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In response to “Now that I'm connected this isn't social isolation, this is engaging with people”: Staying connected during the COVID-19 pandemic’ (Natasha A. Spassiani, Mojca Becaj, Clare Miller, Andrew Hiddleston, Aaron Hume, Stephan Tait)

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1 | ABOUT US

Danielle Garratt is a Learning Disability Voices Network Project worker for Brighton and Hove Speak Out. Speak Out is an independent charity that makes sure people with learning disabilities can speak up and take action about things that matter to them. During the pandemic Danielle discovered a big interest in research. She started up an interview series on YouTube called ‘Speak Out with Danielle’. She interviewed, filmed and edited the recordings by herself. She interviewed many different people including those who have a learning disability and the head of Learning Disability England. She then got asked to help with ‘50 Years of speaking up in England—Towards an important history’ (Walmsley, Davies & Garratt, 2022). Through Speak Out Danielle also worked with Noelle, on a project called ‘Covid Stories from the learning disability community’, where she continued to be able to interview and capture people’s stories and video edit. As a result of doing this project an opportunity come up to write this response. Danielle and Noelle both wanted to work on it and Danielle thought that Nathaniel would make a great third person to help us create a response to our chosen article.

Nathaniel Lawford is the Inclusion and Projects Director of Grace Eyre, as well as a member of Brighton and Hove Speak Out’s ‘Being heard in Government’ group. Nathaniel is deeply passionate about understanding and supporting the voices of humanity in the many diverse forms that exist, and is currently focused through work and volunteering on the inclusion and ownership of persons with learning disabilities and/or Autism. Nathaniel also has Autism as well as active PTSD. Nathaniel found the article most insightful and inspiring, in parts speaking to his lived experience and understanding gained from others, as well as challenging assumptions, especially around the formation of relationships through digital inclusion. A massive thank you to all involved in the research of the article.

Noelle McCormack is a visiting research fellow and member of the Social History of Learning Disability research group based at the Open University. Her interests include life story work and creative research methods. She has recently worked with Brighton and Hove Speak Out, on a project called ‘Covid Stories from the learning disability community’ which recorded experiences of local people during the pandemic.

2 | HOW WE WORKED TOGETHER

We met three times to discuss our thoughts about the article. At our first meeting we had a read through and were each drawn to different parts of the research. Danielle wanted to respond to leadership and digital inclusion, Nathaniel was interested in aspects of relationships and online safety, and Noelle wanted to find out
more about the nuts and bolts of the research methods. We wrote up and emailed each other our first drafts. At our second meeting we read our responses to each other. While each of us was reading aloud we noticed changes we wanted to make, went away and redrafted. At our third meeting we revised our work again and agreed which questions we wanted to prioritise. We sent our combined response to Jan Walmsley and Liz Tilley for them to forward to the authors in advance of our online meeting with them. A Zoom meeting was arranged with the authors, Natasha Spassiani, Mojca Becaj, Aaron Hume and Stephan Tait, where we discussed their answers to our questions. In our article below, we begin each section with a quote from the original paper, followed by our question to the authors, and then the discussion that followed in our Zoom meeting.

3 | DANIELLE’S RESPONSE

At the first look at this paper, Danielle thought it was easy to understand. Danielle works with people who have a learning disability and knows how hard the pandemic was for them. She expected that the article would have some information to do with how the organisation helped people who are digitally isolated as well as digitally included. Speak Out set up a helpline and rang people weekly for a catchup to see how they were doing. Danielle enjoyed reading about how the grassroots disability organisation let people with intellectual/developmental disabilities have a leadership role and were running sessions. Her questions to the authors are about how they got people with intellectual/developmental disabilities to become active leaders. Danielle focuses her bit of the response on the key point of ‘since moving online more adults with intellectual/developmental disabilities took on active leadership roles and felt that the organisation became a community’. When reading this section for the first time it was a very positive and uplifting section but there were some things that struck her about it.

‘Seeing how well the organisation adapted and was able to keep providing services gave members a sense of shared pride because they had an active role in the organisation’s success’.

**Question: Could you explain more about the active roles what members had?**

Aaron told us that the organisation is member-led and that they worked side-by-side to plan events that they then hosted and led. They put new ideas for events to the members and then put them into practice, for example, a ‘Murder Mystery’ event. For this event Aaron worked with another member to plot, write and act out the event, which was ‘interactive, fun and enjoyable’.

‘Within our study, 30 members with intellectual/developmental disabilities created and led all the online Facebook events.’

**Question: How much support did the members have to lead the online Facebook events?**

Stephan said that members were supported in a variety of ways including coaching, mentoring, a tutorial library, and messenger calls. The organisation’s ambassadors and coordinators worked with members to prepare them for how to lead and join online events. They saw a growing confidence in members and less support was required over time. They used a ‘trial and error’ approach. The first time someone was leading an event they had support from ambassadors, which gave them confidence. Everyone was encouraged and supported to try. Stephan found that when he taught one member, they went on to teach another member, which led to a snowball effect. He told us that the only failure ‘was not trying at all, everyone was encouraged to try, and everyone understood that it was okay to fail’. There was a co-ordinator present at every meeting and event.

‘The organisation fostered opportunities and created a platform that allowed for ideas to be brainstormed and developed as a group, where members felt inspired to contribute to content development.’

**Question: What platform was there for members to put their ideas down and brainstorm? Was it hard to teach them how to use it?**

Aaron told us that they mostly worked using Zoom for meetings and private Facebook groups for members to post information and have live events. Zoom was offered by the organisation, but Facebook messenger was for members to keep in touch and create content for the organisation. They created a timetable of when events would take place at their weekly get together, a 1-h meeting called ‘Monday Magic’, when ideas were floated, and members volunteered to host.

‘Our study findings support past research and demonstrates how effective disability organisations can be in educating and supporting people with intellectual/developmental disabilities in staying digitally included.’

**Question: Can this be explained more as teaching people to use the internet is hard and if they do not have the internet then how do you teach them?**

We heard from Mojca that it was never the organisation’s intention to teach people about technology, this was a by-product of trying to keep people connected during the pandemic. Sixty per cent of the organisation’s staff team are people with lived experience. Stephan had made a series of online tutorials and the organisation’s ambassadors supported people until they were confident.

Overall, Danielle thought the discussion section of this article has a lot in it. One of the points that she would like to have some more information on is in the section saying, ‘Our study found that adults with intellectual/developmental disabilities were able to meaningfully participate online and felt socially connected through their computer screen.’

**Question: Danielle would like to know how many people didn’t interact online.**

Mojca told us that at end of the 12 months, 70 per cent of the membership did not engage online, which they were very concerned about. However, it had been one of the most successful years in their history in terms of participation and engagement. The focus of their paper had been about the 30 per cent who did join in with activities online, to tell an upbeat story of record numbers of participation.

Danielle found the answers to her questions useful and interesting. She was pleased to find out more about how the
organisation worked together to encourage everyone to be involved in the planning and hosting of online Facebook events and that everyone was encouraged and supported to participate. She was impressed by the content of the online tutorials and will use them herself in future work.

4 | NATHANIEL'S RESPONSE

The Section 2a titled ‘Increased opportunity to access events’ Nathaniel found a most surprising read, especially given the statement that ‘adults with intellectual/developmental disabilities are able to build positive relationships online … that can have the same benefits as seeing people in person’. This challenged his understanding of the formation of relationships. For while Nathaniel has witnessed many positive relationships being formed through digital inclusion, he always thought that the physical nature of interaction could never be replicated into the digital world. And so, Nathaniel must thank this article for challenging his assumptions and motivating him to revise his thinking. A query Nathaniel found however, was while reading this section and coming across the sentence ‘they are able to find out which other people have similar interests and build true and meaningful relationships’.

Question: The question the above quote inspired is: for the relationships that were created during lockdown, did persons experience friction or anxieties leading up to the end of lockdown when some persons would have returned to in person spaces and others stayed online?

We heard from Aaron that they found significant relationships were established by meeting online. For Aaron it was better because it was more accessible. He told us that the organisation is great because it does both online and in person events so he can choose which events he wants to go along too.

Nathaniel found the focus on persons given autonomy and respect to support or let go of their relationships as they saw fit very much in keeping with respecting the individual’s right to decide the shape of their own lives, including the individuals within it. This is in keeping both with the ethos of Grace Eyre and Speak Out as well as other organisations involved in the learning disability community. Also, the choice of online and in person provision means different platforms remain open so that wider accessibility and opportunity to build and maintain relationships can continue which he found very encouraging.

Nathaniel is aware the hybrid model is essential from the perspective of including the group, but it does pose the question of how easily or how many relationships that were founded during lockdown, when digital meetings were the only way, have fared in the time of hybrid inclusion especially for persons who find themselves preferring different environments when given the choice? Following from above conversation the article explores in 2b ‘increased sense of safety meant people felt more able to take chances/risks’. Nathaniel found this a most enlightening and inspiring read. He found while reading certain points such as familiarity of one’s home environment removing anxiety of new spaces and the removal of the anxieties and distress that can go with transport, spoke true to his own experiences during and shortly after experiencing significant trauma. But given he was able to overcome these barriers, and not wishing to dwell upon those difficult memories, he also had lost the perspective of those who continue to face these barriers as expressed in the article an online meeting can circumvent these challenges, and thus foster a sense of safety. Furthermore, the opportunity for persons to engage in meaningful discussions on their own terms, without direct parental involvement, is a significant step forward and has been a key discussion point in the ‘Being heard in Government’ group he attends that Speak Out facilitates. And he will share this insight with the group in the hope that they can find ways of implementing this approach. This would benefit fostering ownership both between persons with lived experience who are meeting each other and encourage local government to directly engage with the person/s of lived experience where possible directly.

Having said the above, it is also true that through work and volunteering Nathaniel has heard many concerns over internet safety, especially in cases where groups are open to new members joining during the pandemic—‘since membership to the organisation is open to any adult with a disability’—and these new attendees would not be known by the pre-existing group. The difficulty comes when this results in harmful behaviour from the new attendee which could have been screened out more effectively through the process and structures that often accompany in-person groups. Or conversely situations where the new member feels excluded having not had the shared experience of before lockdown with other members of the group.

Question: Thinking about these scenarios that Nathaniel has heard lived experience of, he was wondering during the online events how the organisations that were involved in the study ensured the inclusion of new members during Covid. And what processes were put into place to ensure the safety of the pre-existing group would not be threatened?

Stephan told us that existing members welcomed new people with open arms, like a ‘big cuddly blanket’ to join the community, reflecting the ethos of the organisation. People feeling threatened couldn’t be further from the truth. This was seen in the ‘chat’ where all the messages to new members were warm and welcoming. Mojca added that co-ordinators cross-checked every member, the groups were open to registered members only, and that members signed up to a community agreement to ensure meetings were a safe space for all.

Nathaniel initially found the answer to the question seemed to deviate from the question he had in mind because the answer focused on the mindset of the group rather than the questions of health and safety which he had envisaged the question leading to. That being said, it was really good to hear that everyone is welcome, and that courage to embrace new members links very much to the capabilities and strengths of the community to continue to create and grow relationships in a time of change. Also, when clarifying his question, he did find that the organisation was very much aware of
and had taken actions (such as through the existence of closed groups) to ensure a level of safety within online groups.

Turning from Digital Inclusion from the standpoint of safety to digital inclusion from the standpoint of the ease of access on digital platforms, in 3b the article states ‘Active role modelling may lead to more people feeling confident to take leadership opportunities.’ The article goes on to cover the sense of ownership and problem-solving capabilities within not-for-profit organisations. In addition, the article states ‘Our study findings support past research and demonstrates how effective disability organisations can be in educating and supporting people with intellectual/developmental disabilities in staying digitally included’.

Question: Nathaniel was wondering based upon this if you could expand upon what digital platforms worked well for engagement and the growing opportunity of ownership within these events and meetings, and what digital platforms proved the least adaptable and accessible?

Mocja said that Zoom and Facebook worked very well and that the organisation held training sessions to support people to use the online platforms. The membership found Zoom more accessible than other online meeting platforms.

Nathaniel found it encouraging to hear that Zoom and Facebook were accessible platforms, as these were also the platforms of choice for the friendship group which Grace Eyre supports as well as for meeting purposes (on the Zoom side) for Trustees with lived experience. He wishes he had more time in the session to ask exactly what aspects made them more accessible, but that the general truth holds across organisations, and indeed countries is, he thinks, most promising. Also, it was wonderful to hear about the collective support, as well as training provided on how to use Zoom. ‘We become experts together’, seemed a very fitting and apt statement to reply to this answer and indeed holds true for the answers throughout. Nathaniel would like to thank the individuals for giving their time for a wonderful session, and hopes the community referenced in both the article and the feedback session continue to flourish.

5 | NOELLE’S RESPONSE

The paper is clearly written in accessible language and has an impressive research brief. Noelle was struck by the responsiveness of the grassroots organisation—they clearly know their membership well—and the speed at which they got going with their enquiry, getting the first questionnaire out to participants in June 2020. There is a lot to like about the inclusiveness of the methods, notably the co-analysis of the data and the co-writing of parts of the paper and that members of the grassroots organisation were active participants in the research team. Noelle’s questions to the authors reflect her interest in inclusive research methods and are about furthering her understanding of levels of engagement and participation.

‘self-advocates contributed to analysing the data’

‘[self-advocates] contributed to writing the introduction, results and discussion section’

Question: How did you manage the practicalities of collaborative analysis and writing?

Natasha told us that the research was true collaboration between community and university. They adopted an accessible and inclusive approach to ensure they met the needs of all researchers involved in the project. The analysis and writing took place in a series of Zoom meetings in a safe environment where they could pause at any point if someone wasn’t sure what was happening. The research data was pulled together and what was useful to answer their research question was presented in an accessible format that they were able to talk through, repeatedly asking, ‘Does this make sense?’ The writing took place over a period of 18 months.

Question: How were the participants recruited?

We heard from Aaron and Mocja that participants were recruited from the membership who attended Zoom events. The creation of a weekly 1-h meeting, ‘Monday Magic’, was their response to the Covid-19 pandemic. Members of the organisation were able to take active roles in a self-determined way. A core group of around 30 members came up with some ‘really cool stuff’ every week. And at the end of 12 months this core group had created 415 events (including Facebook live, seated exercise, Zoom events). What they wanted to do as their initial response to the pandemic was to ask if they were still meeting their organisation’s objectives of increasing self-determination, reducing isolation and loneliness, and increasing emotional awareness and resilience. Evidence that they continued to reach their objectives through their online engagement was found in members questionnaire responses.

Question: Were any/all the researchers also participants?

Stephan said that three of the co-authors were also participants. The work was open to all members, and the people who co-authored this paper were those who had ‘stepped forward’.

Question: Why were people with more complex needs not represented?
Stephan told us that at the time only a fraction of the membership was able to access the online offering. An audit showed that people with complex needs were facing multiple barriers to online access, such as staffing support and (maybe) staff attitudes that online events were not for the individual. No one was excluded on the basis of their support needs.

**Question:** How many online activities were recorded in field notes? Were field notes taken at different activities and via different platforms? It would be useful to know given the high number of events taking place each week and the conclusions drawn from the fieldnotes.

Mocja reported that all the meetings were recorded in the field notes and demographics were also noted. Extracts from the notes informed the analysis for their article. In total this included 223 Zoom meetings plus 415 member-led Facebook events in a 12-month period.

**Question:** How did you assess or measure ‘connection and empowerment’?

We heard from Mojca that connection and empowerment was evident in the way that the organisation’s members worked together. Online events were developed and organised through peer-to-peer support. Stephan, get2gether’s digital ambassador had developed a series of online tutorials. The online events were member-led. People made friends. There was a sense of ‘we are all in this together and we will get through this’.

Noelle appreciated finding out more about the processes of the collaborative research. Multiple online meetings that presented material in accessible formats clearly resulted in what Natasha described as a ‘true collaboration’. Noelle felt that the equality of the team’s warm and enthusiastic working relationships was evident when they met together and was reflected in the way that individual responses to questions were presented.

Danielle, Nathaniel and Noelle would like to extend thanks to the British Journal of Learning Disabilities for inviting them to write this In Response piece, and to the authors of ‘Now that I’m connected this isn’t social isolation, this is engaging with people’.

Staying connected during the COVID-19 pandemic for their enthusiastic, thoughtful and inspiring answers to their questions. They hope to keep in touch and look forward to collaborating in the future.

**DATA AVAILABILITY STATEMENT**

Data sharing is not applicable to this article as no new data were created or analysed in this response. Details of Brighton and Hove Speak Out’s Covid Stories project can be found here: https://www.bhspeakout.org.uk/covid-stories/.