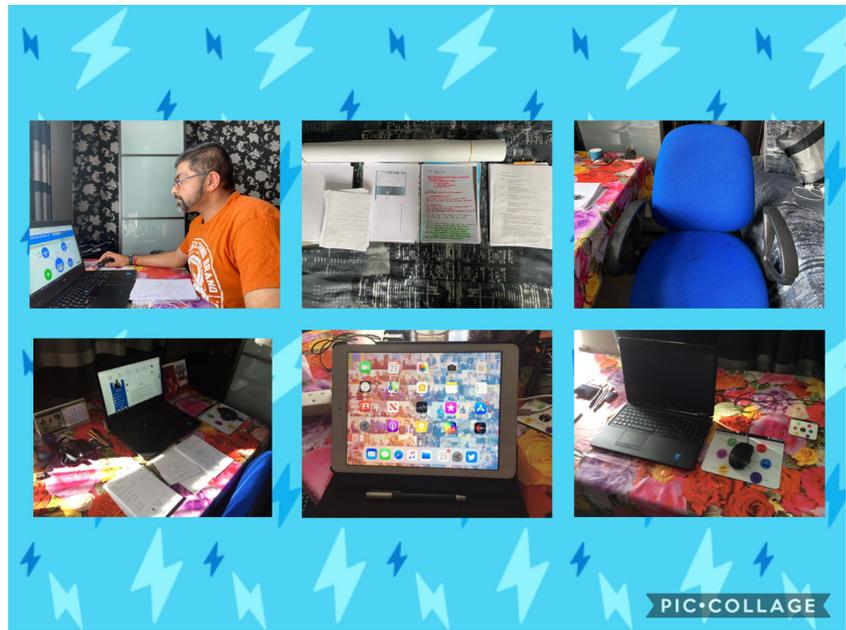
2.1.4 | Technology helps

Ajay Choksi, Wikimaster and trainer at the Rix Centre, came on board enthusiastically, since breaking down barriers through the use of technology is his passion. Here he shares how he built up a routine that worked for him, and, having looked after himself, turned his attention to helping others. He wanted to show that people with learning disabilities have a lot to offer, sharing stories to inspire and motivate others to do the same helps to address issues of equality and inclusion. Ajay met with Gosia Kwiatkowska online via video link and together they reflected on his experience. Gosia took notes and helped structure the story, which Ajay recorded and Nicola transcribed. Ajay said:

When I was invited to join the 'Surviving through Story group' at the beginning of lockdown I was very excited about the opportunity. When lockdown

¹²https://www.survivingthroughstory.com/post/_paul

FIGURE 6 Ajay Choksi's home office [Color figure can be viewed at wileyonlinelibrary.com]



started, I had to personally change my daily routine, work from home and couldn't see my family or friends. It was hard but with support from my colleagues I have managed to adjust and make it work.

When I was invited to join the group, I felt it was important to be part of it as I heard on the news lots of stories of people dying from Covid and constant reminders about hygiene.

I think a lot of people were confused and did not understand the advice from our Prime Minister Boris Johnson. I started creating my own advice for people in a simple accessible way which was much needed.¹³

So, the invitation to join the group was timely.

When I joined the group, we started by sharing our own stories of Covid so far. With support from my colleagues, I worked on my personal plan to create a new office - in my bedroom. Ensure everything is working and is properly set up (see Figure 6).

Then, we looked at my daily routine and how the new routine can look like (see Figure 7).

Lockdown had a big impact on people's wellbeing and mental health, I worked with my colleague

Gosia to ensure that my mental health is not affected.

We adjusted my working hours, ensuring that I have time to go out for my daily walks, for my exercise in the garden, healthy tea breaks and regular meetings with colleagues (see Figure 8).

Once all of this was in place, I was happy that I could share some of my own ways of coping with others. As part of the group I met lots of other people with learning disabilities and talked to them about their Covid stories. Some people were well, others were not. We put all these stories on the website. What I found was that a lot of people were resilient, they were coping well, finding ways of staying connected and in good spirit (see Figure 9).

One of my favourite stories, that is on our website, is from a young lady called Ettie, who was experimenting with cooking and tried to make ham and cheese jelly (see Figure 10). She shared her story—what do you think the jelly tasted like?

As part of my job role, I was teaching other people with learning disabilities how to use technologies especially RIX Multi Me toolkit¹⁴ (see Figure 11).

This is a set of tools like calendar, diary, wiki, goals, circle and others. People can use these tools to connect with their family, friends and support staff in a safe way. I was

¹³<https://www.rixwiki.org/Default/home/ajay-advice-3/good-hygiene>

¹⁴<https://www.multime.com/>

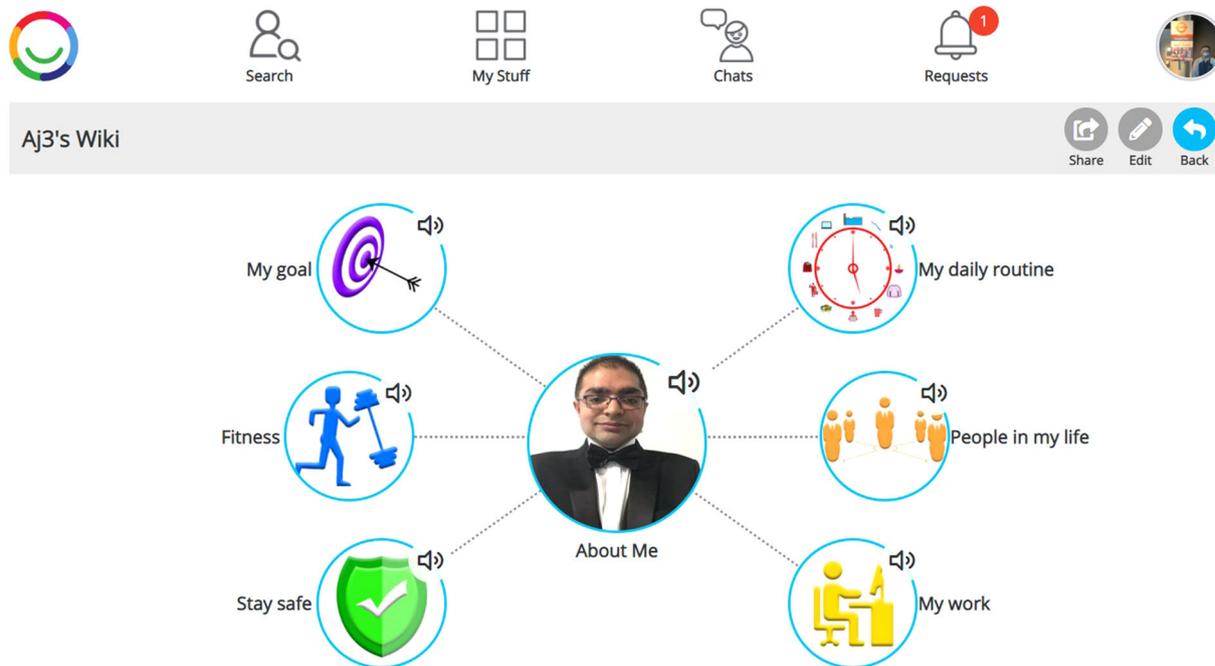


FIGURE 7 Ajay Choksi's new routine [Color figure can be viewed at wileyonlinelibrary.com]

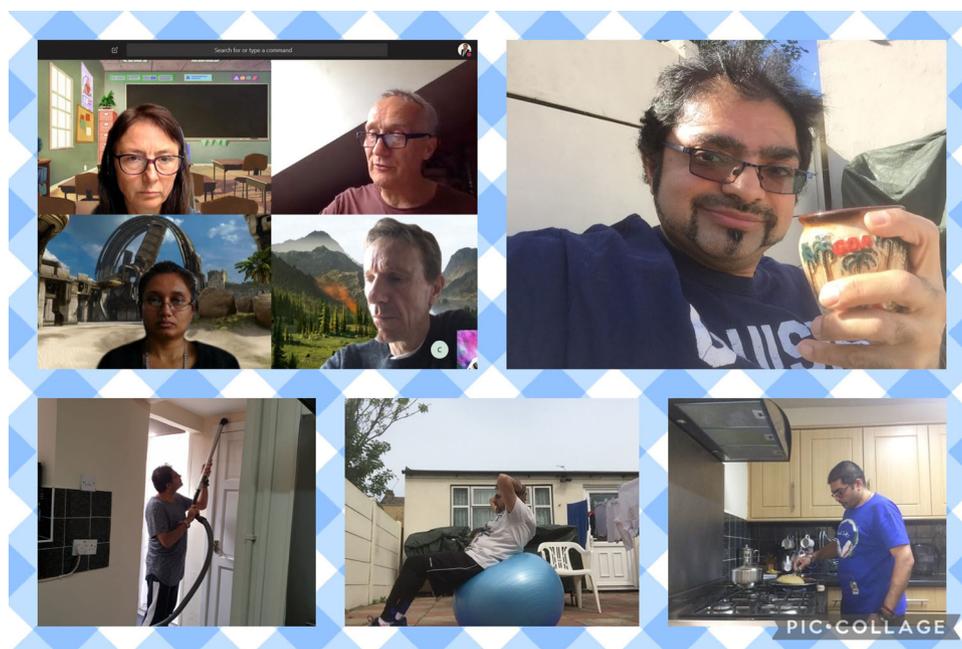


FIGURE 8 A typical lockdown day for Ajay Choksi [Color figure can be viewed at wileyonlinelibrary.com]

teaching other people with learning disabilities, their parents and supporters how to use them.

During the pandemic, I was also working on a project for Digital Unit¹⁵ to build easy to understand course for

people with learning disabilities on how to use Zoom. I worked as part of co-researchers team led by Gosia Kwiatkowska (see Figure 12).

I trained lots of other people who are now digital champions and they are also teaching others. This was really important as we all relied on the use of digital devices during the pandemic.

¹⁵<https://www.digitalunite.com>



FIGURE 9 Screenshot of a surviving through Story Advisory Group meeting [Color figure can be viewed at wileyonlinelibrary.com]



Ettie makes ham and cheese jelly!!

FIGURE 10 Ettie's cooking story [Color figure can be viewed at wileyonlinelibrary.com]

I remember one of the disappointments last year October, November and December time. When we had the traffic light system - green, orange and red, and we were looking forward to various celebrations like Diwali or Christmas. Unfortunately, because of the growing numbers of deaths we couldn't meet with our families and celebrate those important events together. I was disappointed and angry about that; it was such a shame. It felt like prison, no shake hand, no hug (see Figure 13).

Things started looking a bit better and exciting when the vaccine was made available.

But people with learning disabilities were not prioritised. Why! This was so wrong. People with learning disabilities

should have been prioritised and we would have saved the lives of so many. I was pleased to see Saba Salman¹⁶ advocating on behalf of people with learning disabilities (see Figure 14).

I got my vaccination in March, the Oxford one. Next day, my arm was hurting, when I was trying to use my arm, it was hurting, it was a little bit painful. But no headache or anything. Now I have both of my jabs. Yes! I think people with learning disabilities should have been prioritised because they needed it to stay healthy and safe. Being part of the group is important to me so that as a group we can update each other, we can collect other peoples' stories, share them and we can discuss the news and be included in the plans going forward. Surviving through Story is important we need this group to continue.

2.1.5 | Black lives matter

The image of a police officer kneeling on the neck of George Floyd while he is in police custody, handcuffed and saying he cannot breathe will forever be burned into our memory (Ramsden, 2020).

¹⁶Saba Salman is a writer and campaigner. We should note here that many self advocates, families and organisations campaigned vigorously on this issue (see Tapper, 2021); but it was only when a media personality got involved on behalf of her sister that notice was taken, see Terry Bartlett's contribution above.



FIGURE 11 Example of multi-me Toolkit [Color figure can be viewed at wileyonlinelibrary.com]

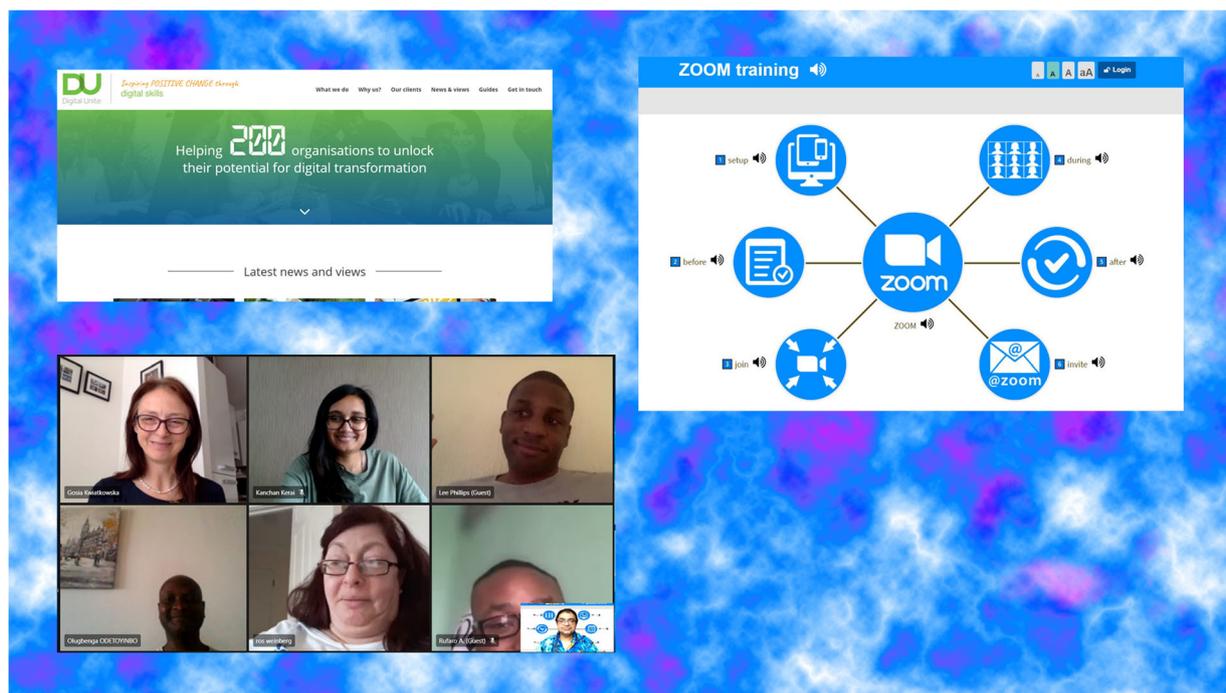


FIGURE 12 Screenshot from Digital Unit Project meeting [Color figure can be viewed at wileyonlinelibrary.com]

On 25th May 2020, during the first lockdown in England, George Floyd died while being arrested by the police in Minnesota, USA. People nearby filmed the arrest on their phones, and it was circulated internationally through social media. The video showed the police putting George Floyd on the floor and a policeman putting his knee of his neck. This meant that he couldn't breathe. George Floyd repeatedly asked for help, but the policeman wouldn't stop putting

pressure on his neck and tragically George Floyd died. This should never have happened. Everyone should be treated equally and with respect.

Here Paul Christian explains to Sue in a recorded online interview, how the killing of George Floyd inspired him to join the advisory group, to speak out against racism as a black person with learning disabilities. As explained in more detail in their article for this



FIGURE 13 Ajay Choksi's celebrations during Covid [Color figure can be viewed at wileyonlinelibrary.com]

edition (Christian & Ledger, 2022), Paul and Sue worked in collaboration to research and write these pieces. Paul said:

After the killing of George Floyd I felt passionate about speaking up for black people. Giving my take and giving space for these missing voices. So I became a member of Surviving through Story, working with the team to make sure that the lives and experiences of black people during the pandemic were fully represented. And to think together as a project about the double discrimination often faced by black people with learning disabilities. We have talked about racism and missing black British history and I am reading an illustrated book by David Olusoga called Black British History, A short essential history (Olusoga, 2020).

FIGURE 14 Tweet from writer Saba Salman, 3rd August 2021 [Color figure can be viewed at wileyonlinelibrary.com]

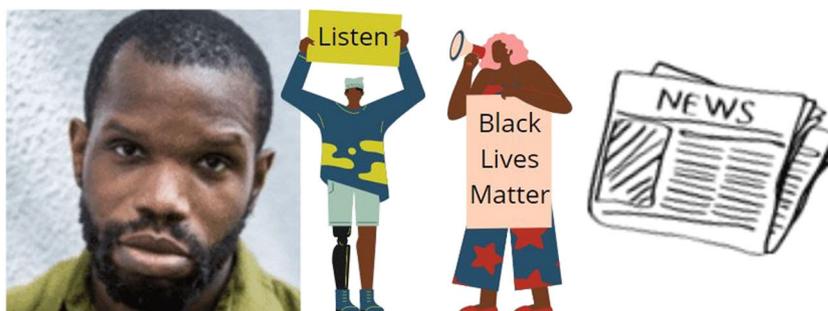


"My sister and others like her are eight times more likely to die of Covid. Yet so little thought has been given to their welfare" ICYMI article by @Saba_Salman



theguardian.com
For people with learning disabilities, 'freedom day' was nothing of the kind | Saba Salman

FIGURE 15 Paul Christian Black Lives Matter [Color figure can be viewed at wileyonlinelibrary.com]



Terry is a member of a Race and racism group¹⁷ who are doing work to end racism.

Paul reflected on what doing this study as part of the project team had meant to him (see Figure 15).

Being a part of Surviving through Story has been a total godsend and saving grace for me. To be able to air some of the grievances of loss and the inner innocence of pain and youth of injustice that black people have faced everyday. Just because of the colour of their skin. That has been so across the globe. I felt like it was my civic right and duty to report on these issues that matter to me and help to educate people from all walks of life to have the knowledge and to better themselves. To think. One day I want to hopefully kick down the door of racism and eradicate the notion of being inferior. Once and for all. Since joining the team I have contributed a number of written articles to the site including a piece about the impact of the death of George Floyd 'George Floyd said I Can't Breathe before he died',¹⁸ an article on the importance of other people getting your name right 'Call me by my name' and my experience of lockdown hair 'Lockdown Hair'.

2.2 | The new normal

Our group has not only survived—we have found new strength through working together, supporting each other and grasping every new opportunity that has come our way. We have all done presentations and talks. We have workshoped our ideas on training for the media. We have written articles together and we held a conference to showcase the experiences and the achievements of people with learning disabilities during the pandemic.¹⁹ Vicky Green dedicated herself to compiling an archive of information sources about Covid-19 for people with learning disabilities, which is now available on the site.²⁰ Here we update what the advisory group have been doing since the summer of 2021, obtained through verbal interviews online and by phone.

Craig was up in Newcastle in summer 2021, completing the Great North Run in a gorilla costume. Despite some challenges along the way—problems on the roads en route, pitching tents at midnight, getting extremely hot inside the gorilla suit (he had to run with the head in his hands!)—he and his friends completed the race



FIGURE 16 Craig's charity run [Color figure can be viewed at wileyonlinelibrary.com]

in 4 h and raised over £100 for Great Ormond Street Hospital. He is now planning his next half marathon to raise money for charity, but said he definitely won't be wearing a gorilla suit next time! (see Figure 16).

Terry has a paid job coordinating volunteers at Generate, which he got partly through the confidence and insight he gained through being part of the Surviving through Story project. Like all the charity staff, he takes regular COVID tests and described in detail the procedures involved and how everyone there knows him and is friendly. He is thrilled to be back volunteering with steam trains. His great joy was to see how the engine started up again, the first time, and the story can be read at the end of this article.

Sharon is now back working at McDonald's, a job she has held for 13 years. She has started college 2 days a week, on an 'Aspirations' course where she is learning new skills (cooking and computers first) and making friends. She is hoping to go on holiday to Dublin in the summer of 2022, travelling alone for the first time ever, to stay with relatives. She is still grieving for Paul. She would like things to go back to normal, as they were before. She hopes to meet up with Susie Gentry to share their experiences.

Vicky has been able to go on several trips abroad, and send us enviously lovely photographs.

Susie's reflections on losing her husband during the pandemic were included in a new book about Covid stories (Grove et al., 2021). In December 2022 Susie and Sue organised a Christmas dinner party at a local pub to remember Susie's husband and to celebrate the publication of her story. At the celebration, Susie's friends began asking to sign her copy of the book. Since then the cover has been signed by over 25 friends all of whom remember her husband Ron. Susie said:

¹⁷At the charity Generate.

¹⁸<https://www.survivingthroughstory.com/post/george-floyd-said-i-can-t-breathe-before-he-died-by-paul-christian>

¹⁹<https://www.survivingthroughstory.com/post/conference-25-november-2021>

²⁰<https://www.survivingthroughstory.com/resources>

Ron would be very proud of me for writing my stories. Next year I hope to go on holiday. I would like to keep writing my stories and to meet Sharon who told her story too. I hope to talk at a conference or on television about my stories.

Paul said: I am continuing with my research into missing black histories and my work as an actor. Next year I plan to work with Sue to research the lives of black people who were admitted to the former learning disability institutions and to write about this. I am also working on a new performance piece with my theatre company.

3 | DISCUSSION

The narratives we tell ourselves and others about our experiences help us to make sense of what happens, to build relationships and resilience and can lead to social change (Davis, 2002; Goldstein et al., 2015). Pat and Nicola discussed the messages emerging from our authors and came up with a set of common themes. These overlap with some of the categories of the stories listed in Figure 3: isolation, missing people and loss; zoom calls, campaigning.

3.1 | Isolation

The pandemic showed how disconnected people with learning disabilities often are; this was reflected in research project findings, which demonstrated the significant reduction in social contact and support that many people with learning disabilities experienced (Flynn et al., 2021; Rouse et al., 2020).

3.2 | Technology

The use of technology is vital to remain connected, and people need to have quality support in place to access and use it. For example, Ajay's story shows how important really good support was for him to keep healthy and to organise his work. Susie was more wary of using technology in particular the safety of the internet and being contacted or harmed by strangers. Although several months into the first UK lockdown she was offered a free computer and support with online access, she firmly declined this, preferring to continue with dictating her stories by phone and then receiving printed copies of the stories as they appeared on the site to share with her friends and carers. She enjoys looking at the site with Sue and has begun to explore the use of Facetime with her carers. People who had support were more able to keep on top of things and understand (Navas et al., 2021). This mirrors the findings of a wider piece of research on people's experiences of technology during the pandemic (Seale, 2020).

3.3 | Political awareness

Historically, women have often been linked with people regarded as lacking intellectual capacity and inferior to men (Goodey, 2011). So it was interesting to read a report on the representation of women's views during the pandemic. Kasova (2020, p. 10) reports that:

The women who are given a platform in the COVID-19/coronavirus story are rarely portrayed as authoritative experts or as empowered individuals but more frequently as sources of personal opinion or as victims/people affected by the disease.

These reflections chimed with the feelings and opinions of our advisory group members, who likewise found themselves represented as vulnerable victims of the pandemic rather than as experts on their own lives. We get the impression that politicians and the media think that people with learning disabilities don't have their own voice and don't know what we are talking about. Evans and Reher (2021) highlight the barriers facing all people with disabilities in standing for elected office. The 'ableism' they identify applies of course even more with a group who are defined by their difficulties in learning. During the pandemic, people with learning disabilities and their supporters have often had to lead the way in campaigning for change (My Life My Choice, 2021; Pickard, 2021; Rouse et al., 2020; Tapper, 2021). Our stories show that we were very aware of what was going on, and that we felt very disempowered by the failure to listen to us. We had a very informed and passionate discussion about vaccination.

This was not just about the pandemic—what happened to George Floyd made us all think about the lives of people from black and ethnic minorities and the racism people they so often face (Bell, 1992; Warmington, 2021). Public Health England (2020) reported 2020 that after accounting for the effect of sex, age, deprivation and region, people of Bangladeshi ethnicity had around twice the risk of death from Covid-19 when compared to people of White British ethnicity. People of Chinese, Indian, Pakistani, Other Asian, Black Caribbean and Other Black ethnicity had between 10% and 50% higher risk of death when compared to White British. This data however failed to identify those with a diagnosis of learning disability, hence not adding to our understanding of the impact from Covid-19 on people from black and minority ethnic communities living with the label of learning disability (Koulla-Burke & Ong, 2021). In this way, the nature of evidence and media coverage that emerged during the Covid-19 pandemic has further highlighted the intersection of race and disability (Connor et al., 2016) and the 'double discrimination' (Baxter et al., 1990; Black Friendly Group, 2004; Black People First, 1994; O'Hara, 2003; BPS, 2020) faced by black people with learning disabilities as an area that requires far more understanding and attention as we move forward into an era of Covid recovery (Joint Committee on Human Rights, 2020; Koulla-Burke & Ong, 2021).

3.4 | Grief and loss

We saw from two people's stories how suddenly the pandemic led to illness and death. Our page on the site about celebrating lives was a very important way of helping people to remember loved ones in a positive way, and creating a community in which people can share experiences and help one another (Borgstron & Mallon, 2021).

3.5 | Care for other people

Everyone who has taken part has expressed their wish to help other people to cope and keep well and safe, and feel better through sharing their stories (Deville et al., 2019).

3.6 | Keeping strong and resilient

We can also see that these stories show how strong people with learning disabilities can be (Rouse et al., 2020). We learned new skills—none of us could use zoom at the beginning! We kept each other going through working together online and through our friendship. However, we need to be vigilant in keeping these memories alive. During World War II there are reports of people labelled as intellectually disabled signing up to fight, and helping to rebuild society in the aftermath, as well as those in institutions taking over caring roles (Grove et al., 2010). These stories do not feature in the history books or news footage of the time, and risk being lost, meaning that the stereotype of people with learning disabilities as vulnerable victims persists unchallenged.

3.6.1 | Limitations

We recognise that this article represents a snapshot of stories and perspectives, and does not reflect purposive information gathering in the way that funded research would have done. We attempted over the 18 months that the site has been live to gather stories from those in residential accommodation and from people with high support needs, but both proved elusive, despite call outs. Our findings and our writing have also been constrained by the need to work under pressure and online. For example, we would ideally have brought all the authors together and presented the ideas gleaned from reading and research so that all self-advocates could have taken part in the selection and analysis of relevant research. Nevertheless, we feel the work we have done represents a real contribution to the study of learning disability history.

4 | CONCLUSION

In conclusion, we—like Cronin and his co-authors (2020)—agree that as we look forward to building a new world, people with learning disabilities need to be more in control and have a voice on the

political stage. That is a key message from our recent experiences. It has been argued that a story's 'tell-ability' is historically sensitive (Andrews, 2007). The pandemic, which has exposed historic and systemic inequalities in our society, has opened up new spaces for people to present their perspective and argue for change. Surviving through Story has given us a platform to record the stories we tell as part of this wider social movement. But we also need people to *listen* to our stories; others need to improve their capacity to hear what we have to say. Change won't happen if people continue to ignore us. We hope Surviving through Story will help other people to hear about our lives, our experiences and our ideas, and change their attitudes and actions (Courtenay & Perera, 2020; Grove et al., 2020, 2021).

We would like to leave our readers with Terry Bartlett's written story, of the waking of a sleeping giant with fire in her belly, as a symbol of our determination to achieve these aims:

The steam locomotive sits in the shed. At the moment the crew has all left due to the pandemic, but a year later, we open up the firehold door and we light the fire, add the coal and the wood and rags and the boiler pressure begins to rise. Steam builds up and before long the pressure reaches 250 lb a square inch, and we blast the whistle and...off she goes. She's fully awake. We woke her up from a long sleep. Clanline has a job to do. She pulls the carriages forward and begins her journey to the Surrey Hills. The engine puffs with all her might, pulling her heavy load...she needs to climb many hills to get to Chertsey to take on water. She comes to a stand at Guildford. Many passengers wonder, what is this thing? like back out of the 1950s. And in fact it is. It's a steam train back in business. After so long, everyone can enjoy the sight and sound of steam. Clanline gets the green and off she goes. Her driver keeps her going. Its' been over a year since the famous Surrey Hills have heard the sound of a steam engine. Clanline speaks for herself, pulling up the hills and then back to Victoria safe and sound. And that's what you call a sleeping giant that's woken up fully. We were all surprised how she woke up, just like that! And now it's time for Britain to do the same. We wake up sleeping giants, we wake up our city after a long hard sleep. (<https://www.survivingthroughstory.com/your-stories-1>)²¹

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²¹The site will continue to be maintained during 2022–3, and will feature stories collected through a funded project on Covid experiences, run by Brighton and Hove Speak Out <https://www.bhspeakout.org.uk>

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CONFLICTS OF INTEREST

Some of the authors have received payment for talks and training associated with their work for Surviving through Story.

DATA AVAILABILITY STATEMENT

The data supporting the findings of this paper can be found at <https://www.survivingthroughstory.com>.

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