

Miro Griffiths – Luke McFarline – University of Leeds ICY Podcast - May 2021 Transcript

ICY Narrator: [00:00:00] Welcome to this podcast series on inclusion and education from the university of Leeds. Our research brings together experts in education, childhood, and youth studies with an aim to promote equality across family, education, policy, legal and community settings. To read more about our work. Please visit the school of education website.

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Luke Mcfarline: Hello, my name is Luke McFarline and welcome to the sixth episode of the podcast. Today, we have a very special guest. Would you like to introduce yourself?

Miro Griffiths: Uh, yeah. Sure. My name's Dr. Miro Griffiths and I'm a Leverhulme early career researcher. In the school of sociology and social policy at the university of Leeds.

So my current research is, [00:01:00] um, funded by Leverhulme trust and the university of Leeds and it's exploring young, disabled people's resistance practices and their experiences of disability activism. And by extension their participation within social movements across Europe with a particular interest in, in disabled people's social movements.

And this is because I want to understand how young disabled people participate, um, how they influence and how they affect the ways in which activist networks and disabled people's social movements engage with challenging, the marginalization, that disabled people experience, and also offering alternative visions for how society is, um, produced and how we, how we organize the social world.

Um, and this, it is got four parts to it. So there there's a survey currently, um, live where we're [00:02:00] asking young disabled people to um, give their perspectives on opportunities and challenges to engage in activism and social movements. And this will be followed by, uh, semi-structured interviews and also a couple of, uh, future laboratory workshops where we'll ask young,

disabled people from across Europe to imagine what an inclusive and accessible society looks like in the future, because we often use these terms, but they're quite abstract.

And they don't have a lot of grounding in, in the everyday practices and everyday politics. So, so I'm interested to understand how young disabled people imagine inclusion and, uh, accessibility and a just society. And finally, we'll be producing a documentary film, uh, capturing the ideas and experiences of disability, youth activism across Europe.

So it'd be a very busy project until 2023.

Luke McFarline: When will the documentary film be released?

Miro Griffiths: Uh, the release of the documentary will, will coincide with the end of the research. So it'll be around October [00:03:00] 2023 um, and it's gonna be a mixture of, um, you know, interviews with young, disabled people, with policy makers, because we're also interested in how activism and resistance practices of disabled people influence the policy making processes.

And it'll be also a way to capture and understand how young disabled people are engaging in activism and resistance beyond disability because disabled people have, um, you know, interests, they have ideas, they have opinions on a range of different issues beyond, uh, the premise of disability. So it's important to think about how disabled people are supported to engage in resistance on matters, such as environment, uh, feminism, gender, sexuality, and so.

So thinking about the intersectionality of, of resistance and activism is also something we want to explore in the documentary.

Luke McFarline: In 2017, you [00:04:00] did research into the UK disabled people's movement, the DPM, what were the major hurdles that stopped disabled young people from effectively taking part in this movement?

Miro Griffiths: So this, so again, you know, the research I'm looking at now across Europe started, um, or was born out of the research you just, you just referenced. Which was my doctoral research. And, and that was a research study, exploring young, disabled people's experiences and opportunities to participate in activism and the disabled people's movement in the UK context.

And what I wanted to try to do was understand the experiences and the perspectives of young people and established members and activists within the

movement to get a sense of the current position of disabled people, young disabled people's engagement and participation in disability activism. And what was quite interesting was this, there was, there was three areas identified.

So [00:05:00] one was around membership. The second was around organization and the third area was around future considerations. So in terms of membership, what we've identified was contemporary understandings of, of youth. When that intersects with disability was often rooted in, um, dominant ideals and normative practices surrounding the notion of youth.

So in, in, in everyday life that meant young disabled people were often shut out or marginalized from conversations and discussions because the, the notion of youthhood was seen as being passive dependent, not really an adult. So you don't really have autonomy or influence or self-determination. And when you translate that into an activist activist or social movement, um, context, what you found was young, disabled activists, not being able to, um, have opportunities to influence their views and were often only to validate [00:06:00]

the established members' perspectives on, on key issues affecting disabled people. And you also found that the, the, the, when they were asked for contributions, young, disabled people were often only engaged as members of the movement when it mattered on youth issues. So they could only really give an opinion if it was linked to.

You know, a, a campaign or a topical issue surrounding youth in the notion of, of disability youth. Whereas actually there was a lot of, um, frustration and, and, and anger felt by young, young disabled activists, because they wanted to have their experiences, their ideas, their values on a range of different issues to do with inclusion accessibility, part of the melting pot of activist discourse and activist practice.

When you're having activists come together to strategize and to think about how society should be challenged or what should be the alternative vision put forward. So when it came to membership, young people were trapped in its notion of, of not [00:07:00] quite being an established member, not quite being a respected member and only being confined to discussions on youth.

When it came to organization, there was this, um, tension, I think, between. Young disabled people who were wanting to engage in disability activism as part of a reformist agenda. So trying to push forward with the existing conditions of how society is arranged and organized, and those who wanted to

use activism as a way to engage in, in radical alternatives to the way society is currently organized.

And that showed that the way in which young disabled people thought about movements and activism was what we refer to in social movement studies is this idea of interlinking or meshwork movements. So rather than seeing this movement as a kind of self-contained disabled people's movement, it's actually a set of interlinking movements with activists, [00:08:00] engaged for different purposes, for different key topics and having different ideas as to what future organization of society should look like when it comes to inclusion, accessibility. And part of that as well, was this issue of the social model and the social model of disability remains a big idea within, uh, disability activism. But when young disabled people wanted to engage with the idea of the social model to think about its application or it's relevance in their everyday life and within their, everyday expressions of, of, of, of politics and resistance and power because of the first issue I raise in terms of, you know, youth, the notion of youth, they were, uh, disengaged, or they were mistrusted when it came to, uh, engaging in social model discussion. So those in established positions would try to shut down their conversations for fear that they would jeopardize or destabilize movement activity. And this [00:09:00] felt a, a real frustration, but it also meant that many disabled activists were excluded. And that links to my last point, really, which was this issue of future considerations, because I wanted to understand what is key to young disabled people's, uh, sustainability or development of a legacy within, uh, social movements and, uh, and disability activism and on this issue, there was real concerns about the sustainability and legacy of, of disability activism in the UK. And for the research, three issues were kind of highlighted for, for subsequent, uh, study. One was the development and the production and the archiving of knowledge. So how do we capture activists, capture activist ideas about contemporary past or future issues to do with disability and inclusion. And how do we provide that information in an accessible way to people, but not as a way to [00:10:00] determine, uh, Who should have access to activism and who should not? Because current ways of archiving knowledge within disability, activism, activism meant some young disabled activists were expected to know a lot of great detail on particular matters in order to justify their inclusion within activism and social movements.

So when information was not accessible, when the, you know, previous, uh, archives of knowledge was not available to them or not accessible to them. Or they didn't agree with it that, uh, contributed to their exclusion within disability activism. So whether we're thinking about the future, whether we're thinking about the ways in which, or movement are organized, or whether we think about an individual's influence and their participation as a member of a

social movement, there were real concerns for young, disabled people in contemporary society.

Luke Mcfarline: Were there any issues in securing and conducting interviews with individuals within the D P [00:11:00] M, were there any additional ethical considerations that you had to take as well?

Miro Griffiths: Um, there was obviously considerable ethical issues we had to, we had to think through, um, and there was also, there was also an additional issue in terms of my position because I.

I come at this, uh, not only as a, uh, a disabled academic, um, but I'm also engaged in disability policy and I as an advisor to governments and to organizations, but also I am a disabled activist and I've been engaged in disability activism, uh, since I was 14 and I'm 31 now. So for quite a long time, and within that, then when I was approaching this research, I had to think about my insider status or insider position as an individual researching activism and social movements who also belong to these [00:12:00] activists networks and social movements and have been around for a long time. So, you know, a lot of people have been aware of, of my contributions. I'm not saying my contribution are grand, but because you've been around for a long time, you, you do get to formalize and, and create sustainable networks of, of engagement.

with other disabled activists. So sometimes, you know, I would be having conversations with participants and they would be saying, well, remember when you Miro did this project or did, did this campaign and how that impacted on the way I felt about, uh, my activism as a participant. So there was a dilemma there and of how to provide a safe space for activist to discuss and think about the issues they wanted to tell me, but also being conscious about the power that I had as somebody who is familiar with the activities that they're engaged with and that the concerns that they may raise may be about individuals or groups who have a connection to me. [00:13:00] So this was about trying to build trust, um, with participants and to rec, like, as I said, recognize my, my insider position.

And a lot of this comes back to the way I think about the, the purpose of research. And I was heavily influenced when I was an undergrad, by the likes of Michael Oliver, when, uh, a disability studies scholar, when he talks about, um, the significance of research, being meaningful to, to disabled people and being meaningful to the, uh, political and economic outcomes for disabled people to, to, so that we ensure that research is leading us in a direction towards the disabled people's emancipation.

I was also, you know, thinking about that in line with, um, Howard Becker's re uh, who was a, a scholar in the seventies who talked about, you know, having to take decisions between being on the side of the oppressed or being on the side of the oppressor, because there's no, you know, neutral ground. So, so when I [00:14:00] approached this research, I thought, well, how can I do this in a delicate way?

Which takes account of the, the power I have as a researcher, but fundamentally is going to be rooted in trying to realise or contribute at least to, uh, the path towards disabled people's emancipation. So to do that in terms of practicalities, it meant, uh, engaging with this, with this idea of vulnerability, because often disabled people in research are positioned as being inherently vulnerable and, uh, as, uh, scholars and activists, uh, scholars within disability studies and activists have said for many years.

You know, vulnerability is contextual. It depends on the circumstances. And it depends on the resources and the support given to an individual as to whether they are placed in vulnerable situations. So I was thinking about how do I ensure that we meet, uh, disabled people's access requirements to take part in the research, not just as a respondent, but also me as a researcher who has a severe physical [00:15:00] impairment.

It was a recognition of what needs to be in place, um, throughout the research production. To ensure that people felt, uh, in a position of influence and authority as a respondent. So they could challenge when things either weren't accessible or were uncomfortable during their participation. And finally, I suppose, within that, uh, area as well, there's the issue of reciprocity and what is it that my research is giving back to disabled people.

And I'm, I'm pleased that, you know, a lot of research now within disability. Has moved towards co-production and collaboration, and we need to explore that further. And I make no, um, statements, you know, my research wasn't collaborative in that sense, it was done for a very particular purpose, a selfish purpose, which was obviously a doctoral, uh, doctoral research.

But there was a question throughout all my research, which was how do I create as best I can a reciprocal arrangement between myself as a researcher and [00:16:00] my participants. How do I ensure that this. Or my interactions with them benefits them. And for many of them, they told me just having the space to think through and, and to articulate their ideas on activism, on inclusion, on accessibility was significance for their own personal journey in disability activism.

Um, and hopefully, you know, as we have more people getting engaged in activism and social movements and more research is engaged in the resistance practices of disabled people. We can hopefully continue that contribution towards realizing disabled people's emancipation.

Luke Mcfarline: So one final question, which are, which is what are the barriers, which are stopping disabled people from effectively being represented in social policy formation. And what would you think would be the effective way of combating this.

So it's like if there's barriers, can you [00:17:00] see, or has research shown any clear way for better representation to, uh, effectively happen?

Miro Griffiths: Well, social policy formation. Um, it it's key, I think. And I'd say this as an academic and as an activist, um, is social policy and engagement in social policy.

Is key to disabled people's emancipation, because what that means is a realization of how welfare, social security services across the different arrangements in society, in terms of education systems, in terms of health systems, labor market access, and participation. So on, if we're going to have opportunities for disabled people to participate and have valued contributions within those different systems and arrangements.

It requires a reconfiguration of the social policy process to ensure [00:18:00] that disabled people take, take part in that. And I think at the moment, you know, we start with your first point, which was barriers. I think there's an issue with the current representation at the moment within social policy process, when it comes to disability, often a lot of attention is given to, uh, traditional charities to organizations that are not led by disabled people.

And that have got a history in, uh, the continuation of institutionalised forms or traditional forms of, of, uh, support and provision. And that has shut out or silenced many disabled activists and made disabled people's organizations and being part of that, of that, of that, um, conversation as part of that discourse surrounding the, the, the reimagining of welfare and social security.

So the first point I think, is, is this issue of, of who is currently represented within discussions. And then I think there's a problem with the way that we, [00:19:00] that we imagine welfare as it is at the moment. Often, you know, we think about it in a UK context because of our geographical position. Often we see welfare being provided in, in residual forms.

It's rooted in the idea of self sufficiency. Um, so individuals taking responsibility for their needs. Um, and of course we can equate that to ideas of neoliberalism but ultimately we have situations where disabled people and other people who rely on social security welfare are positioned as not taking responsibility for themselves as being deviant, as being, uh, mistrustful around access to, uh, welfare security.

And that creates a major problem for the way that we want to think about the importance of support for people. and I'm really fascinated by a lot of the literature with in disability studies that talks about the notion of interdependency and actually the way that [00:20:00] we organize society, our social world is organized on the basis of interdependency.

You know, as a disabled person I need support from others as much as others need support from me in terms of what I contribute in my communities in terms of what I think and how I participate in my communities. So it's thinking, I think about how we root interdependency within, uh, our welfare and our production of, of, of welfare systems and disabled people's experience of interdependency, of utilizing support for self-determination is evident.

And we see that through, uh, coalitions to disabled people internationally, we see that through statements made to the United nations committee on the rights of persons with disabilities. So the evidence is there. So I think it's about. Reconfiguring who's at the table. And it's also thinking about how to reimagine welfare differently, where it has interdependency at the central point of, [00:21:00] of, of, of building our welfare systems.

And finally, I think, and again, it's a kind of barrier and an opportunity is an issue of intersectionality and intersectionality often gets, uh, MIS misplaced or dismissed. I feel within social policy process. because it creates social policy, creates the ideal citizen, the ideal person within the process of accessing a service or a system or, or, or, or benefits.

So if you don't fit that ideal, uh, uh, archetype image, you are then seen as being problematic to the, to the, uh, to the provision of support, you can't get support, because you're seen as not being, you want benefit from it or you're seen as being deviant in the first place you don't deserve it. And when it comes to disability policy, often, this is, it, it, it, it creates a homogenized view of what it means to be a sale person.

So take something like social care. For example, social care. We [00:22:00] often equate to being for older people. And of course there are key issues

affecting older people utilizing social care. But what about people of working age? What about young people? Young children? Who access social care as a, as part of their everyday experiences of participation and engagement.

So if we think about that example, there are different experiences. There are different needs. There are different, uh, issues that are important to think through in order to make sure that support meets the needs of those different cohorts and groups. So I think trying to embed. Intersectionality within our critique and analysis of current and future social policy is key.

And again, by improv improving the disabled people's access to that, you'll have opportunities where significance of intersectionality alongside different ways that we function and be and exist in terms of interdependency, in terms of, um, contribution, the way we [00:23:00] want to rethink what it means to have a valued contribution

or to be valued by society. You can use the example of disability to unpack that and disentangle some of the ableist or oppressive tendencies that we place on the way that society is, is currently organized. And that's where social movements and activism has a key place and will remains at remain integral.

If we are to, uh, address the widespread marginalization and oppression experienced by disabled people.

Luke Mcfarline: Thank you very much for coming on the podcast. Goodbye.

Miro Griffiths: Thank you.

ICY Narrator: Thank you for listening. For more information about our work, please visit the school of education website. If you have any questions about our research, or if you would like to study with us at the university of Leeds you can contact the research center director, professor Michalis Kontopodis for further detail.

You will find all relevant links and contact [00:24:00] details in the program description.