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Take a breath: Re-imagining the disability research process

Centre for Disability Studies, University of Leeds; Keynote 2026

Introduction Section

Slide 1: Take a breath

I want to start by saying a big thank you to everyone who is involved in organising this wonderful conference. To Hannah Morgan; to Ruby Goodley and Johanna Knebel and all of the postgraduate volunteers supporting the conference; and to the Centre for Disability Studies here at Leeds, thank you.

My being here today is quite a full circle moment: I gave my very first ever conference talk as a very nervous PhD student in 2010, when this conference was based at Lancaster. I was giving a talk about disability and sex work, and I met so many wonderful people who went on to shape and support my career. To be here today means a lot to me.

My talk today is entitled, *“Take deep a breath”: Re-imagining the disability research process.* (Image description) On this slide is a cartoon image, drawn by animator Josh Slack, and adapted by Louise Atkinson, of a person sitting at a desk, against a pink background, wearing a breathing device.

Slide 2: Dedications

Before I start, I’d like to take a moment to remember a number of key disability thinkers that, as a community, we’ve recently lost. Disabled people who have challenged, fought, thought, contested and revealed the emotion, joy and art of disability.

This talk is for Anita Ghai; jes sache; Gemma Nash; Patty Burne; Judy Heumann; Alice Wong; Lucy Watts MBE; and Sally Whitney-Mitchell.

(Image description) On the slide is an image of artist jes sache’s notebook, scribbled in a bar at the end of a workshop we’d put on together for students at George Brown College, Toronto in 2012. It reads: “I live and breathe and crap disability; it is my great love affair”

In only a way jes could, jes is probably describing the relationship with and to disability that many of us in this room share.

Slide 3: Situating myself

Before I go on to share what I want to talk about today, I want to situate myself and my background a little for you. (Image description) This is me, on the right of the slide, aged about 6 I think. Sat on a beach sticking my tongue out to my Mum, who was taking the photo.

My life has always been entangled with critical ways of thinking about disability. It began as a disabled child, with deep experiences of exclusion. Even then, by weird coincidence, I was lucky to have a mother who just so happened to work with some of the brilliant British disability studies scholars of the time - people like John Swain, Vik Finkelstein, and Sally French. (Image description) On the slide I've put images of some of the texts my Mum co-edited and co-authored.

Specifically, I remember on 'poorly days' going into work with her at the Open University. I would spend my days being entertained by Vik Finkelstein being silly with the photocopier. Being around these activist scholars at the same time as navigating the difficulties of raising a disabled child in the 1980s was quite revolutionary for my mother. I was nothing but a lucky recipient. When I later became a young carer, and then adult carer, for my Mum, I learned about disability, illness, injury and care through a whole new lens.

These experiences led me to disability studies, where I found home as an activist scholar and researcher.

Garland-Thompson (2005, p. 1557) calls feminist disability studies 'academic cultural work with a sharp political edge and a vigorous critical punch.'

It was though learning and reading disabled women's *own* theorisations of the world - women like Carol Thomas, Jenny Morris, Liz Crow and Donna Reeve - that gave me the tools to centre lived experience, emotion and embodiment as core axes through which to understand the everyday lives of disabled people and their families.

Slide 4: Today
So, in my talk today I want to try and build on this history, and critically explore the power and potential of co-produced and Crip research methodologies.

This talk emerges from over 15 years of critical disability studies research around sex and love; identity and youth; disabled childhoods; studies of the pandemic; D/deaf studies and media; academic ableism; and more recently, respiratory health and illness. (Image description) On the slide are four images of books with my name on, the majority of which have been co-authored and co-edited. As a caveat, then, the majority of what I'm sharing here has not been produced by me alone - I really am indebted to the forms of collaboration and community that have produced much of the work I'm speaking about today.

Specifically, then, I want to explore how we imagine, design and enact co-production in our current moment in the academy, focusing on **intimacy, temporality (or time), and bureaucracy.**

Thinking about intimacy in research means my talk is at times purposely personal, reflexive, and emotive which, as Hiemstra and Matthews (2025: 542) suggest, helps to undermine the 'buzz-wordification' and vacuous use of coproduction' and instead provide 'an open and honest reflection on the emotional side of academic life.'

A further focus on time, forms of institutional bureaucracy, and precarity and power, avoids the perils of romanticising co-production (see Goodley et al. 2025; see also Oliver 2019 and Williams et al. 2020).

I purposefully speak *through* inquiry today 'to capture those moments of disruption, transformation and change offered by the presence of disability in the university via the research project' (Goodley et al 2025: 124).

The "data" I use in my talk are my personal stories, photographs, memories, diary excerpts, and scribbles - an archive of research experiences that I hope are valuable to you today.

Slide 5: Access
In terms of access, I've kept my slides purposefully quite simple; a copy of my script is available, and I will aim to audio describe any substantive images I use on my slides.

Some slides feature QR codes, which aren't accessible for everyone, so they also include embedded links.

To describe my physical self, I'm a short, White-skinned woman in glasses, who is wearing [describe].

In terms of my own access needs for today, as someone who lives with respiratory failure, please know that every word of my talk is purposefully scripted as a way to manage breath. I (quite literally) don't have the lung capacity to ramble, which is probably a relief to you!

I also include colleagues' voices at points to give me space to take a breath, but also to reiterate the deeply collaborative nature of our work.

Finally, I want to offer a content warning; my talk today includes themes of death, grief, illness and loss.

PART 1 - Learning from Sally - Why co-production matters

So, to begin, I want to talk through a personal story about the life, love and loss of my friend, Sally.

(Image description) On this slide is a picture of Sally, in her electric wheelchair wearing a bright pink coat (Sally *loved* pink; you'll notice she's dressed in pink in literally every photo I'm about to show…) In the photo, Sally is accompanied by her doting assistance dog, Ethan, a black Labrador, who never left her side.

I first met Sally in 2017, when she applied to become a co-researcher in a project I was working on at the time with Dan Goodley and Katherine Runswick-Cole called, *Living Life to the Fullest: Life, death, disability and the human*.

Looking back, I had no idea at that time how significant she would become to me; how she would sketch herself into my heart and soul with indelible ink; and how her life and death would reshape my personal and professional worlds.

Slide 7: Living life to the Fullest: Life, death, disability and the human
To give you a bit of background, *Living Life to the Fullest* was a three year co-produced project which aimed to explore the lives, hopes, desires, and *contributions* of disabled children and young people living with types of impairments that can bring about short/er lives and life expectancies. It is a unique disability experience that has been both theoretically and empirically overlooked (see Runswick-Cole 2010).

Reduced life expectancies tends to elicit feelings of pity and notions of despair (Runswick-Cole 2010). However, for us this didn't - or doesn't - capture the richness of young people living shorter lives.

Through virtual research environments, we established a Co-researcher Collective of disabled young women, which co-led inquiry. Through the project, co-researchers' own analyses highlighted how disabled young people are living their lives to the fullest whilst not shying away from the many complexities involved in doing so in a world shaped by ableist norms which routinely devalue them (Goodley 2014).

Not surprisingly, we found - through the stories of young people and their families - that short/er lives, regardless of length and span, are vital, desired, and valued. And that collecting and curating new stories of disability *with* disabled young people enabled a disruption of dominant and neoliberal-able (Goodley et al., 2017) fantasies surrounding lifespan, quality of life, and productivity as the root of human worth. The project had a focus on futurity embedded in an affirmative politics of disability – acknowledging disability as that which can bring new perspectives to a world obsessed with reifying normalcy and eradicating difference (see Goodley et al., 2021).

RESOURCE On the slide there is a QR code and a link that will take you directly to the Why Can't We Dream? Co-production Toolkit, which was co-produced with the Community Researcher Collective.

Slide 8
To return to Sally, on the slide is one of Sally's first messages to me upon answering our call for co-researchers; she said,

> (Image description) *Hey Kirsty, checked out the website and the list of research management people. They all have a LOT more experience than I have. I've tried university and medical school 3x and always ended up in hospital in intensive care. I used to be academic but I'm not so hot anymore. Anyway, I thought I'd give you the heads up. I'm more than happy to try and would definitely be keen to follow your direction and learn but just wanted you to know. And obviously, I still am quite sick so sometimes I might not be able to do the amount of things required on time. If this hasn't put you off, I'm excited to start!*

This early message really sums Sally up: vibrant and passionate, but with a skewed sense of her own value, exacerbated by internalised ableism and the experiences of being routinely excluded from education and work - not dissimilar to many of the disabled young people in the project.

Sally developed multiple life threatening conditions in her teens; school quickly became inaccessible and unaccommodating. She took exams from her bed and battled into university - another context which failed to meet her needs, causing her to leave prior to qualification.

Despite her brilliance, Sally was always deeply self-conscious at what she labelled as being an “uneducated person” working in an academic project.

Slide 9: Making waves: belief, trust and value

But having the flexibility to create a co-produced process that was based largely on virtual approaches, gave us the opportunity to learn with and from Sally. Throughout the project Sally challenged all of us to think differently about disability, life, death and what it means to be human.

She also challenged the way the University works, demanding that everyone think differently about what a ‘research job’ might look like, and how it can be done remotely and even, at times, from a bed or a hospital ward.

(Image description) You can feel Sally’s pride in the images on this slide. The first (top) is of Sally actually here at this conference with her fellow co-researcher, Katy Evans, and their canine partners Folly and Ethan. Sally came to present some project findings; she felt so welcome at this conference - which I think serves as a reminder of the kinds of academic spaces we should be creating.

(Image description) Other photos on this slide show Sally, Katie, Ethan, Folly and I working at our Analysis Retreat; and at a coffee date to celebrate the publication of our project text.

There’s also a quote on the slide, written by Sally in our project text (*Living Life to the Fullest: Disability, Youth and Voice)*, which she co-authored. She said:

> *‘The Co-Researcher Collective is a group of amazing, strong, young disabled women who are making waves in and outside the spheres of disability studies and activism. They have challenged me to believe in myself more, value and trust my own experience and allowed me the space to grow in the field of research. Not only that but they are bold, powerful women who have taught me that I am far more capable than I realise and inspired me to push the limits of my own and society’s expectations’ (Liddiard et al, 2022: 10).*

This is, for me, the very essence of co-production: democratising our research processes to ensure a co-created space where lived and embodied experience are meaningfully valued and shape analyses (see Liddiard et al. 2019).

Sally went on to find employment on research projects with Youth Employment UK, large disability charities, and the Open University. She also led the Canine Care project with the charity Canine Partners, who had introduced her to Ethan just years before.

RESOURCE On the slide there is a QR code and a link that will take you directly to the Canine Care Project Report, co-written by Sally.

Slide 10: Love, intimacy, grief and loss, inside and outside of inquiry
As I intimated earlier, working together, across multiple projects and pieces of writing, Sally and I developed a close relationship marked by love, intimacy, and deep solidarity as disabled women.

(Image description) On the slide are two photographs from my research journal which show the relationship Sally built with my young son. Sally adored [NAME], and [NAME] adored Sally. In the first photo, Sally is bending down from her wheelchair, engaging in floor play with him and his toy train. The second photo shows [NAME] and Ethan. Not surprisingly, Ethan's calm kindness meant that he and [NAME] quickly became the best of friends, too.

Coincidentally, when during the project I was also diagnosed with a progressive illness, Sally taught me calm in the face of panic; how to plan, prepare and persevere in contexts of uncertainty; and, most importantly, how to always find hope and joy in the everyday. When Sally died in 2024, at the commencement of a new project, which I will talk about next, the grief was quite unimaginable.

Mine and Sally's friendship was just one of many across the Living Life to the Fullest project. Co-researchers explained that their emotional ties to one another through the project were enabled through an understandable solidarity as young people living shorter lives, as well as 'access intimacy' - what feminist activist Mia Mingus (2011: np.) refers to as that 'elusive, hard to describe feeling when someone else "gets" your access needs'.

Through sharing stories, Whatsapp threads, joys and troubles, meals, trips, social care assessments and tribunals - and quite literally surviving the inequities of a global pandemic together (see Goodley et al. 2023; Liddiard et al. 2022) - we found that affirming and digital project worlds cultivated new forms of Crip community and kinship (see Fritsch and McGuire 2026).

As someone who's always been interested in an intimate politics of disability, this urges us to think about, as Alves-Bryan (2025: 75) maintains, 'the nuanced nature of love as both a binding force and a potent tool for resistance within academic research'. It also shows the value of an emotionally engaged approach that acknowledges the possibilities of co-production as a deeply intimate and relational practice.

PART 2: Thinking through Crip (slide 11)

I want to move forward a little now.

When I look across my research, an ethic of what I've come to know and describe as "Crip" is always threaded through how inquiry is imagined, designed, curated, and delivered.

Slide 12: Thinking through Crip
Aimi Hamraie and Kelly Fritsch (2019: 2) position Crip as 'the non-compliant, anti-assimilationist position that disability is a desirable part of the world.'

Crip purposefully pushes boundaries, works the edges, and contests normativity.

This understanding follows others - thinkers like Eli Clare, 1999; Robert McRuer, 2006a; and Carrie Sandahl, 2003 - who have politically reclaimed and re-defined Crip from a dis/ableist slur to that which positions disability as productive, creative, vital and joyful.

Ultimately Crip is transgressive with its repositioning of disabled lives as vital, valuable and dynamic (see Wilkerson, 2002).

For me, Crip is also connected to Rosi 'Braidotti's (2019a; 2019b) concept of affirmative ethics: the philosophical, methodological and political project of affirming the possibility of a here and now that is liveable and sustainable' (Goodley et al 2025: 122), and a focus on positive, collective, and generative actions.

Slide 13: Introducing Betty
Having shown you how I think of Crip, I now want to introduce you to a new project called *Cripping Breath: Towards a new cultural politics of respiration* (226472/Z/22/Z) - a 5-year Wellcome Discovery Award project that centres the experiences of people who have had their lives saved and sustained by ventilatory medical technologies.

Importantly, Cripping Breath builds upon the kinds of co-production we developed with Sally and others in the Living Life to the Fullest Project.

The original desire to think critically about ventilation actually emerged from my own lived experiences of becoming a ventilator user as someone now living with respiratory failure.

(Image description) On the left of the slide is a picture of Betty - she's my lovely Bipap ventilator - she supports my breathing while I sleep; to the right of that image is a photo of [NAME] playing with Betty like a toy (which he does often, usually against my direction!)

Over the last 8 years together, since diagnosis, Betty has transformed my life. Through a Crip lens, co-breathing with Betty enables my core identities of mother, carer, partner, friend, and researcher.

Her affirmative offerings infinitely challenge the typical ableist understandings of ventilation as that which is used only at end-of-life; or for those with failing or ailing bodies; and ultimately those who are deemed to have, in cultural terms, lives of lesser value (Abrams et al 2021).

So the project centres these very intimate understandings of what it's like to live on ventilation.

Slide 14: Cripping Breath: towards a new cultural politics of respiration (1/2)

But Cripping Breath is also exploring what we are currently calling a ‘new cultural politics of respiration’.

If we think about ableist cultures of pandemic recovery and response; the suffering, injury and debilitation caused through global climate crises; crises that are caused, as Fritsch and McGuire state (2026: 247), by ‘globalised structures of violence’ and ‘continuous and ongoing colonial ecological destruction’ (Mitchell 2024: 51); not to mention the acute intersections of social deprivation and respiratory health; and more recently, energy poverty and cost of living crises (see Bligh 2025; Glover et al. forthcoming), **we can see that breathing is far from only autonomous and automatic.**

Breathing is a social, political and embodied process which emphasises the need for intersectional conversations about respiratory health - both in an ongoing pandemic and as we imagine post-pandemic futures.

(Image description) On the slide are a collection of news stories, headlines and reports that reveal such inequities. For time’s sake, I’ll only give a couple of examples. On the slide is an image of Ella Adoo-Kissi-Debrah, a Black British girl who became the first person in the UK to have air pollution listed as a cause of death; and Awaab Ishak, a Black British boy who died in December 2020 from prolonged exposure to black mould in his social housing. **Entanglements of systemic ableism, disablement, environmental racism, classism and injustice.**

In Cripping Breath, we are sketching out these relationships between the micro (the lived and the embodied) and the macro politics of breathing. Our overarching aim in the project is to focus on why and how breath matters for us all as co-respirators (Górska, 2021), repositioning breath as an example of relational interdependence in that we share and embody the air as humans and non-humans, elevating breath - which is so often neglected - in analyses of some of the key socio-political issues of our times.

Slide 15: Cripping Breath: towards a new cultural politics of respiration (2/2)
In Cripping Breath, Artists-in-Residence, community researchers, academics, community organisations, and clinicians are working in collaboration to curate and coproduce new understandings of the experiences of ventilated people.

Across the project, we make use of artistic, narrative, ethnographic and archival methodologies. These are embedded in partnerships with disabled people’s organisations (DPOs), and arts, culture and heritage organisations, which centre certain kinds of knowledge within the academy in ways that can both trouble and transform theory, methodology and analysis (see Goodley et al. 2025).

On the next few slides, some of our Cripping Breath team members will take you through these approaches. Afterwards, I’ll move on to share how we are working together, centering things like intimacy, care, solidarity and community in the research process.

Slide 16: Ethnography (RECORDED)
So firstly, in our Ethnographic Stream, led by me, Julie Ellis, we are using creative ethnographic approaches with patients and clinical staff at Sheffield Teaching Hospitals to

understand more about the initiation of ventilatory treatment. Here we also want to capture the social lives of ventilatory technologies: how ventilator users' live with, relate to and emotionally engage with it as a form of life saving and sustaining technology and treatment.

Slide 17: Arts (RECORDED)
In our Arts Stream, led by me, Grace Joseph, and our two Artists-in-Residence to the project, Louise Atkinson and Jamie Hale, we are working with a group of disabled Artist and Theatre collaborators - Kate, Tatum, Stephanie, Chris, Rachel and Libby - who have lived experience of ventilation and who are co-curating artistic data via research-informed theatre and contemporary arts residencies about breath, breathing and ventilation.

Slide 18: Narrative (RECORDED)
Our Narrative Stream is being led by me, Jen Kettle, and Suzanne Glover and our Community Researcher Cooperative - Vicky, Amanda, Mitch, Libby, Ruth, Conor, Jenny, Haffizah, Connor and Sarah. The Cooperative is employing virtual narrative methods, including online interviews and photographic storytelling, to capture a range of participants' stories of ventilation.

Slide 19: Archival (RECORDED)
And finally, in the Archival Stream, Kirsty, and me, Louise Atkinson, are undertaking virtual archival research with three lived experience archival researchers, Annie, Haffizah and Ruth.

Our first foray into moving away from the more traditional approaches to archival research has been through our Museum of Breathing, led and created by me as someone interested in collections.

In my own words, *The Museum of Breathing treats social media as both exhibition space and research repository. The feed becomes a living collection shaped by visibility, access, platform governance and audience interaction, raising urgent questions about preservation and authorship in digital contexts. By “cripping” archival material, the Museum of Breathing proposes a more inclusive, process-led model of collecting, one that documents artistic research as archival practice and reframes collections as dynamic, politically charged and collectively negotiated sites of knowledge production.*

RESOURCE On the slide there is a QR code and a link that will take you directly to the Museum on Instagram.

Part 3: Cripping the temporalities of the research process (slide 20)

Now that we’ve told you about the project, I want to move forward to talk about how we are develop a working ethic of Crip across the project; creating the kinds of project environments and cultures whereby intimacy, care, and community are not accidental by-products, but desired, curated and at the centre of knowledge creation.

Slide 21: Taking our time, slowing down, and speeding up
As Goodley et al. (2025) state, ‘disability drives a rethink of how we understand and work with one another in the university’.

Driven by the legacy of Sally as the lynchpin in our relational approaches to co-production, in Cripping Breath we see Crip time as a way to think about temporality, connection, and interdependence.

In practice this means embracing flexibility, adaptability and radical care across the team, recognising we all bring various types of impairment, embodiment, and chronic illness (see Piepzna-Samarasinha, 2018), as well as forms of caring responsibilities for intimate others.

As we know, Crip time refers to the relationships between disability and time. Alison Kafer says of Crip time (Kafer 2013: 27): 'Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen on time, recognising how expectations of "how long things take" are based on very particular minds and bodies….'

Petra Kuppers (2014: np.) states '...there is the day we lie in bed, the time of pain blooming in our bones, the end of the street impossibly far for limping legs, the meeting and its noise assault set against the reassuring tick of the wall clock at home'.

For Rodgers et al. (2023: 1482), speaking in relation to the ableist temporalities of the neoliberal university, they say 'the concept of crip and cripping time in relation to disabled academics opens up new ways of thinking, doing, and being that are not constrained by normative (clock) time that marginalises disabled subjects'.

RESOURCE On the slide there is a QR code and a link that will take you directly to a blog post some members of the Cripping Breath team wrote in the online medical humanities blog, *Polyphony*.

So, I want to now offer some concrete examples of how we are trying to embed and enact working in Crip time in the project.

Slide 22: Timescapes of co-design
Firstly, it began at the stage of co-designing the project in preparation for the funding application. To enact a co-production process that recognised it as a relational labour rooted in a feminist ethic of care, we took our time, and never felt rushed; and accounted for illness, vulnerability, slowness, and forms of ableism within the development process. Importantly, to support this, we gained seed funding to pay partners and collaborators to co-author the project application (see Liddiard et al., 2024).

Secondly, we co-designed a 5 year project (2024–2028). This allowed us a full first year to come together as a very large and diverse team of 34 people: One PI (me); 3 co-investigators; 4 research associates; 2 Artists-in-Residence; 10 community researchers; 6 clinical advisors; 6 artist and theatre collaborators; 3 archival researchers (and a partridge in a peartree)! We all enter the project from different backgrounds, disciplines, locations, experiences and career levels and contexts. Such transdisciplinarity and *difference* demands careful work, to appreciate each others' perspectives and enact access in considered ways.

Thirdly, to recruit and establish our Community Researcher Cooperative, we enacted a purposefully slower timeline. To recruit, we developed an accessible process that embedded plain English, British Sign Language, and Easy Read applications, followed by online accessible interviews, and a flexible and welcoming onboarding process (see Foulds 2025).

In the next slide, our Community Researcher Lead Suzanne Glover will share her work with the Collective.

Slide 23: Our Community Researcher Cooperative (RECORDED)
Such approaches led to us recruiting a beautifully diverse team of community researchers (image description) shown here on the slide. Aged from 18 to 60+, with varied experiences of ventilatory technologies, some using for just a few months, others for a lifetime. People with congenital and acquired respiratory illness; people with myriad life experiences, skills, knowledges and passions.

Upon coming into the project, a programme of work commenced for the Cooperative which centred on things like co-authoring a collaboration agreement, learning about narrative research together, and undertaking a collaborative institutional ethics application.

Importantly, we designed a specific 5 year project post - our Lead Community Researcher - me, Suzanne Glover - to support community researchers' work over the course of the project. Learnings from previous projects reiterated the efforts needed to make conventional research processes accessible to those who are often new to inquiry (see Liddiard et al., 2022).

Slide 24: Flexibility, fluctuation and facilitation
The space for community researchers to explore and co-create on the project is organic to the often-changing needs of the team. The Co-operative encourages flexible working patterns which aim to dismantle neoliberal-able (see Goodley, 2014) needs for consistency and routine. Instead, the Co-operative facilitates a space that enables fluctuating work patterns around other commitments, periods of ill-health and simply harnessing windows of "good health" to 'live'.

Practically this is implemented with online meetings, recordings, asynchronous working, one-to-one informal conversations, group messaging and short and discreet reflexive tasks - spaces not bound by specific means of contribution, but instead open to input in ways most comfortable to community researchers. Our Lead Community Researcher (Suzanne Glover) and Research Associate (Jen Kettle) work closely to weave and bring together ideas into a shared vision with the Co-operative.

Slide 25: Depth Vs deadlines
Furthermore, we spent our first year deeply exploring the contexts in which we wanted to collect data: gallery and theatre visits to build relationships with partners; time in hospitals to learn the cultures in which our ethnography will take place; sitting in (virtual) archives exploring the histories of medical tech; and collectively thinking through inclusive ways to recruit our community researchers.

So, rather than jumping into data collection or systematic literature reviews as often happens in the first year of a funded project, we've built in time together, learning and exploring, thinking critically together.

This “pacing” challenges what William Viney calls the “projectification” of academic research.

Viney states, ‘projects attempt to resolve research aims, questions, collaborating organizations, methods, and outputs before beginning their work…In the economic life of the project human lives – contract workers, participants, ‘patients’ – are rendered as technical inputs and outputs, so the performance of projects can be measured, graded, and optimized’ (Viney, 2024: np).

Similarly, Loureiro (2024) highlights the ‘endless array of metrics imposed by research funding agencies to assess the so-called “quality” and “return on investment” of our research’ and ‘an endless cycle of bureaucracy to prove we meet these arbitrary criteria—before, during, and …after we acquire funding’. I will return to bureaucracy later.

(Image description) On the slide is a piece of art - a clock featuring a yellow background with the words work, eat, sleep, shit, fuck, panic in bright pink letters - by artist Real Hackney Dave. This image represents our desire in Cripping Breath to ‘push the boundaries of what’s possible (or not) in the neoliberal academy’ in relation to pace and time; and to play with fixed and accelerated timelines’ (Liddiard et al., 2024: 11).

Slide 26: The everyday realities of sickness, slowness and vulnerability
There’s also the realities of our material bodies to consider. For the wider team, everyday project processes can and do get slowed down by prioritising flexibility around hospital appointments, taking time off sick, waiting for antibiotics and other medications to kick in, and managing sudden hospitalisations and surgeries. Without doubt, ‘living with forms of respiratory impairment can mean dealing with fatigue, breathlessness, limited energy, and a sensitivity to minor illness, whereby something as simple as catching a cold can mean weeks of recovery’ (Atkinson et al., 2024: np).

In essence, we are a project of very vulnerable bodies.

In practice, actively making space for the team to rest, recuperate and recover takes on a new meaning as we try to build in contingencies.

(Image description) On the slide are images of the types of medications and equipment it can take me to get through a work day while unwell For me, winter often means continuous chest infections from September to March.

Currently in the project, we are working through the relational ethics of contingency, as people who are ill *often*. Some advocate time off, rest, and space to recover; but this can rub up against the reality that if we didn’t work while ill, many of us just wouldn't work.

We are also considering what it means to *speed up*, thinking again through Crip time, to acknowledge that timescales are different in the context of short/er lives: the desire to progress, achieve, make a mark and build a legacy often overtakes the realities of “stopping” while unwell.

Slide 27: Death as part of the process

Another reality we are dealing with in the project is death. Early in the project, we lost Sally, and two of our community researchers, Stephen and Seán.

Markedly, as Borgstrom and Ellis (2020) assert, there is a relative lack of focus about death in research in the literature, and more specifically, its impact on researchers (see also De Laine, 2000).

Crip time is a useful lens here to resist cultural desires to sequester death away quickly and neatly - as Ellen Samuels says, ‘Crip time is grief time’ (Samuels, 2017; np).

Some key questions arose: What happens when someone dies in the research process? How should we talk, think, and feel about death in a research project? What kinds of human, and humane, responses are needed?

To all of us in Cripping Breath, these are important questions in research that aligns itself with the politics of Crip (McRuer, 2006). Death is, and will be again, present in Cripping Breath, and we need the time and tools as a team to make sense of the emotionality it brings (Harrison, 2021; Samuels, 2017).

It also requires us to think in flexible ways about who is ‘in’ the team - about the role of legacy within disability research - of Sally’s, and others’, indelible contributions. Crip time is again central to these questions of legacy because of the ways it challenges normative ideas around time, bodies, and lifespans, and specifically, the finality of death (see Ljuslinder et al., 2020).

Part 4: Bending bureaucracy (Slide 28)

For the final part of this talk, I want to focus on bureaucracy. Without doubt, research that takes place in institutions causes and demands a bureaucratic response (see Goodley et al., 2025).

(Image description) On this slide I’ve made a mock up of what an average working morning can look like in my job at the moment. For access purposes, I’ll read it out:

> 8AM - Spend an hour composing an email to the deputy vice president for research and innovation about lack of library access for artists-in-residence and artist and theatre collaborators…
>
> 9AM - Meet with the contracts team about amending collaborator agreement and IP issue
>
> 10AM - Liaise with funder about why we need to transfer funds from the university to partner
>
> 11.00AM - Meet with finance team about how we pay access support workers
>
> 12.00 - Do the IR35 process with new archival researcher roles
>
> 13.00 - Meet with research associates to discuss university restructuring implications for the project…

14.00 - Union meeting (UCU) (EAT LUNCH HERE...!)

Slide 29: Unexpected bodies, diversification and the classification of work
As you can imagine from that - as researchers and research leaders - we are required to engage with the ‘performative and bureaucratic machinations of the university’ (Goodley et al. 2025).

I want to take recruiting people outside of the academy to the project as a key example with which to think through bureaucracy.

Recruiting community researchers and others into university employment contracts was/is a (slow) process that routinely pulled us back into the administrative demands of the university.

In total, we recruited and employed 13 community researchers on casual employment contracts - the only contractual mechanism available in the university that could offer access to university systems (things like library access, email, forms of training, and *some* employment rights). HR refused to provide longer term contracts for people who worked so few and flexible hours.

However, by the very nature of “casual” employment, our community researchers have to take an enforced month-long break after six consecutive months of working so we don’t break employment law. This creates understandable disruptions to the co-production process.

We often have to find risky workarounds. In this case, we divide the Cooperative into two groups at each project phase to cover gaps, disrupting both their work and relationships as a team.

Across the project, we haven’t yet found a way of recruiting and consistently paying people through the university that actually fits the rhythms and ethics of co-production; and I think that’s significant.

Furthermore, early on, an extensive amount of labour was expended with Human Resources (HR) over why we needed small, flexible contracts at all. We also had to advocate strongly for a UK postdoctoral pay level for people who are from a range of educational backgrounds.

We certainly hit institutional and ableist barriers here in terms of what labour looks like in the academy, and who is expected to be doing it.

The institutions’ attempts to notice, manage and classify types of workers here reiterates bureaucracy as Tanya Titchkosky (2020: 200) describes it - ‘written rules developed by offices subject to lines of hierarchical organisation’.

Such bureaucratic governance reveals the university as ‘a pathological system where disabled colleagues are often not imagined to be present nor participating’ (Goodley et al. 2025: 122) and surfaces ‘the hidden labours that often get lost in the formal language of contract’ (Goodley et al. 2025: 126).

To offer another workaround, when it came to working with our Artist and Theatre Collaborators, we were conscious of the poor reputations of universities in arts communities - things like universities' parasitic values around intellectual property and slow and inflexible payment systems. This meant that we chose to recruit and pay Collaborators through our partner, CRIPtic Arts. While this facilitates a more ethical and flexible process, such an action does little more than pass administrative demands (and costs) onto our partners and let universities off the hook.

We are also now attempting to use university finance mechanisms to fund the hourly rates of access support workers for team members across the project. While tentatively agreed in multiple meetings, we have been quietly told by supportive professional services colleagues to be vague on paperwork so it doesn't get "flagged up" in the finance system. We've learnt, though, that the institution misses nothing, and we are anticipating a raft of questions and queries from the system about the reasons for - and costs of - access support, another form of labour the institution struggles to recognise or value.

It's also worth noting that all of this bureaucratic work is taking place within unfolding economic crises in British universities - rolling waves of restructuring and redundancies, particularly within the professional services infrastructures that support our research.

(Image description) On this slide is a piece of art by artist Finnegan Shannon. Shannon's *Do you want us here or not?* series challenges art institutions on their lack of seating options by providing custom-made blue benches with white text painted on top. This one reads 'it was hard to get here. Rest if you agree'. This image is symbolic of how hard it is to get into the Academy with a sick, slower or ill body, and how as suspicious bodies we can never really rest in asserting our value as disabled workers.

Slide 30: The bollocks of bureaucracy…is endless
Much of this speaks to the deep bureaucratisation of co-production as I engage with what feels like the endless performative and bureaucratic regime of the university (see Goodley et al. 2025).

Engaging with university bureaucracy might be read as what Bottero (2023: 533) calls a 'grudging act … activities in which we really would rather not participate but which we perform nonetheless'.

Furthermore, we engage in the emotional labours of bureaucracy - the 'lip service, undertaken through gritted teeth, heart sinking, keeping our head down, going through the motions, holding our nose, rolling our eyes or shrugging our shoulders' - as we negotiate project complexities while often being complicit in maintaining the status quo of the university.

But I'm trying to channel Tanya Titchkosky's (2020, 198) encouragement for us 'to explore disability's bureaucratisation in our universities, precisely because this helps us to learn something about the organising force of bureaucracy in all our lives' (see Goodley et al 2025: 125).

We could see bureaucracy as: (i) a set of practices that helpfully exposes the inequities and hierarchies of the university; (ii) a lens that shores up and makes visible top-down ableist processes; and (iii) that which reminds us of the uniqueness and power of co-produced, creative and participatory methodologies that are always complex, adaptive, and entangled.

Slide 31: Drawing some conclusions
To return to where I began - with Sally. Sally once wrote that it is through sharing our stories that hope can live (Whitney 2018).

Without doubt, the relational forms of co-production needed to share our stories of disability life are worthy of attention, now more than ever.

- I hope that my rather **messy** unpacking in this talk has emphasised the possibilities of co-production in disability research as a deeply relational, intimate and artful practice.

- Furthermore, where co-production is embedded in the politics of Crip, things like intimacy, compassion, community, connection, flexibility and radical care are made possible and can even cultivate forms of Crip community and kinship.

- I hope I’ve shown that disabled, ill, sick and slower bodies and minds can bend research design and shape methodologies in powerful ways, while resisting the very neoliberal-able temporalities within the current projectification of research and inquiry (see Viney 2024).

- Finally, I hope I’ve made visible the bureaucracy, advocacy and labour that enacting such forms of relational inquiry takes in the context of the current hostile climates and endless crises within our universities, research councils and funding bodies. We must always question the costs of bureaucracy towards the relational dynamics of co-production which ultimately rests upon trust, empathy, belonging, equity, and care.

Thank you!

Slide 32: Related talks - please come!
While I have you, I want to share that we have other talks from Cripping Breath here at the conference.

252 Cripping Breath: Co-production, community and complexity
Jennifer Kettle, Suzanne Glover, Haffizah Ali, Libby Bligh, Ruth Bridgens, Mitch Coles, Amanda Jones, Vicky Mozley, Jenny Negus, Conor O'Kane, Connor Thompson, Sarah Waters, Kirsty Liddiard University of Sheffield, United Kingdom (10:45am - 12:15pm Wednesday, 15th April, 2026)

314 Cripping Breath through Text and Performance
Grace Joseph[1], Jamie Hale[1,2], Louise Atkinson[1,3], Kirsty Liddiard [11]University of Sheffield, United Kingdom. [2]CRIPtic Arts, United Kingdom. [3]University of Leeds, United Kingdom (2:45 - 3:45pm Wednesday, 15th April, 2026)

Slide 33: References and resources.

Slide 34: References and resources.

Slide 35: References and resources.

Slide 36: References and resources.

Slide 37: Thank you

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