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Big ideas that changed the world of disability: Exploring theory with self-advocates

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Abstract

Background: Inclusive research has sidelined discussion of theoretical issues with researchers with intellectual/learning disabilities. This is a situation which the Big Ideas initiative sought to change. Between 2021 and 2023, the Open University, Leipzig University and the University of Koblenz organised nine workshops to explore influential theories in disability research. The objective was to share a theory (Big Idea) that sheds light on disability with self-advocates and discuss how it relates to their experience. By making theories accessible and discussing how they relate to lived experience, we aimed to inform self-advocates and activist researchers about key concepts in disability, deepen their capacity for research and campaigning, and better equip them to activate for change.

Methods: The online workshops were evaluated by observers. These observations were used by an inclusive group of activist researchers as the basis for an overall evaluation of the project.

Findings: People with learning disabilities can engage with complex theories if these are presented accessibly alongside opportunities for reflective discussion. Input from self-advocates helps to broaden and deepen theoretical understanding.

An unanticipated but important finding was that the Big Ideas workshops created a new space in which academics and self-advocates could learn together as equals.

Conclusions: Making theory accessible and easier to understand is both possible and valuable.

KEYWORDS

empowerment issues, inclusive education, learning (intellectual) disabilities, research, teaching and learning

Accessible summary

- This paper describes workshops called Big Ideas that changed the world of disability. Experts use plain language and pictures to share important theories with self-advocates, activist researchers and academics.

- The workshops include an explanation of the theory and information about the person who developed the theory, a fun activity linked to the content of the theory and a discussion of the relationship between the theory and lived experiences.
- Learning together as equals is an important aspect of the workshops.
- Evaluations indicate that the workshops strengthen people's confidence and skills.
- Knowledge of theory matters if people with learning disabilities are to thrive as researchers and activists.

Theory really opened my horizons, showed me how small I am in this world (Steffen Martick, activist researcher, Leipzig University)

1 | HOW WE WROTE THIS ARTICLE

The article was written by members of the team which organised Big Ideas. It includes an overall evaluation by members of Barod, a group of activist researchers from Wales. This section of the article is in a different font to make it clear who wrote it. A draft of the article was sent to members of the Project Advisory Group, who added comments and reflections before it was submitted. A similar process was applied before resubmission following the valuable comments made by referees.

1.1 | Terminology

We use the term *self-advocates* to denote people with learning disabilities who use their lived experience to represent themselves. The term *activist researchers* refers to self-advocates involved in research, as advised by members of Barod. We use *professionals* to denote participants who work in the field,[1] some as *academics*. As this is a British journal, the term *learning disabilities* refers to people who globally have a label of intellectual disabilities: the term *intellectual disability* refers to the concept itself.

2 | INTRODUCTION

Inclusive research is a partnership between activist researchers and professional academics, arising from an emphasis on human rights and the rise of self-advocacy (Walmsley & Johnson, 2003). This partnership should be empowering and informative for all involved and depends on trusting and equal relationships (Chalachanová et al., 2020). In 2022, the Inclusive Research Special Interest Group (SIRG) was set up within the International Association on Intellectual and Developmental Disabilities (IASSIDD). Their manifesto[2] sets several criteria for inclusive research, including the following: making sense to people with learning disabilities; genuine partnership; respecting lived experience; and challenging people who exercise power. They argue for the use of creative, fun and funky ways to explore new ideas.

Traditionally, the roles taken by activist researchers involve designing questions, interviewing, discussing and relating findings to lived experience (Nind & Vinha, 2014; Strnadová et al., 2022). There are some accounts of participation in data collection and data analysis (Kramer et al., 2011; Sitter, 2015; Tilley et al., 2021). However, to date, there is little recorded evidence that activist researchers engage in considering and selecting the underlying frameworks and theories used to design a research project and interpret findings.

This issue was addressed by participants in Nind and Vinha's research, who argued that the inability to name a theory does not imply an inability to understand its impact on lived experience (Nind & Vinha, 2014, p. 71). Nonetheless, we, as the authors of the present paper (both academics and activist researchers) would argue that being able to recognise, name and discuss important theories and their influence contributes to an expansion of capacity and skills, and accompanies the transition from 'subject' to researcher.

References to learning about theory are scarce in the inclusive research literature. Embregts et al. (2018) investigated the competencies that academic and activist researchers thought were essential for inclusive research. The focus was on how to collaborate effectively, with no mention of access to theory. A guide to inclusive research from Australia outlines why and how to engage with activists, emphasising the role of lived experience; identification of topics and questions through discussion about what is important and relevant in this context, and gaps in existing research (Strnadová et al., 2022, p. 12). There are no references to theoretical frameworks as a way of informing research questions, selecting methods, and making sense of data.

This omission of theory as a component of the activist researcher's toolbox may reveal assumptions about intellectual disability, intelligence and capacity and inadvertently serve to exclude

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[1]The workshops were not aimed at family members

[2]https://iassidd.org/sirgs/inclusive-research/

people from full acceptance in academic communities. Theories can be particularly helpful in understanding and challenging such assumptions. Take, for example, two papers written about definition, diagnosis and support:-

In their description of the AAIDD (American Association of Intellectual and Developmental Disabilities) Diagnostic Manual, Schalock et al. (2021) claim that it employs a transformed functional and holistic approach that will empower individuals and families through a systems perspective. Despite this commitment, they neither identify nor analyse such a process, and they do not consider how diagnostic labelling erects barriers to self-determination. Here, a lack of attention to underpinning theory masks oppressive practices.

In contrast, Pariseau-Legault and Holmes (2015) use Foucault's ideas about surveillance and oppression (1975) to critique the AAIDD manual. They point out that despite passing references to social factors, the AAIDD model continues to rely on medical categories. They call this process 'biomedical paternalism' (p. 260) and suggest (using very complex language) how Foucault's ideas can explain inequalities:

This process allows both the collection of information on and self-regulation of the subject. The anatomico-politics of the body consists of individualising techniques and procedures that seek to subdue individuals by simultaneously exploiting their strengths, aptitudes, and docility (p. 253).

Pariseau-Legault and Holmes are saying that Foucault shows how the biomedical model individualises disability, making it something that must be constantly observed and measured against what is 'normal'/nondisabled. The diagnostic process reinforces this because those who are 'normal'/nondisabled, tell people who are disabled what their strengths and needs are. This means that people with learning disabilities define themselves by other people's standards. This is a type of oppression. Their conclusion is that practitioners must actively defend a person's rights, challenge unhelpful perspectives, and support self-advocacy and resistance. This is an example of how theory can illuminate lived experiences, broaden our perspectives, and support active campaigning.

The team involved with Big Ideas believe that we need to go beyond even the recommendations of Pariseau-Legault and Holmes. The valuable insights gained through reading Foucault need to be shared with the subjects of the bio-medical gaze—disabled people themselves. This supports wider calls to 'depathologise' universities to address the ableist logic that features acutely in the histories and practices of so many academic institutions (Goodley, 2024). We are interested in the role that accessible theory might play in helping to create new spaces for joint learning between activist researchers, self-advocates, academics and other professionals. Our starting point (and aim) is that exposure to theory may generate new opportunities for research, advocacy and activism across communities and academic institutions. The ambition of Big Ideas is to make critical theories easier to identify and understand. Our belief is that these ideas could, in turn, be used by all activists (whether or not disabled) to fight for their rights. As Walmsley suggested in a discussion with Nind and Vinha's research team (2014, see above), people with learning disabilities can learn about theories if the presentation is engaging and accessible.

Bigby et al. (2014) describe three approaches to inclusive research: (1) Where people with a learning disability give advice about what to do, (2) Where people with a learning disability lead and control research, and (3) Where people with and without learning disabilities work together as a group. Big Ideas uses the third collaborative approach, grounded in a social-interactive perspective on disability (Mckenzie, 2013), which sees competence as located in the community rather than in individuals. Competence arises from context, as opposed to being located solely as the 'property' of the individual. Looked at in this way, the academic community adapts to enable others to engage with theory; the onus is on those in possession of theoretical knowledge to share it in ways that can be more easily understood and digested by people with learning disabilities, most of whom have had very few (if any) opportunities to engage with theoretical concepts through formal schooling. This is a clear example of how disability has the potential to both disrupt and transform academic institutions (Goodley, 2024). It also offers a mechanism to challenge wider societal assumptions about the supposedly inherent nature of 'ability' and 'intelligence'. As such, our Big Ideas work is shaped by a focus on capabilities (Nussbaum, 1997) and co-produced knowledge (Richards et al., 2018). Conceptual understanding and knowledge is seen as a dynamic process that is situated (Haraway, 1988) and context dependent (Borghi et al., 2019; Frizelle et al., 2019).

2.1 | History of the project

Special words (jargon) and complicated language structures are perhaps inevitable when grappling with difficult ideas. However, theorists often use jargon needlessly. This can serve to maintain the status of researchers and to exclude others (Brown et al., 2020). Grove has been an academic researcher and lecturer for 40 years. Faced with theories outside her field of knowledge, she struggled to follow certain presentations at a Disability Studies Conference held some years ago. There was no attempt to explain critical theories in ways that she—and the many self-advocates with learning disabilities who were present—could understand. In discussion with two other participants, the idea of 'simple theory' was developed: workshops that explore theories with self-advocates, building their understanding and skills as researchers and campaigners.

Since 2013, there has been some movement towards the use of theories with activist researchers. Nind and Vinha's work (2014) on inclusive research shared and debated the ideas of Paulo Freire. Grove and Kremsner ran a workshop in 2014, where self-advocates engaged with ideas from Foucault, Deleuze et al. (1987) and Spivak (1988), applying them to their own lives. One person described Deleuze's theory about power structures in society (top–down, vertical, or spread as a horizontal network), as 'working in the kitchen of a café, compared to being with my friends in the group'. Participants could also relate to Foucault's insights into the effects of constant observation and assessment. Subsequently, Kremsner ran similar workshops in Austria with self-advocates. These enabled one self-advocate to take the lead in teaching undergraduate students.

TABLE 1 Big ideas workshops 2021–2023.

Workshop title	Presenter(s)	Activity	Attenders*
1. What's the problem? Medical and social models of disability 2021	Tom Shakespeare London School of Hygiene & Tropical Medicine	Snakes and Ladders board game: barriers and strategies	27(13)
2. Who knows? Paulo Freire and education for change 2021	Sadbh O'Dwyer, Hilra Vinha, University of Southampton	Brazilian Bingo—what have we learned during the talk	24(12)
3. Can I speak now? Gayatri Spivak 2021	Gertraud Kremsner, University of Leipzig and Nicola Grove, University of Kent	Cinderella Talkshow—interviewing everyone but not allowing Cinderella to speak	22(10)
4. Who is normal? Wolfensburger, Normalisation and social role valorisation 2021	Jan Walmsley, Open University	Mr and Mrs Normal fashion parade. You lose points if you look too 'normal'	18 (6)
5. Who wins? The theory of eugenics 2022	Simon Jarratt, Birkbeck College, University of London	Super top trumps card game—superheroes compete using their special powers.	17(9)
6. Who works? Karl Marx and the reserve army of labour 2022	Lee Humber, Ruskin College	Interview role play.how low will you go on pay?	17(9)
7. What is the cause of our suffering? Buddha's view of disability 2022	Mai-Anh Boger, University of Regensburg	Build or draw your place of safety. What will you take with you when you leave?	21(12)
8. Who can know? Donna Haraway and situated knowledges 2022	Lea Klöpfer, University of Koblenz	Jack's review drama: everyone in the life of Jack (from the Beanstalk fairy tale) has different views on what should happen in his life.	24(17)
9. What is your capital? Pierre Bourdieu 2023	Steffen Martick, Leipzig University Gertraud Kremsner University of Koblenz	Building Trump Tower: using different materials to represent different forms of capital	31(14)

*Numbers who self-identified as having a learning disability or autism.

As activists take more prominent roles in research (Frankena et al., 2018; Strnadová et al., 2022), it was timely to propose to three universities a series of workshops to share significant theories used in thinking about disability. Thus Big Ideas was born.

3 | THE WORKSHOPS

Nine online workshops are the subject of this paper, and they are summarised in Table 1. More were in preparation at the time of writing. Funding was piecemeal, so workshops were planned in groups of three over a 6-month period. The first series was exploratory, as the team was unsure how successful ZOOM workshops would be. The project grew organically as a result of the interest and commitment shown.

3.1 | Management

For the first six workshops (2021–2022), topics, titles and presenters were chosen by Grove and Walmsley, who originated the project. Modest University funding was then obtained for an advisory group of self-advocates from two organisations, Barod[3] and Sunderland People First,[4] with between four and

seven individuals attending meetings at 3 monthly intervals. This group discussed and selected topics, agreed on titles and reviewed materials. Members of Barod are also co-authors of this paper.

3.2 | Participants

Invitations were emailed to around 60 people, including six self-advocacy groups known to the organisers to be involved in research in England and Wales. Over time, as word spread, other groups joined, whilst others dropped out because of competing commitments. Some self-advocates attended as individuals. Colleagues from the Universities of Leipzig and Koblenz, including two activist researchers with experience in teaching theory to students, joined in the autumn of 2021. Other self-advocates and professionals subsequently joined from the Netherlands and Eire (the Republic of Ireland).

3.3 | Preparation

Theories were selected on the basis of their influence on research, historical importance, and their impact on the lives of people with disabilities. Presenters were generally known to the management team, knew the theory well, and were willing and

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[3] https://www.barod.org
[4] https://sunderlandpeoplefirst.com

able to present it in an accessible way. Titles were written as simple questions that expressed a key aspect of the theory, such as 'Who or what is normal' (Social Role Valorisation) or 'Can I speak now?' (speaking rights of colonised people). Information packs were prepared and sent in advance to participants. These comprised the following:

- Biographical details about the presenter and the featured theorist.
- Summary of the theory and applications.
- Description and instructions for an online activity.
- Definitions of keywords.
- Further reading.

Before each workshop, Grove and Walmsley reviewed the PowerPoint presentation and worked through it with the presenter to make it as accessible as possible. One important learning point was to focus on one aspect of any theorist's work. For example, when Karl Marx was the theorist, the presenter was asked to focus on the reserve army of labour as particularly relevant to people with learning disabilities.

Each pack and associated presentation took around 4 days to produce.

3.4 | Delivery

The workshops were held on ZOOM (see Figure 1) and lasted for 90 min (if held in English) or 120 min (if held in German due to the need for interpretation) at the same time of day on the same day of the week. One person from the management team acted as chairperson.

Each was in five parts:

- Introductions and agenda.
- A 20 min PowerPoint presentation of the key points of a theory presented by an expert. People were encouraged to indicate if anything needed more explanation or to put observations and questions in the chat function for discussion at the end of the talk.
- 5-minute comfort break.
- Fun activity to illuminate the theory and reinforce the learning—drama, role play, game.
- Discussion—picking up on questions and observations in the chat function, inviting people to comment upon how this relates to my life and work.

Being on ZOOM, people could contribute both verbally and through the chat function. People took turns in speaking. One facilitator chaired the meeting, and the other monitored access, technology and the chat. The workshops were recorded. Table 1 summarises the topics, presenters, activities and participants.

4 | EVALUATION

After workshop 1, each workshop was independently evaluated. Five different individuals, all academics or PhD students, volunteered for the task. They worked to a simple template to record:

- number of attendees and their roles,
- topics discussed,
- how participants engaged, and
- any notable comments.

Barod later undertook an overall Project Evaluation. Their members had attended every workshop, and had been part of the Project Advisory Group. Barod is a co-operative of people with and without learning disabilities and/or autism. There is a research team of four, three of whom live with a recognised disability. Barod does social research and evaluation, reviews academic papers for journals, and is involved in leading research projects.

The following section of this paper comprises their evaluation. To clarify that this is Barod's work, a different font is used.

5 | METHOD

To do this evaluation, we drew on:

- Our experience as members of the advisory group and workshop participants.
- Observer evaluations of each workshop.
- Recorded comments in saved chats.
- Advisory group minutes.

To start with, Bryan Collis (support worker), had 1:1 conversations with each of us about the workshops, asking

- how we had taken part,
- how we felt during the workshops,
- what we had learned, and
- what we had used in our work or personal life.

Then we read the evaluation reports. We agreed on some questions to ask—about ourselves and the evaluation reports.

Bryan took notes on these activities, and he then wrote this report. The other three members of the team checked it and agreed with its conclusions.

6 | FINDINGS—BAROD'S PROJECT EVALUATION

The Report is structured around the questions we agreed on.
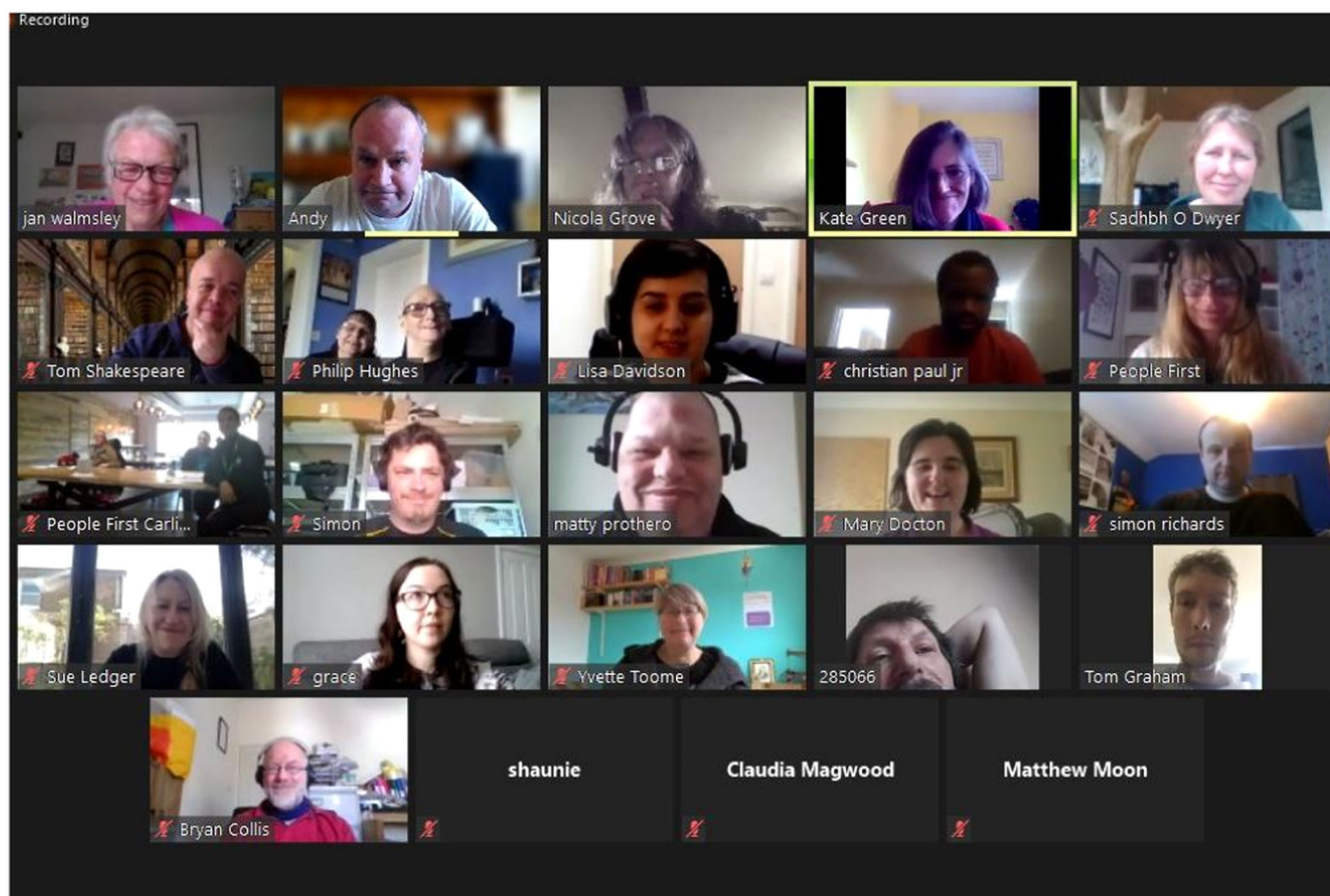
FIGURE 1 Online workshop participants. [Color figure can be viewed at wileyonlinelibrary.com]

6.1 | Who took part?

There was no formal demographic information about who was there. The evaluators went by what they saw. Each workshop had a mixture of people with and without learning disabilities, and a mixture of gender and age noted from the participants' general appearance. Ethnically, the majority were White, as were eight of the presenters, with a regular group of five individuals from British Black and Asian backgrounds. Nationally, people came from the UK (England and Wales), Germany, the Netherlands, Eire and, on one occasion, Australia. The language used was English. German participants were welcomed with some general phrases in German, and German self-advocates had a translator.

The speakers had an academic background—except for the last workshop when an activist researcher was mainly presenting.[5] They were from the UK, Eire, Austria and Germany. One had a German–Vietnamese background. There were seven women and three men speakers.[6]

We commented that the speakers' understanding of their subjects was shown in the way they could explain one key aspect of the theory in plain English. For us, this provided good learning opportunities compared with trying to read the theorist's work.

6.2 | How many people attended?

Details are provided in Table 1. The take up rate was good, given the many barriers to attendance there are for academics as well as self-advocacy groups. Thirty-three self-advocates attended at least one workshop.

Most people joined alone. One group joined on Zoom as a group with a supporter. A leading German self-advocate joined with a translator.

Having been represented at every workshop, Barod, with three self-advocates, was a regular. Three other people attended at least four workshops, including people from Berkshire, Germany and Sunderland.

Things changed during the years the project has been running. In 2021 the world was still in the shadow of Covid. The self-advocacy world was still in lockdown. As activities re-started throughout 2022, some groups became too busy to attend. Twenty people had only been to one workshop. We asked Jan Walmsley to find out why. The answer from the five who replied was that time pressures, including a

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[5]There were at least two more workshops when activist researchers were mainly presenting, but these took place after the evaluation round we used for this article.
[6]There were two presenters in two of the workshops.

(a)

The Open University
Social History of Learning Disability Group

UNIVERSITÄT KOBLENZ · LANDAU

UNIVERSITÄT LEIPZIG

BIG IDEAS THAT CHANGED THE WORLD OF DISABILITY

WORKSHOP 3. Information Pack

Can I Speak Now? Spivak's Big Idea

Nicola Grove and Gertraud Kremsner

About the Workshop

About Nicola and Gertraud

Background to Spivak's big idea

Cinderella Talkshow

(b) **Gayatri Chakravorti Spivak and her big idea**

Gayatri Spivak was born in 1942 in India. She now lives in the USA and works at Columbia University.

She is interested in
- people who are oppressed in many different ways
- how people at the margins of society can speak for themselves.

Spivak calls people who have difficulty speaking up '**subalterns**' - like soldiers who have to do as they are told.

She saw this happening in India where poor, uneducated women often do not have a voice.

The situation is worse in countries which were taken over by other nations. We call these countries 'colonised countries'.

For example, India was ruled by Britain, and South Africa was ruled by white people, although those who had lived there for thousands of years were black.

"Subaltern" people can be found everywhere in the world.

Spivak says that people who are left out don't have a say at all. They are ignored
- by society and
- by intellectuals who claim to speak for them.
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Some people actively speak AGAINST subaltern people. Others may mean well when the speak FOR them. But in the end, even they do not let them speak for themselves. They do not have the right to speak.

Gertraud did research together with people with learning difficulties in institutions. Many of them recognised themselves when they learned about the subaltern.

FIGURE 2 (a–c) Some pages from the pack for Workshop 3.[7] [Color figure can be viewed at wileyonlinelibrary.com]

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clash of meetings at the scheduled time, were the main reason they dropped out.

6.3 | How accessible were the workshops?

The titles, short and relatively simple questions, were helpful (see Table 1). Most self-advocates would understand '*Who is normal?*', '*Can I speak now?*', '*Who can know?*', or '*Who wins?*'. The titles were clear enough for one of us to opt out of the '*Who wins?*' (Eugenics) workshop as they did not want to think about difficult issues.

At every session, we spent at least 10 min on introductions because there were always new people to welcome. It meant that everyone's voice was heard at least once.

By responding to everyone, either on screen or in chat, the workshop leaders indicated that all opinions were valued. This led to a friendly and often lively discussion.

Our observation was that supporters could help make the learning richer by encouraging people to contribute and providing continuity of learning. We noted times when the support worker prompted self-advocates to remember when similar issues had been discussed in their groups. After each workshop, Bryan asked us what we had learned, which helped us remember the key points.

6.4 | Resources: Were the right resources used? Were there any good ideas or new ideas for resources in the workshop?

The materials provided beforehand and the slides used during the workshops were interesting and had picture support. Where there harder words that needed to be used, these were explained, and some feedback was requested to make sure people had understood. Figure 2 provides an example.

There was always a fun activity, a game, role play, on one occasion building something. These were designed to be a change of pace and to reinforce learning. So, to hammer home the message about who is allowed to speak (Spivak Workshop 3), there was a Cinderella role play. 'Cinders' was silenced not only by her enemies, the ugly sisters but also by her fairy Godmother and even the Prince, people who were supposed to be on her side. This really made us think. People could choose to take part or just watch. When a role play was planned, people were invited in advance to say if they wanted a part.

The workshops improved as people built experience. For example, the game in the first workshop, 'Social Barriers Snakes and Ladders'[8] required people to print things at home. Some were not able to do that and could not participate. We learnt to avoid asking people to print stuff.

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[7]Images were used extensively but are deleted for publication of the figure.

[8]In this game you throw the dice and you may land on a barrier like a set of steps to climb, or people showing bad atttitudes. This sends you down a snake, but if you can think of a way to deal with the problem, you move to a ladder and go back up. This works well in person with materials to hand, but not online.

(c) **The Cinderella Talkshow**

This shows Gayatri Spivak's point that people who are not valued, low status "subalterns" do not get speaking rights

This talk show is about the amazing romance between the Prince and Cinderella. We want to hear from everyone involved in the story. This being a national TV channel, we have to be even-handed….

And as for Cinderella herself… well, she will get her chance… at some point…

You are the audience. You can join in. You will meet:-

The Talk Show Host He is running the show. He thinks the Prince is wonderful and that the Royals are there to rule us. He loves it when people argue and get upset on his show, as then it gets in the papers.

The Prince knows he is very important and that he has done a beautiful thing by marrying a poor humble girl who will look up to him. He does like it when people bow down to him…

The Stepmother and stepsisters They feel very upset that nobody sees things from their point of view. It's not easy taking on someone else's child. They did their very best. But, honestly, this girl loves housework !

The Fairy Godmother is a real advocate for Cinderella. She made the whole thing possible and she couldn't be more delighted. Cinderella is very shy, so it is good that her godmother can speak for her.

Cinderella Nobody has actually asked her yet what she thinks.

Spivak, G. C. (1988): Can the Subaltern Speak? In Cary Nelson & Lawrence Grossberg (eds): *Marxism and the Interpretation of Culture*. Chicago: University of Illinois Press

FIGURE 2 (Continued)

Comments about the fun activities were mostly enthusiastic:

The game is good idea, it allows people to breathe and be comfortable within your own skin

The game was great

I like that idea of taking this game to the Westminster. You and me both take it to Parliament and see what episodes they have in Access and capacity in who we are and not WHAT we are

One person preferred discussion:

I prefer discussion, I found the game non-productive

6.5 | Were the workshops effective? Did they achieve their goal of helping people learn theory?

There was evidence in all the workshops that self-advocates were able to relate the big idea to their own lives or the lives of people they knew. People told stories from lived experience, such as not being listened to. Big Ideas helped people generate new insights for themselves.

Saved chat messages illustrate that professionals did not dominate.

Twenty different self-advocates contributed 137 messages; 20 professionals contributed 132 messages.

6.6 | What was the impact on participants?

For Barod, whose three self-advocates have attended seven workshops, a discussion in the team showed that people remembered the workshops over a year later. The workshops related to people's lives and helped to understand some things in a new way.

These were the impacts cited:

Big Ideas helped us to contribute to other projects, such as the *Humanising Healthcare Project*[9] where the team helped to write the application as part of the decision-making Executive group.

Sunderland People First members reported that they had been more assertive in their work with University-based researchers.

After the workshop on '*Who works*?' (Marx)', Barod's members requested a follow-up ZOOM meeting to discuss our project with the speaker. It offered a different framework for looking at employment. As a result, one of Barod's team is looking at how

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[9]Sheffield University, ESRC funded project.

employment for people with learning disabilities is changing after COVID-19.

One participant said that the Big Ideas workshops had broadened his horizons and helped him to see different ways of looking at things. He valued the international links, which showed him that the issues faced by people with learning disabilities were similar in different countries. Another commented on how useful a workshop had been for his own writing:

> I'm researching Paulo Freire because I'm writing my own monograph and it's helped with that and on co-productive research.

Two self-advocates found the session on Eugenics, 'Who wins?' more challenging. One member avoided the workshop because the topic did not feel appropriate to their cultural background. We discussed in the advisory group whether to avoid subjects like Eugenics. Self-advocates from Sunderland People First were in favour of airing these difficult topics. They explained that their organisation campaigns on health inequalities and why people with learning disabilities die younger than other people. One was in a group that discussed LeDeR (Learning from Lives and Deaths—People with a learning disability and autistic people), the way statistics on deaths of people with learning disabilities are collected in England. All had seen that people with disabilities were low on the priority list for treatment and vaccination, both in the UK and in Germany.

> It's not historical, it's happening all the time. During Covid people's human rights were challenged, there were the DNR[10] notices. That was the reality we were facing as a team. It's important that we talk about the hard areas.

> We learned to be bolder as a team in challenging. It's what makes us strong.

> It can be a hard topic, disturbing but needs to be discussed. It wasn't easy but it's made me a better person challenging that stuff."

> I've done a small amount of eugenics work. I have my suspicions that there are people who believe in this. It's very important to keep exploring new ways to tackle it. What we are is trying to push back against it. People's lives aren't sufficiently valuable. Goes beyond DNR.

> I realised how present the theme of eugenics was. In Germany there is discussion about triage for treatment—

> disabled persons were lower on the hierarchy. So it's very present and popular.

> Learning about Eugenics meant people had a better understanding of what was behind things that happened.

6.7 | The next steps: Self-advocate leaders

Self-advocates and activist researchers from Barod, Sunderland People First and Germany were members of the Big Ideas Advisory Group. Gradually, we began to take the lead in selecting workshops—we decided on Disability in Buddhist Culture; the work of Donna Haraway on situated knowledges; Pierre Bourdieu (getting power through who you know), and Power in Schools, about Foucault, based on a book recently written by the Leipzig team.[11] The Bourdieu workshop was the first to be co-led by an activist researcher and an academic.

6.8 | Evaluation conclusions

1) Consistency of attendance is important. If it is more or less the same people at each workshop, over time, people get to know one another and are more confident in sharing views.
2) The most successful workshops have been where:
   - there was a clear agenda explained at the beginning of the workshop;
   - people were reminded that they could interrupt or use the chat during the presentation;
   - the fun activity is one where everyone can join in if they wish to;
   - people had opportunities to share experiences and get to know one another.
3) Good presenters are important. They
   - know the subject really well, so they can explain it in simple language;
   - react positively to the thoughts and ideas of people with learning disabilities.
4) Opportunities for self-advocates to lead or colead workshops will enhance the learning from Big Ideas.

6.9 | Reflections from the authors

In this section, the authors reflect on how the project has evolved into a partnership of activists and academics, learning from each other, with activists, over time, taking more prominent roles in planning and delivery. The key issues are as follows:

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[10]DNR—Do Not Resuscitate notices were given to people with learning disabilities in hospital and care comes without their consent during the early stages of the COVID-19 pandemic.

[11]This book is co-authored by self-advocates and academics. It includes texts in easy-to-read, simple language and academic language: https://www.klinkhardt.de/verlagsprogramm/2540.html

- The role of academic partners.
- Selection and adaptation of content.
- Developing scholars.

6.9.1 | The role of academic partners

As Ellis (2018) reflects, as an academic partner, it is easy to imagine that the intention to empower is enough. There were many instances, especially at the outset, where academics took the lead or closed down options—in planning meetings, for example, the agenda was set by an academic, and at the outset, academics made the decisions about which theories to select. Online, however, the chat option allows everyone who can write to contribute freely, and activist researchers and self-advocates took full advantage of the chat function from the start. This became a vivid example of a social-interactive perspective on disability (Mckenzie, 2013) where context (in this case, the role of technology) created opportunities to express their views and convey personal insights. Our competence was located in our disabled/non-disabled community rather than in individuals. Learning together in this community was genuine. Many academics and supporters were unfamiliar with, or unsure about, some of the theories being presented, as this comment illustrates:

> I have always found Donna Haraway's work really really difficult. I think I understand it a lot better now, thanks Lea! And thanks for everyone's comments which helped me understand it even more. (Academic participant)

The willingness of academics to acknowledge their own difficulties helped to equalise the balance of power and reinforce the idea that competence was located in our community. This led to a blurring of roles and identities, which contributed to the sense of a level playing field and meant that every comment was treated as worthy of a response.

Working with new ideas seemed to lead to receptiveness to different perspectives and contributions. Bryan, Barod's support worker, commented in an advisory group meeting:

> These (sessions) are unique. We don't know of another space with this mix of perspectives and it's part of what makes it special. It should grow and keep going to give others this experience. We are academic partners like a seminar in a (university) department. We know each other well enough to be ourselves and express our opinions.

The workshops created a shared, co-learning space where support workers, academics, and students learned together with self-advocates; this was a powerful experience.

Support workers both act as enablers of the learning for self-advocates and as learners themselves. Learning about theories with people who have lived experience is different from learning in a classroom or lecture theatre. It can be transformative. This shared learning experience with the people they support cements social bonds.

> One of the things I've loved. we seem to have turned a corner, we're not an add on coming in at the end. (Self-advocate in Advisory group meeting)

6.9.2 | Selecting and adapting content

Presenters made decisions about what aspects of a theory to include through their own experience and through discussion with Grove and Walmsley, the facilitators. The activities—games and role plays—proved to be popular and engaging, promoted discussion, and demonstrated in other approaches to complex topics with people with learning disabilities (Grove, 2005; Nind & Vinha, 2016; Reynolds, 2015). For example, after the Cinderella drama where the 'talk show host' keeps muting her in favour of the other characters to highlight Spivak's idea of the Subaltern,[12] there was an animated debate, with many personal examples of being oppressed by professionals or family members.

> My mum used to take care of me and treat me as a slave. My mum used to keep my money and since then I changed my idea. I have a new carer and they care for me. It's like the Cinderella story, my story. I look after my own money now.

Activist researchers gradually moved from being members of the audience to co-designing the Big Ideas programme. Workshop 9 was planned and delivered with an activist researcher, and this model was adopted for developing further workshops.

6.9.3 | Developing scholars

Much inclusive research has been underpinned by activist researchers engaging with issues that connect to their lived experience (see e.g., Armstrong et al., 2019). Big Ideas has highlighted that activist researchers are also interested in grappling with conceptual ideas that go beyond their own lived experiences—and that they are able to use them and to work with them. This is critical to a broader social vision where people with a label of learning disability are viewed as 'people first'; contributing to wide ranging societal conversations and social action, in line with Nussbaum's (1997) capabilities framework.

There were several examples in the workshops of questions that were interesting for everybody. These observations during the Haraway workshop from two self-advocates are insights that transcend the topic of disability:

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[12]Spivak used the metaphor of the junior officer who has to seek permission from seniors before he can speak.

Knowledge can never be neutral. When people produce knowledge they always produce it from their own perspective. And every perspective, both of the privileged and the less powerful people, is important and valid.

Another example is from the workshop on Buddhism. The activity was to build the palace of safety that you would have to leave to engage with the real world. The following comment showed insights relevant to our broad human condition:

My palace is inside my own head: We have to step outside our own palace to hear other people's perspective.

Experienced activist researchers who can appreciate and apply theories have the potential to take their place as scholars who can explore a wide variety of topics of interest, enriching and broadening the experience of academics and students alike (Goldbach et al., 2020).

It seems entirely feasible to incorporate the choice and application of theories within the model of co-research produced by Strnadová et al. (2022). Table 2 gives some suggestions.

7 | DISCUSSION

If we take the human right to inclusive education seriously, we must also give people with learning disabilities access to *theoretical knowledge* which transcends *experiential knowledge* in the context of their own biography (Schuppener & Hauser, in press). Otherwise, participation—in higher education and beyond—will remain restricted.

Big Ideas can contribute to *depathologising universities* (Goodley, 2024) by bringing together people who are interested in discussing theories—irrespective of labels. The ableist logic that pervades so many educational contexts assumes that only a certain kind of person can read, write, develop and understand theoretical concepts. Many of us—inside and outside of academic institutions—carry these assumptions with us as part of our biographies and day-to-day experiences. They (unhelpfully) risk inflecting our work, advocacy, activism, teaching and research practices at every turn. Assumptions about who 'gets' theory can also influence our individual self-concept and perceptions of what we are/are not capable of understanding. The Big Ideas workshops demonstrated that learning and understanding can be generated by and through the community and that knowledge is not simply the possession of an individual (Mckenzie, 2013). The workshop also showed that the boundaries between teacher and learner (and academic and non-academic) can be upended and disrupted quite quickly (and significantly) when theory is shared in creative and engaging ways. In this way, Big Ideas offers a radical mechanism for addressing the 'incubated forms of (…) ability privilege' which characterise so many of the institutions in which research and knowledge production takes place (Goodley, 2024, p.6).

TABLE 2 Adaptation of co-research protocol to include theory.

Training
Learning about major theories used in disability research
Connecting the theory to lived experience: making applications in real life
Reading research papers in accessible formats and discussing what underlying theories are relevant; or suggesting how a different theory could inform alternative interpretations.
Working together on choosing a theoretical framework that is helpful—or theories that can explain what has been observed
How to read and critique research papers
How to adapt, explain and present a theory to colleagues

Initiating and planning stage
What theory or theories are relevant to this research topic?
Could it/these theories add value to what we plan to do?
What would it/they add?
Does the theory relate to the lived experience of co-researchers?

Doing
Does the theory suggest what information we should collect and how we should do it?
For example, using the idea of situated knowledge in our research might suggest interviews with a range of people and professionals; Using ideas about surveillance and power might suggest analysing policy documents and observing decision making processes.

Sense making
Does the theory we have chosen explain and help us to understand what we have found out? Could another theory work better? Is there a problem with this theory? Do our findings show some new insights into this theory?

Sharing
What are some exciting ways to share our findings that bring out the role of the theory in developing our understanding?

With reference to the model by Strnadová et al. (2022), it can be said that the Big Ideas workshops facilitated the development of multi-perspective *reflection skills*, notably enabling people to

- educate themselves further and analyse their own situation,
- better understand the background of research and higher education, and
- explore the significance of theory and research for their own lives.

These reflections are associated with *emotions* because, for example, dealing with theories of power can highlight one's own experiences of discrimination or exclusion (Hauser & Schuppener, 2023). This can be painful, but the knowledge that arises from the assimilation of theoretical content can also be empowering, especially when shared. Spaces are therefore needed so that *everyone* can acquire new, relevant knowledge. In these spaces, there needs to be room to process the associated insights and emotions so that they can have a constructive impact on the lives of people with learning disabilities. Big Ideas contributed to dealing with difficult issues

experienced on a personal level by taking into account theoretical models, which helped to better understand one's own situation. Considering the criteria for inclusive research from Chalanachová et al. (2020), it can be stated that the workshops met their original aim to be empowering and informative for all involved. But particularly, through the *theoretical* aim and approach, the workshops also opened space for trusting and equal relationships, e.g. when both activist researchers and academics shared experiences of being powerless, albeit on different levels. Questions remain about how to effectively include people who use alternative communication methods such as signing or technology, whose literacy skills are insufficient to take part in the chat, whose first language is not English, or who have severe or profound cognitive impairments.

8 | CONCLUSION

The conclusion is in two parts. The first part is by the full authorial team. The final word goes to Barod's activist researchers.

Big Ideas pioneered the teaching of theory to activist researchers and self-advocates. The understanding of theory has, we have argued, been missing from considerations of how to equip people to be activists or co-researchers. Big Ideas set out to bridge that gap.

Evidence from independent evaluators and from participants indicates that it is possible to explain most theories—including ones which appear to be challenging—in a way that has meaning for people with learning disabilities.

Big Ideas has also pioneered a partnership approach, where the planning of the series has increasingly been a shared endeavour between academics and activist researchers. The sense of being equal partners has been important to members of the Advisory Group, whose next step is to lead workshops of their own choosing—for which external funding was secured in 2023.

Big Ideas had to contend not only with barriers perceived to be created by learning disability but also language barriers, being a partnership between England, Wales and Germany, with participants also from the Netherlands and Ireland. Its apparent success is all the more to be remarked upon. We look forward to joint explorations with co-researchers acting as leaders to extend and deepen our involvement with the community of activists with learning disabilities. If successful, concepts such as Big Ideas could function as permanent offerings. This would allow universities to fulfil their third mission to be socially responsible and truly civic (Goldbach et al., 2022; Goodley, 2024).

8.1 | Barod's conclusions

Looking ahead, we would like to see self-advocates and activist researchers continue to lead workshops. We have funding to develop this side of our work in 2024.

We are really trying to challenge unspoken assumptions, to show that it is possible to talk about and write about theory in ways that are accessible, relevant and useful to people who are not experts in that theory. We are also showing that people with learning disabilities, who are so often shut out of education systems, especially at further education and University level, can and do engage with theory if it is presented in appropriate ways. This represents a major, radical challenge to the forces that shape higher education and research. There are also implications for how many other groups in society could be supported to engage with complex ideas.

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