Living Life to the Fullest: Co-Production, Disability & Youth

Collaboration, Creativity Complexities, June 2019, Manchester Metropolitan University

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Twitter: @FullLivesESRC

E·S·R·C Economic & Social Research Council
Good Things Foundation Improving lives through digital
The University Of Sheffield.
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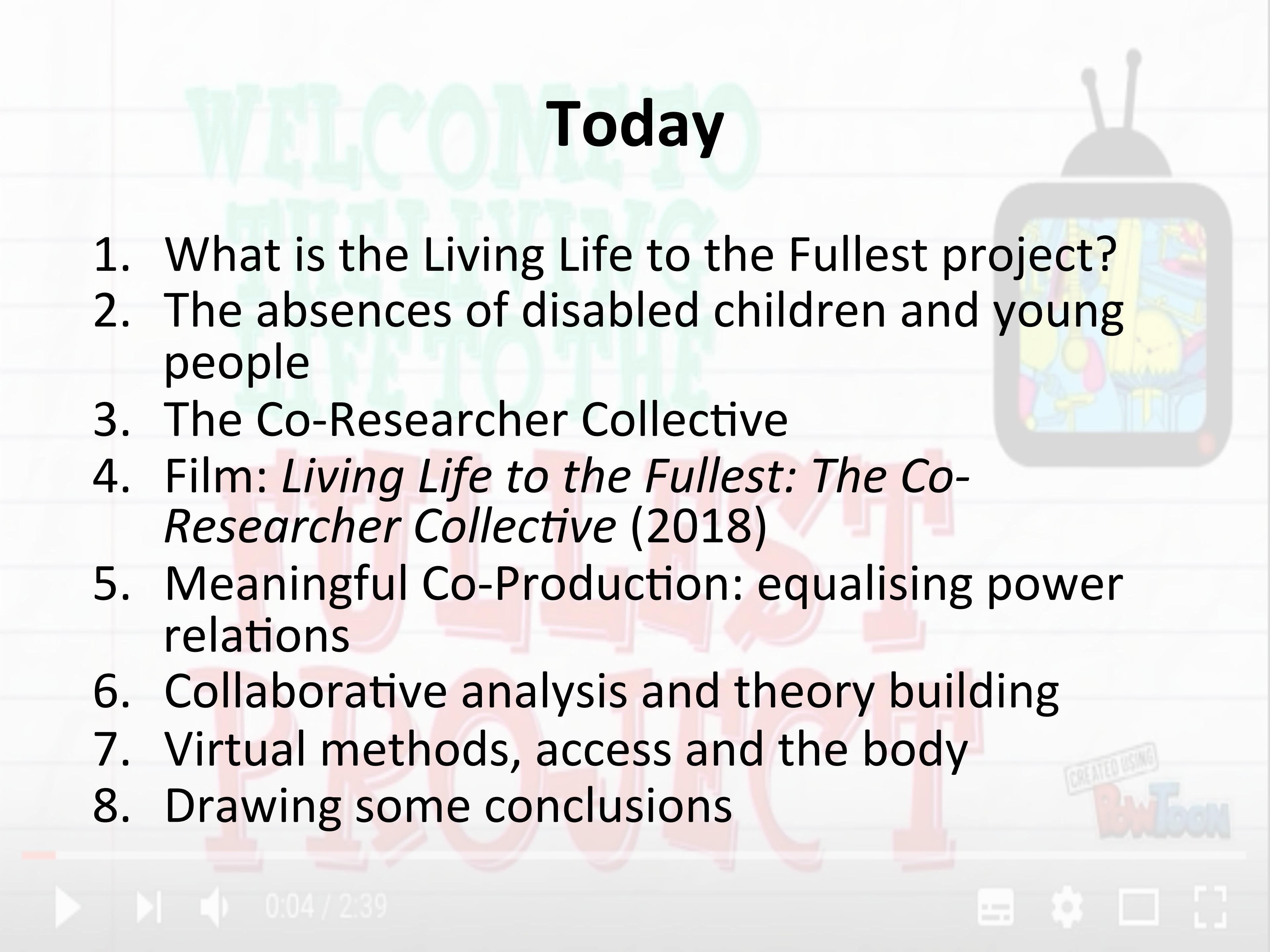
Today



1. What is the Living Life to the Fullest project?
2. The absences of disabled children and young people
3. The Co-Researcher Collective
4. Film: *Living Life to the Fullest: The Co-Researcher Collective* (2018)
5. Meaningful Co-Production: equalising power relations
6. Collaborative analysis and theory building
7. Virtual methods, access and the body
8. Drawing some conclusions

1. What is the Living Life to the Fullest project?

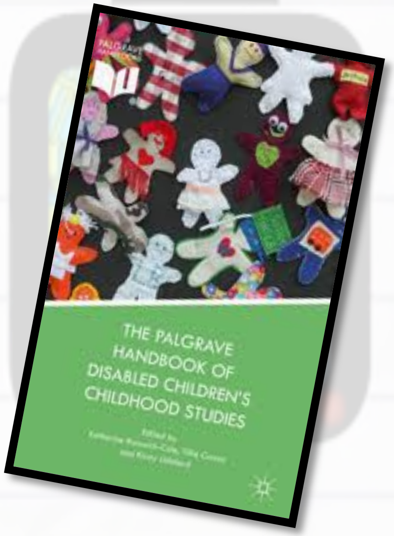
- ESRC-funded arts informed co-produced research project exploring the **lives, hopes, desires and contributions** of disabled children and young people with life-limiting and life-threatening impairments (LL/LTIs) and their families.

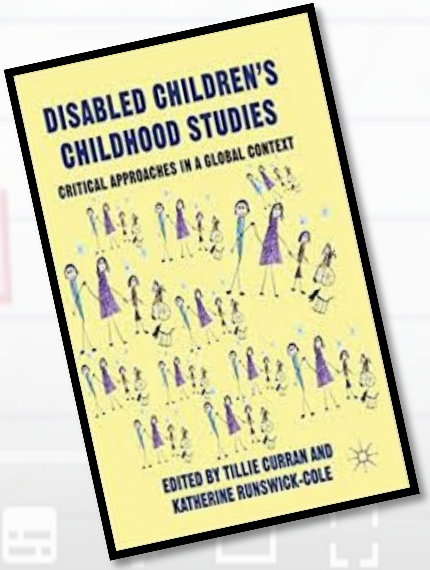
- Embedded in Disabled Children's Childhood Studies (Curran and Runswick-Cole, 2013, 2014; Runswick-Cole et al. 2018)

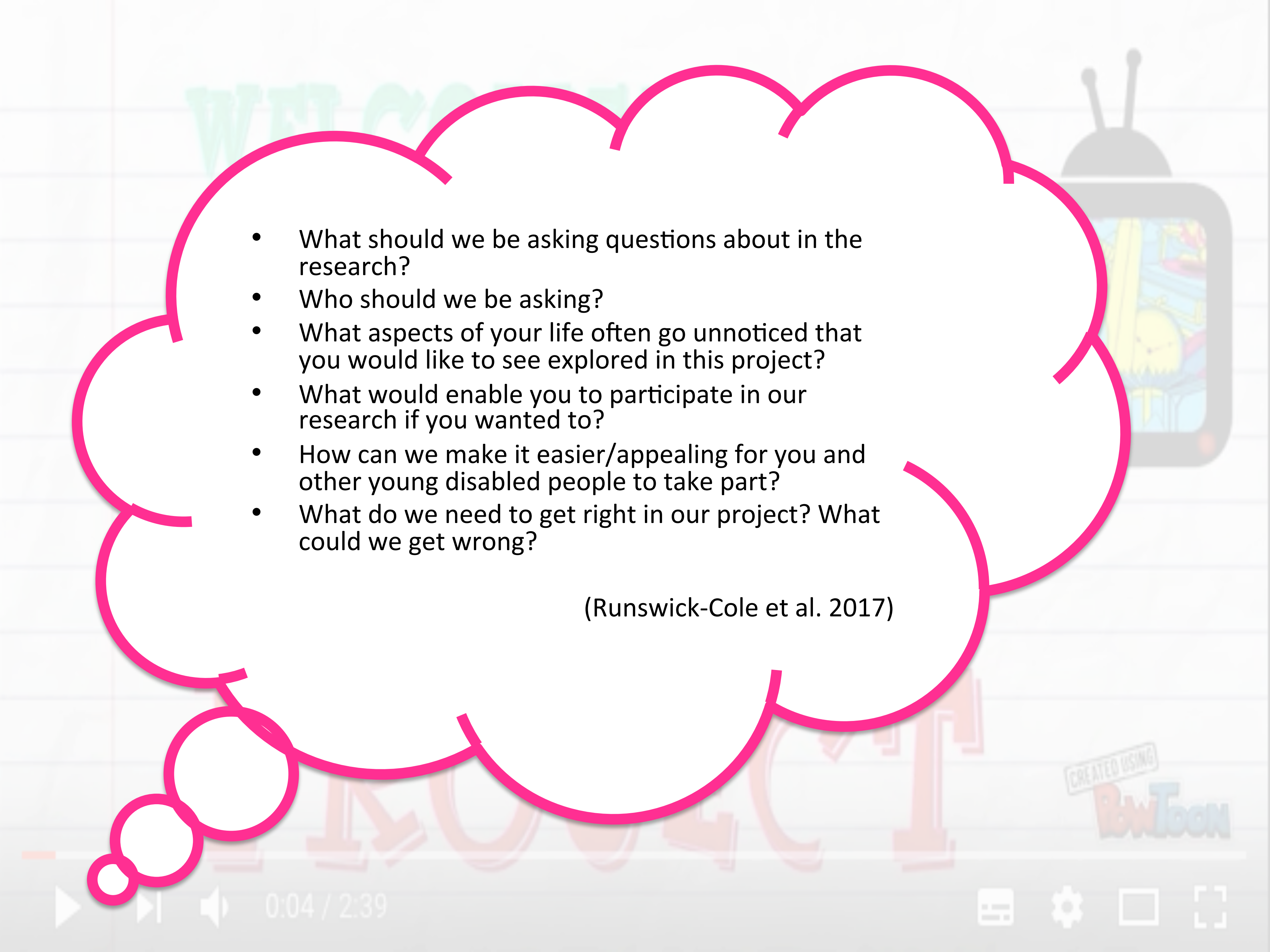
- Meaningful Co-Production: The Co-Researcher Collective, young disabled women as leaders: *"Living Life to the Fullest is a vital project looking at young disabled people like me"* – Lucy Watts MBE, Lead Co-Researcher

- Community Research Partners as vital collaborators: 1) DMD Pathfinders; 2) Purple Patch Arts; 3) Good Things Foundation

- Co-Produced from the very beginning…







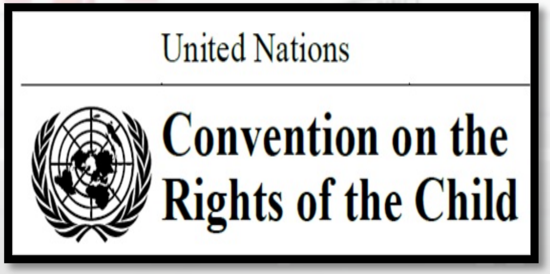
- What should we be asking questions about in the research?
- Who should we be asking?
- What aspects of your life often go unnoticed that you would like to see explored in this project?
- What would enable you to participate in our research if you wanted to?
- How can we make it easier/appealing for you and other young disabled people to take part?
- What do we need to get right in our project? What could we get wrong?

(Runswick-Cole et al. 2017)

2. The absences of disabled children and young people

- ‘Articles 12 and 13 of the UNCRC require that children should be informed, involved and consulted about all decisions that affect their lives’ (Kelley 2005: 1).

- In both childhood studies and in disability research contexts emancipatory and participatory approaches (Oliver, 1992; James and Prout, 2004) have emerged.



United Nations

Convention on the Rights of the Child

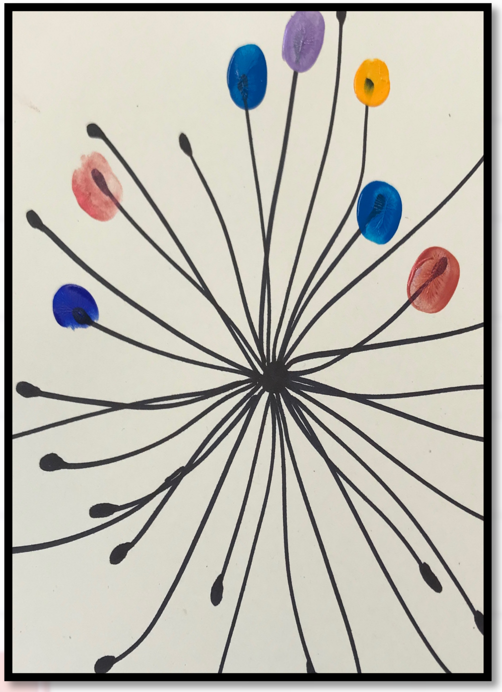
Children and young people as 'active' researchers

- '…the movement towards children as 'active' researchers has been influenced by the perceived lack of children's own voices in research about their lives and as a response to the inevitable power inequalities which are present in adult-child research' (see Kellet, 2005a).

- 'an alternative, legitimate expertise to that of academic researchers' (Nind et al. 2012: 660)

Some tensions?

- We think it is important to explore such shifts critically, not least because …
    - continued exclusion of disabled children from research;
    - continued lack of ethical response;
    - focus on adult concerns, not those of children and young people (Curran and Runswick-Cole, 2014).
- ‘Adult manipulation, unequal power-relations and the adult focus of such research’ (Kellett 2005: np).
- Carter and Coyne (2018: 172) ‘a fundamental commitment to believing that children and young people can and will shape your research, construct and challenge your ideas and bring their own ideas and agendas to the table’ .



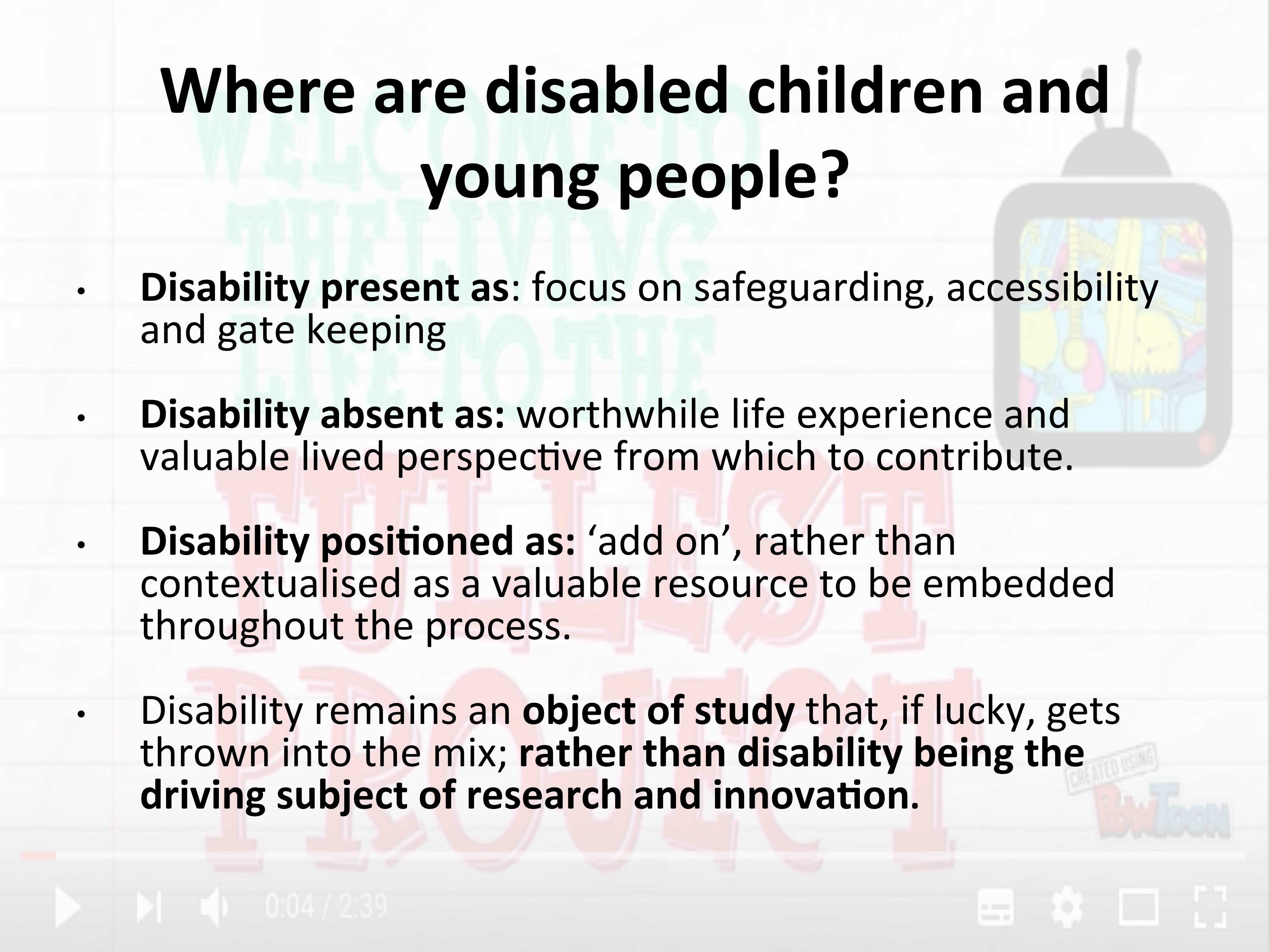
Producing Guidance…

- **National Institute for Health Research (INVOLVE, 2016)** developed guidance that stresses the importance of participation across the research process while being cautious of aspects of the research that might be 'too challenging, sensitive or inappropriate for children and young people' (INVOLVE, 2016: 3).

- **Save the Children's *Young People as Researchers*** examines issues that should be considered before undertaking research with young people, including whether or not carrying out research is appropriate, and the kind of support and resources that are often required to make the process successful' (2000: 3).

- **Joseph Rowntree Foundation's *Involving Young Researchers: How to enable young people to design and conduct research*** (Kirby, 2004), also argues for the early inclusion of young people into the process, alongside a political positionality that understands children and young people as vital contributors to health and social care research.

Where are disabled children and young people?



- **Disability present as**: focus on safeguarding, accessibility and gate keeping

- **Disability absent as:** worthwhile life experience and valuable lived perspective from which to contribute.

- **Disability positioned as:** ‘add on’, rather than contextualised as a valuable resource to be embedded throughout the process.

- Disability remains an **object of study** that, if lucky, gets thrown into the mix; **rather than disability being the driving subject of research and innovation.**

3. The Co-Researcher Collective…

4. Living Life to the Fullest: The Co-Researcher Collective (2018)

Living Life to the Fullest
The Co-Researcher Collective

Available from: https://www.youtube.com/watch?v=Ofb4MaLHz8k&t=4s

5. Meaningful Co-Production: equalising power relations

The Co-Researcher Collective – virtual leadership:

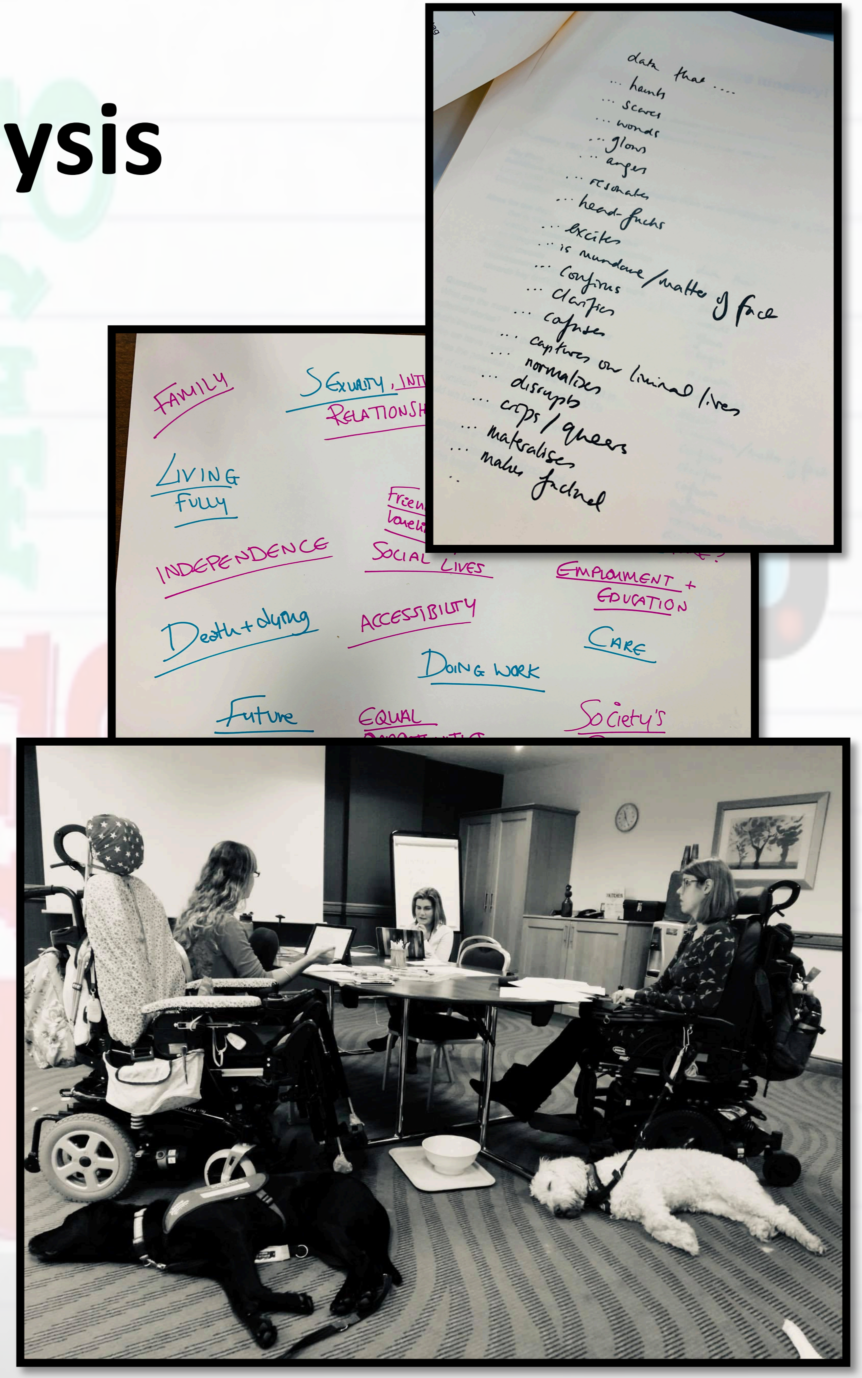
(i) Supporting research design through discussion (planning both narrative and arts-informed approaches);
(ii) Co-writing interview schedules for young people and parent participants;
(iii) Recruiting participants for data collection and carrying out online interviews through email, Facebook Messenger and Skype;
(iv) Planning the project's impact strategy and building relationships with impact partner organisations;
(v) Working with our community research partner organisations;
(vi) Meeting regularly via the Research Management Team to co-manage the research process as a whole;
(vii) Writing blogs and making films that communicate and document our processes and preliminary findings;
(viii) Presenting at conferences and research festivals;
(ix) Undertaking various public engagement and knowledge translation activities (online and offline);
(x) Co-authoring articles for publication (Whitney et al. in press; Liddiard et al. 2018).

6. Collaborative Analysis

- Some proponents of child and youth-led inquiry argue that, inevitably, there are aspects of the research process that are better managed by adults (see Nind 2008) – we disagree!

- Our co-researchers have 'an alternative, legitimate expertise to that of academic researchers' (Nind et al. 2012: 660; see also Bucknall).

- Lived experience as vital to the process.



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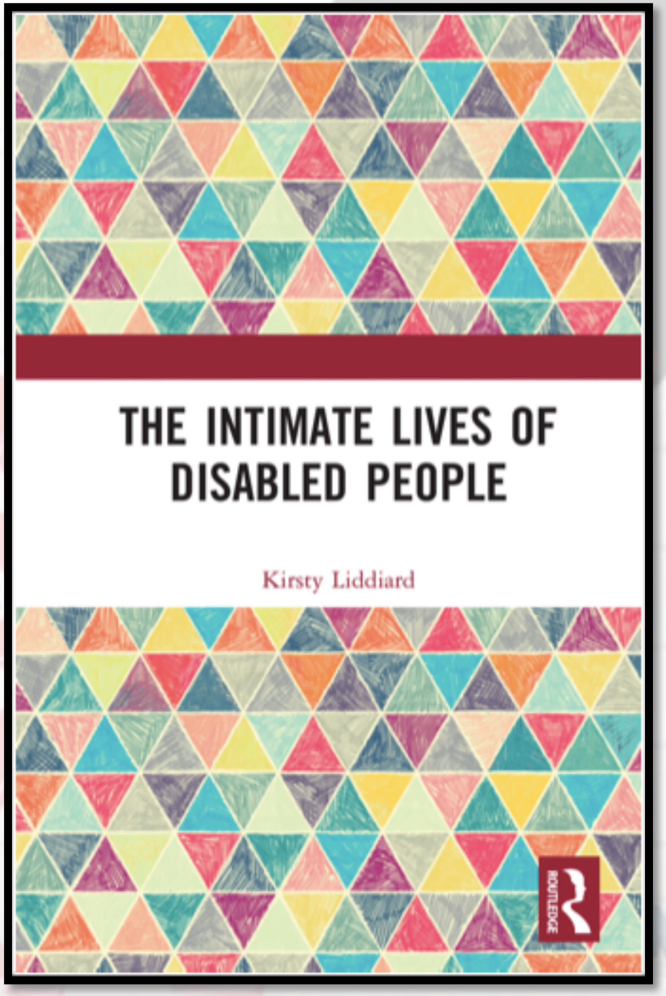
EMPLOYMENT + EDUCATION
Death + dying
ACCESSIBILITY
CARE
DOING WORK
Future
EQUAL
Society's

Identity and materiality

- Liddiard, K. (2018) *The Intimate Lives of Disabled People.* New York and London: Routledge

- Disabled identity and material and physical embodiment of impairment as ever-present within the research context.



THE INTIMATE LIVES OF
DISABLED PEOPLE

Kirsty Liddiard

Collaborative theory building

Comment from the Field

Lancaster Disability Research Conference 2018 (#CeDR18)

Katy Evans and Sally Whitney
Independent Scholars

We proudly represented the Co-Researcher Colle
the Fullest (LLttF)—an arts-informed research pro
Sheffield funded by the Economic and Social Res
at the Lancaster Disability Research Conference
for Disability Research, Lancaster (CeDR). The C
is a group of young disabled people with life-lim
conditions, who work as co-researchers in the projec
of the project from making decisions, co-leading th
collaborating in data analysis, and writing and sha
findings. The bi-annual CeDR conference, this ye
brings together people with an interest in disabil
opportunities for academics, activists, and allies to
Here we discuss our impressions of the conference
the experience.

What Were the Aims of Attending the Conference?

Sally: My aim for the conference was to represent our
Fullest, the best I could. I knew I could enthusiastica
for the project. I also knew that the film we were sh
Fullest: The Co-Researcher Collective (2018)—stood fo
co-researchers on film were amply able to promote ou
believe in what we are doing.

Katy: Disability studies was always so much more th
an opportunity to develop my identity as a disabled
who I am. It was a welcome liberation after a chil
medical model. Through disability studies, I began

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'Provocations for critical disability studies'
By Dan Goodley, Rebecca Lawthom, Kirsty Liddiard & Katherine Runswick-Cole
In: Disability & Society
Download at: https://www.tandfonline.com/doi/full/10.1080/09687599.2019.1566889

This article introduces and discusses Critical Disability Studies.

Critical disability studies thinking has developed in some complicated ways over a number of years.

We are asking some questions.

1. What is the purpose of critical disability studies?
2. How inclusive is critical disability studies?
3. Is disability the object or subject of studies?
4. What matters or gets said about disability?
5. How can we pay attention to disability and ability?

We hope these questions will help us all to think about critical disability studies.

Children & Society

CHILDREN & SOCIETY (2018)
DOI:10.1111/chso.12308

"I was Excited by the Idea of a Project that Focuses on those Unasked Questions" Co-Producing Disability Research with Disabled Young People

Kirsty Liddiard, Katherine Runswick-Cole, Dan Goodley, Sally Whitney, Emma Voge
Lucy Watts MBE
School of Education and Institute for the Study of the Human (iHuman), University of Sh
, UK

rticle, we detail the politics and practicalities of co-produced disability research w
eople with life-limiting and life-threatening impairments. We centre an ESRC-f
co-produced research project that has brought together a Co-Researcher Collective
eople. Co-production is an established approach; however, our co-researchers hav
inclusive research practices that engage with online social research methods in inno
tail our experiences, we aim to encourage disability studies researchers and others t
ironments when researching with and for the lives of disabled people. © 2018 Th
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ds: co-production, life-limiting, online, virtual, youth.

ction

ng research that involves children and young people has burgeoned across
ucational sciences over the last 20 years (Bailey and others, 2014; Clav
hlin, 2010; Hallett and Prout, 2003; James and Prout, 1997). The politics of
consulting with children, both inside and outside of the Academy, has
ological and political shifts through a prominent children's rights discours
ed an acknowledgement of children and young people as subjects-with-vo
jects of study and intervention) and experts in and of their own lives (se
nd others, 2010; Kay and Tisdall, 2017; United Nations Convention on the
d, 1989). According to Nind and others (2012: 654), such shifts have emerg
itical and intellectual backdrops of the 'new sociology of childhood and
standpoints about the importance of children's voices and children as soc
e, in a disability research context, emancipatory and participatory approach
which have emerged alongside disabled people's claims for civil rights, hav
disabled people as social actors with rights, and research as a potentially d
vity aligned to disability politics with ethical approaches rooted in social j
Zarb, 1992). Research is positioned as inherently political (Swain and oth
such has the potential to empower and/or exploit those who are its subject
itional power relations inherent to academic research must be destabilised f
n the interests of disabled people's emancipation. Thus, there are many ov
s between emancipatory disability research and child-led inquiry that are
n (Kellett, 2005b). It is important to note here that our project predominan

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medium, provided the original work is properly cited.

LIVING LIFE TO THE FULLEST
by the Co-Researcher Collective

Living life to the fullest… a simple statement, but what does it mean? And what does it mean for the lives and futures of young disabled people with life-limiting and life-threatening impairments?

This is a question being asked within our project, Living Life to the Fullest, a partnership research project of the University of Sheffield and leading disability and arts organisations, DMD Pathfinders, Purple Patch Arts, and the Good Things Foundation, as well as other supporters, like the brilliant MDUK Trailblazers.

The aim of the project is to use the arts to understand the lives, hopes, desires and contributions of this unique group of young disabled people. In today's culture, most people don't often think of young disabled people – or young people in general – as making vital and important contributions to their families, schools, wider communities and civil society.

Living Life to the Fullest recognises that disability experiences are

within the health, education and care policy that governs their lives.

Want to get involved?
Living Life to the Fullest runs from April 2017-March 2020. Currently we are looking for young disabled people and their families to participate in the following ways:

- online interviews (via Facebook Messenger, Skype and/or email) and/or telephone interviews
- an Art Retreat Workshop, run by Purple Patch Arts.

If you have any questions or want to know more about the research, do get in touch with us at k.liddiard@sheffield.ac.uk

www.livinglifetothefullest.org

Living Life to the Fullest is funded by the Economic and Social Science Research Council (ESRC)

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doi: 10.1111/1467-9566.12962

Working the edges of Posthuman disability studies: theorising with disabled young people with life-limiting impairments

Kirsty Liddiard, Sally Whitney, Katy Evans, Lucy Watts, Emma Vogelmann, Ruth Spurr, Carrie Aimes, Katherine Runswick-Cole and Dan Goodley

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Abstract This paper is built upon an assumption: that social theory can be generated through a meaningful engagement with a co-researcher group of disabled young people. Our co-researchers are theoretical provocateurs and theorists in their own right who, through their activism and writing, are challenging us to reconsider the meaning of life, death and disability. Their work on our funded Economic and Social Research Council (ESRC) project has enabled us to consider the promise and potential of humanist and posthuman epistemologies, theories, methodologies, interventions and activisms. The paper introduces the research, the authors of this paper (academics and co-researchers) and then explores three layers of analysis that work the edges of posthuman thinking; sovereign and assembled selves; affects and desires; mourning and affirmation. We conclude by asserting that as a research team we are engaging with a DisHuman approach to theory and activism: one that blends the pragmatics of humanism with posthuman possibilities.

Keywords: disability, youth, palliative, coproduction, research

Introduction

This paper is built upon an assumption: that social theory can be generated through a meaningful engagement with a group of disabled young people. This paper understands co-researchers of disabled young people as theorists and, crucially, promotes them as theoretical provocateurs. It is not simply the case that young people would explicitly identify themselves through the language or concepts of theory. Nor would they necessarily identify as theoreticians. Rather, our work with them has demonstrated the possibilities that they offer us to think about the world in different ways, which we offer here as but one definition of theory.

Our interest in posthuman disability studies has been heightened through our work on the research project, *Life, Death, Disability and the Human: Living Life to the Fullest* (hereby Living Life to the Fullest). Our study takes place in the UK with disabled young co-researchers via a Co-researcher Collective - currently five disabled young women aged 19-30 who identify as living with 'life limiting' and 'life-threatening impairments' (hereby LL/LTIs) - from across

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7. Virtual methods, access and the body

- The use of the Internet has been argued to be transformative within social and educational research (Hewson, 2014).
- In an information age where new social technologies are rapidly (re)shaping human communication, online spaces can proffer new forms of inquiry.
- Online and electronic research methods can 'substantially enhance the development of methodologies that relate more closely to the needs of research participants (Seymour 2001: 147-148)

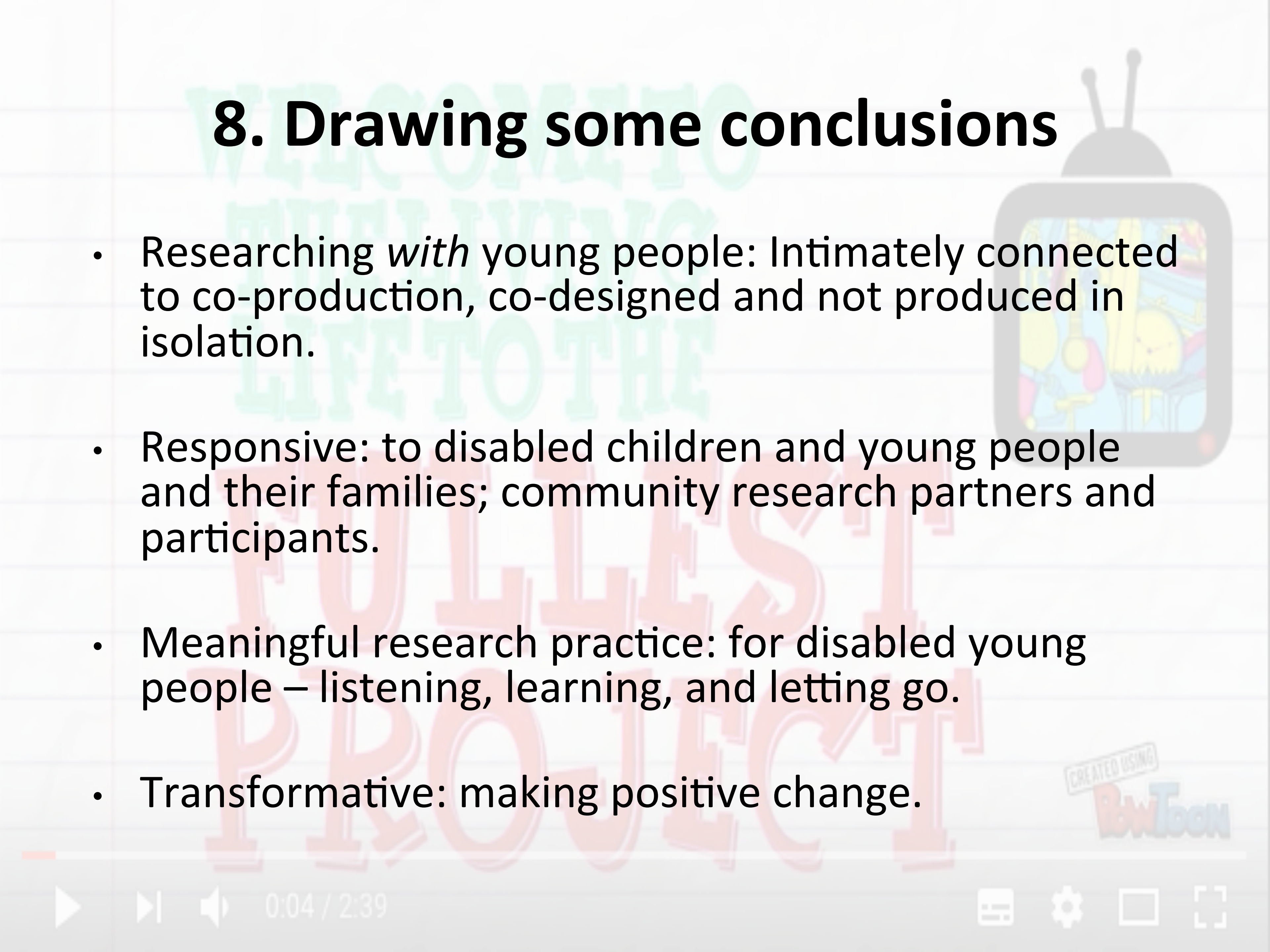
- Crip time (Kafer 2013); in Living Life to the Fullest, Crip time invites new temporal frameworks of research that embody alternative orientations in and to time.
- The realities of ‘needing more time’ - vital moments to rethink and reconsider conventional temporalities of qualitative methods and research processes.
- Centring the materialities of impairment and illness – for the benefit of researchers and participants.
- Impairment as more than an ‘unwelcome presence’ (Shildrick, 2009: 32, but that which can disrupt the embodied norms of inquiry.

Living Life to the Fullest

livinglifetothefullest.org

A research project of the University of Sheffield and funded by the ESRC

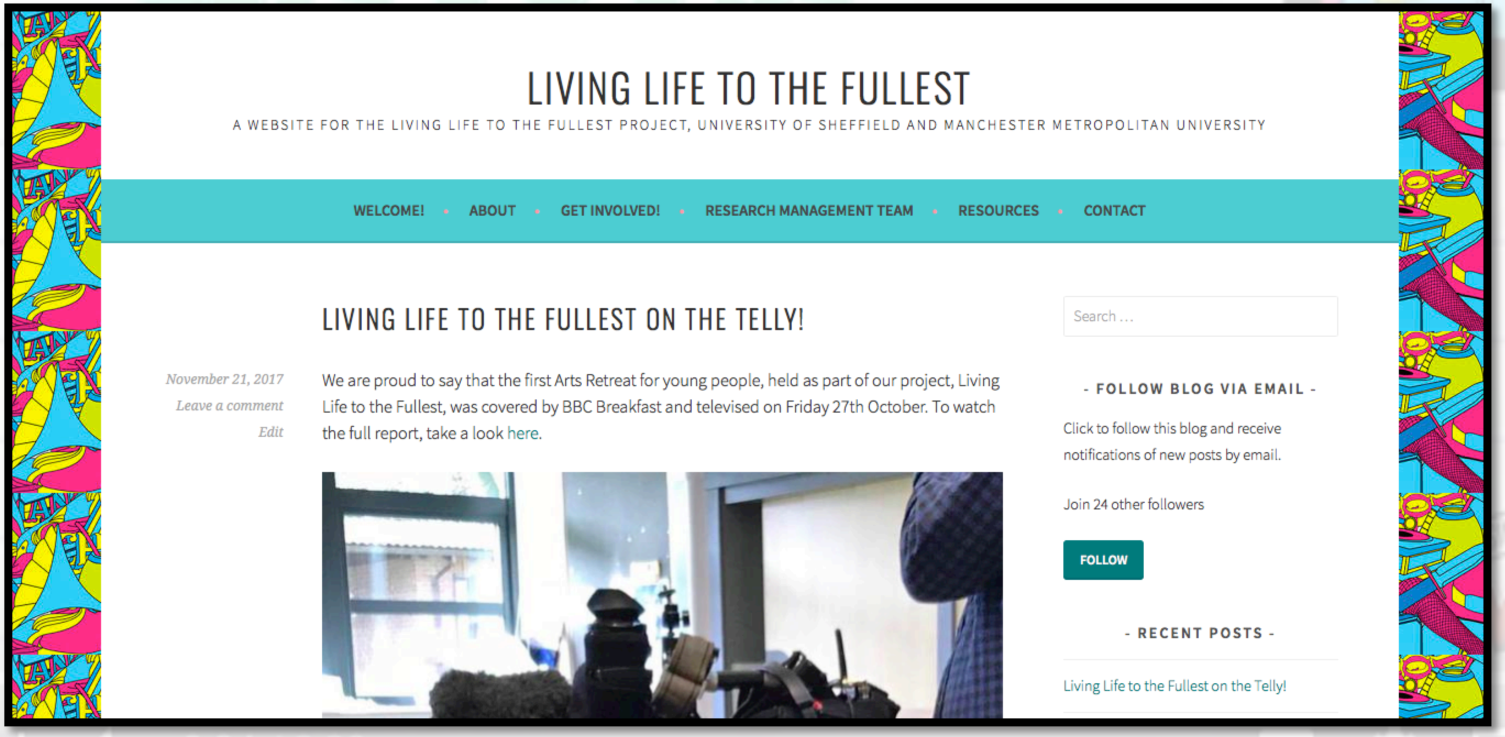
8. Drawing some conclusions



- Researching *with* young people: Intimately connected to co-production, co-designed and not produced in isolation.
- Responsive: to disabled children and young people and their families; community research partners and participants.
- Meaningful research practice: for disabled young people – listening, learning, and letting go.
- Transformative: making positive change.

Follow our project!

- Livinglifetothefullest.org
- @FullLivesESRC



LIVING LIFE TO THE FULLEST

A WEBSITE FOR THE LIVING LIFE TO THE FULLEST PROJECT, UNIVERSITY OF SHEFFIELD AND MANCHESTER METROPOLITAN UNIVERSITY

LIVING LIFE TO THE FULLEST ON THE TELLY!

November 21, 2017
Leave a comment
Edit

We are proud to say that the first Arts Retreat for young people, held as part of our project, Living Life to the Fullest, was covered by BBC Breakfast and televised on Friday 27th October. To watch the full report, take a look here.

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Living Life to the Fullest on the Telly!

Project Publications

- Goodley, D., Runswick-Cole, K., Runswick-Cole, I. Ktenidis, A. and Liddiard, K. (in press) ‘Future Directions for critical disability studies’, *Disability and Society*.
- Whitney, S., Liddiard, K., Goodley, D., Runswick-Cole, K., Vogelmann, E., Evans, K., Watts (MBE), L., and Aimes, C. (2019) ‘Working the edges of Posthuman disability studies: Theorising with young disabled people with life-limiting impairments’, *Sociology of Health and Illness*, Early View
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Thank you ☺

We thank all of our Co-Researchers and Community Research Partners for their expertise, skill and commitment to social change for young disabled people.

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