# LIVING LIFE TO THE FULLEST

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## Disability, Youth and Voice

BY

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emerald
PUBLISHING

United Kingdom – North America – Japan – India
Malaysia – China

Emerald Publishing Limited
Howard House, Wagon Lane, Bingley BD16 1WA, UK

First edition 2022

**British Library Cataloguing in Publication Data**
A catalogue record for this book is available from the British Library

ISBN: 978-1-83909-445-3 (Print)
ISBN: 978-1-83909-444-6 (Online)
ISBN: 978-1-83909-446-0 (Epub)

ISOQAR
REGISTERED
Certificate Number 1985
ISO 14001

ISOQAR certified
Management System,
awarded to Emerald
for adherence to
Environmental
standard
ISO 14001:2004.

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**Sally Whitney-Mitchell** is an Academic Researcher with a specialist interest in the lives of disabled young people, their access to work and the impact of assistance dogs in their lives. Using methods of co-production and virtual technologies, she works and writes (both academically and for wider audiences) from the comfort of her home as a co-researcher in various projects with the University of Sheffield, Scope, Youth Employment UK, Canine Partners and the Open University. She has consequently led the Canine Care Project in collaboration with Canine Partners, who partnered her with her own assistance dog Ethan. Both Ethan, and her strong faith, have helped her navigate her chronic, complex illnesses and spur her passion to make the most of every situation.

**Katy Evans** works as an Associate for Changing Our Lives, a rights-based organisation which champions the rights of disabled people and people with mental health difficulties to live ordinary lives. She was also an Advisor to the government during the 2014 Special Educational Needs and Disability reforms. Alongside this, she worked with the Council for Disabled Children to improve co-production with disabled young people nationally. She writes about her lived experiences of disability and being a trauma survivor and her difficulty accessing appropriate, non-pathologising mental health services. She has been a Co-researcher on the Living Life to the Fullest Project for four years and is keen to continue research in this field.

**Lucy Watts MBE** is a proud young disabled woman with a passion for the great outdoors, for writing and photography, who dedicates her time to making a difference for others and lives life to the fullest with support from her assistance dog Molly.

**Ruth Spurr** is a blogger and part-time model for Zebedee. She blogs about illness, youth, young people's lives and her assistance dog, Willow. Our Living Life to the Fullest Co-production Toolkit, *Why Can't We Dream?* was titled by her. She also regularly gives talks to primary school children on disability, her story and her mission to live life to the full.

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**Katherine Runswick-Cole** is Professor of Education and Director of Research in The School of Education at the University of Sheffield, UK. She is known for her work critical disability studies and disabled children's childhood studies and is Co-editor of *The Palgrave Handbook of Disabled Children's Childhood Studies* (2018, Palgrave).

**Dan Goodley** is Professor of Disability Studies and Education and Co-director of iHuman, University of Sheffield. His recent publications include *Disability and Other Human Questions* (2020, Emerald) and *Disability Studies: An Interdisciplinary Introduction* (2016, Sage, Second Edition).

**Harry Gordon** is a UPS Teacher at Greenacre Special School in Barnsley. He has developed the research partnership between Greenacre School and the University of Sheffield's iHuman Research Institute. Through his passion for developing the ways in which schools and academies co-produce research in the classroom, he has championed a change in practice to enable Special Educational Needs and Disability students to have greater influence over the decisions that affect their lives. He and his students collaborated with Dr Kirsty Liddiard to co-produce the 'Why Can't We Dream?' toolkit (see Chapter 8). He is proud to lead Wellspring academy trust-wide training on co-producing research in the classroom: training practitioners in the methods, language and skills to enable young people with disabilities to have their voices heard on the issues that matter most to them.

# ACKNOWLEDGEMENTS

Firstly, we would like to thank all of the children and young people and their families and allies who made The Living Life to the Fullest Project possible. The stories, contributions and energy you have shared with us are documented and honoured through this book.

This work was generously supported by the Economic and Social Research Council (ESRC) under grant ES/P001041/1, *Life, Death, Disability and the Human: Living Life to the Fullest*.

We also thank iHuman and the School of Education at the University of Sheffield for the continued support.

We thank our Community Research Partners, Impact Partners and other valued contributors for their support and insight throughout the project:

Purple Patch Arts
Pathfinders Neuromuscular Alliance
Good Things Foundation
Together for Short Lives
MDUK Trailblazers
Action Duchenne
Canine Partners
Louise Atkinson
Harry Gordon
Greenacre School, Barnsley and the Wellspring Academy Trust
Greenacre Co-researchers: Jemma, Marconi, Logan, Alex, Stevie and Emily
Rainbows Children's Hospice
Attenborough Arts Centre
Sipho Ndopu

We thank Carrie Aimes, an original member of The Co-Researcher Collective, who supported our early arts focus.

We would like to thank our assistance dogs, who have supported us in our work: Ethan, Folly, Willow and Molly.

We also thank Holly Yuille for her patient and kind contributions and expert proof-reading of the final drafts of many chapters in this book.

# 1

# LIVING LIFE TO THE FULLEST: OUR PROJECT

SALLY WHITNEY-MITCHELL AND KATY EVANS

## ACCESSIBLE SUMMARY

- This chapter introduces The Living Life to the Fullest Project: our research into the lives of disabled young people.
- We introduce The Co-Researcher Collective – a group of disabled young women who co-led the project.
- We tell you more about what follows in this book.

This book contains a multiplicity of voices: the voices of disabled young people, university academics and researchers and school children (specifically Chapter 8), all of whom have co-authored and contributed across chapters in order to make space for and document the human value of disability. Some of us write as disabled people. All of us write with personal experiences of disability in our families. As such, these voices have been central to the co-produced research project which sits at the very centre of this book: *Living Life to the Fullest: Life, Death, Disability and the Human* (ES/P001041/1; hereby The Living Life to the Fullest Project). Our project was funded by the Economic and Social Science Research Council and took place between 2017 and 2020. We tentatively began writing this book together in late 2019. Surely enough, as the Covid-19 global pandemic hit in spring 2020, and as a diverse research team working together, we began to realise this book's newfound importance and timeliness. Disabled people and their families became some of the hardest hit through the pandemic. Since March 2020, over 127,000 British people have lost their lives to Covid-19; and two-thirds of these have been disabled and chronically ill people, with people of colour and people with learning disabilities being disproportionately affected (Brothers, 2020). Thus, we began writing with gusto: eager to claim space to amplify the lives, hopes, desires and contributions of disabled children and young people living with life limiting and life-threatening impairments (LL/LTIs). We untangle such labels through each chapter as we come together as collaborators, co-authors and co-researchers. We want to clarify early here that this book is not a uniform research text. It is far more. This book represents to us a change to the standardised ways in which research is conducted, reported and written, typically only by academics and people in positions of power. Whilst this book *is* a coherent and reflexive account of our key findings across the project as they relate to the lives of disabled children and young people and their families, it is also a labour of love. It is a legacy. A legacy of our project, but also of the lives of The Living Life to the Fullest Project co-researchers, most of whom are living with LL/LTIs, and who are eager to leave their mark on the world. We hope, too, that is a readable and accessible text.

## LIVING LIFE TO THE FULLEST

The Living Life to the Fullest Project was a three year co-produced arts-informed research project which aimed to explore the lives, hopes, desires and contributions of disabled children and young people living with LL/LTIs. Such impairments typically 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). It is important to say this early on that we used this kind of language – for example, ‘life limiting’ and ‘life threatening’ – within the project because it was familiar and known to our participants and their families. At the same time though, as disability researchers, disabled people and allies, we also resist these kinds of medicalising labels and understandings of disability; this is just one tension we explore through this book (see Chapter 2).

In The Living Life to the Fullest Project, we wanted to explore young people’s lives in *full* and facilitate accessible ways for them to tell us about their own experiences. Co-researcher Emma, from The Co-Researcher Collective, highlighted that over her lifetime, although she had often been asked about her experiences, she felt many important topics were shied away from (Liddiard, 2018b, n.p.):

> *As a young disabled person I answer a lot of surveys on my disability, my care and other similar topics. But I'm rarely asked about what it is really like to be 24 and disabled. No one has asked me whether I'm scared about my future or whether my life-limiting condition has impacted my life choices. These are not pleasant things to think about, but I can promise you, nearly every disabled person has thought about them. When I was asked whether I wanted to be a co-researcher for Living Life to the Fullest, I was excited by the idea of a project that focuses on those unasked questions. I wanted to help find out what our lives are really like and how we really feel about them.*

Emma's words encapsulate the driving force behind the project. The context of LL/LTIs tends to elicit feelings of pity and notions of despair (Runswick-Cole, 2010). However, for us this doesn't capture the richness of the lives of young people living with these types of impairments. Therefore, we wanted a project title that reflected this and challenged dominant notions of tragedy. Through the project, and this book, we highlight how disabled young people are living their lives to the fullest whilst not shying away from the many complexities involved doing so in a world shaped by ableist norms which routinely devalue them (Goodley, 2014). Ableism refers to a world view – a dominant reality – that assumes and values those deemed to be able-bodied and minded. In many ways, this research project and its findings became an act of resistance for both participants and co-researchers against ableism and also disablism. The latter refers to the specific forms of exclusion and marginalisation that people with sensory, physical and cognitive impairments are subjected to. So, our book makes mention of ableism and disablism: precisely because they often feature in the lives of people with LL/LTIs. If disability is but one element of the human condition; disability also poses a question – to what extent are disabled people allowed, supported and encouraged to live lives as human beings when they are so marked by disablism and ableism (Goodley, 2020)? Many Living Life to the Fullest Project co-researchers experienced this project as life changing as it provided a safe space to challenge their own internalised ableism and disablism (Reeve, 2002) and grapple with difficult concepts which often get silenced in the lives of disabled people. Possibly one of the ways we were able to elicit such rich, detailed accounts from our young participants was because we ourselves are disabled young people with similar experiences. We had the freedom to develop questions that perhaps other researchers had never dared to ask us. We recognised through this omission our experiences were going unheard and we wanted to put this right.

## BACKGROUND TO THE PROJECT

As a project that sought to forge new understandings of the lives and contributions of disabled children and young people with LL/LTIs, The Living Life to the Fullest Project embodied the ethical and political principles of disabled children's childhood studies (Curran and Runswick-Cole, 2013, 2014; Runswick-Cole et al., 2018). This interdisciplinary field of research, writing and the arts actively positions the voices and experiences of disabled children and young people at the centre of inquiry. Or as Pluquailec (2018) suggests, as an approach to research it rightfully makes space to acknowledge disability as (positively) disruptive towards the typically ableist and disablist boundaries of research theory and practice (see Chapter 3). In the context of our project, we understood co-production as an aspirational approach where academics work together with a range of partners to produce research and outcomes not possible in isolation (Runswick-Cole et al., 2017). According to Durose et al. (2012, p. 2), co-produced research 'aims to put principles of empowerment into practice, working "with" communities and offering communities greater control over the research process'. For Olsen and Carter (2016, p. 7), the co-production of knowledge 'can promote respectful integration of ideas'. By extension, then, for us research is not a process about or for disabled children and young people with LL/LTIs and their families, but conducted with and by them (see Fudge et al., 2007). Moreover, the research questions, methods, strategies of analysis and plans for impact and public engagement reflect the ambitions of disabled children and young people and their families and community stakeholders. Thus, co-production became a necessary part of shaping inquiry at the very early stages, prior even to any funding.

As such, our bid for funding was co-authored in collaboration with disabled children and young people, their parents, carers and allies and key representative non-governmental organisations (NGOs) Purple Patch Arts, The Good Things Foundation and Pathfinders Neuromuscular Alliance, who later became our funded research partners. In this context, co-writing for us involved the discussion of ideas and research and impact planning through a number of writing workshops and meetings. We asked disabled children and young people many questions, such as: 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 disabled young people to take part? What do we need to get right in our project? What could we get wrong? With permission, we posed these questions via a short accessible film posted to the Facebook pages of disabled young people's organisations and related charities. Disabled young people either 'commented' below our posts or sent an email containing their thoughts.

Ultimately, our emphasis at this early time was to work in ways that ensured the inception of the research process was both accessible and enacted a shared distribution of responsibility from the outset. Integral to this was our Research Management Team – at that time made up of disabled and non-disabled academics (at a variety of career levels, from PhD to Professor); young people with LL/LTIs; parents and family members; allies and campaigners; researchers, practitioners and representatives of our NGO and community research and impact partners, many of whom occupy several of these subject positions. They invited us to engage with their communities outside of the academic context. The Co-Researcher Collective – established later in the project (after funding had been awarded) – quickly overtook Research Management Team as the day-to-day leadership of the project. Ultimately, we critically engaged with a co-production methodology that provided space for partners to inform the running of the project, the kinds of findings that emerge and ideas for impact and public engagement that were creative rather than prescriptive. Co-production can be a contested field, but we purposefully made space for unknowing and uncertainty, letting research relationships with disabled young people and partner organisations lead, with the aim that stakeholders take ownership of the research in ways unforeseeable at that time.

The Co-Researcher Collective consists of six disabled young people (all women) who live with LL/LTIs. In recruiting co-researchers, the only 'criteria' placed upon participation was a desire to explore disabled young people's lives and contribute to the process through undertaking project-related activities of co-researchers' choice. Initial groundwork to build the Collective began early in the process – after funding was awarded and following co-authoring the bid for funding. After meeting Lucy Watts MBE, a prolific young disabled campaigner who currently serves as an Ambassador for the national charity Together for Short Lives – and now Lead Co-researcher in The Living Life to the Fullest Project – we were advised as to the benefits of online spaces towards building meaningful relationships with disabled young people. Lucy explained how virtual environments are critical to her advocacy and activist work and, in short, we listened, and this conversation significantly shaped inquiry moving forward. From this, online advertising through the project website and social media led to prospective co-researchers making initial contact (typically through Facebook Messenger) and eventually joining the Collective, enabling a radical revision of the didactic ways in which research into disabled young people's lives is typically carried out.

## THE CO-RESEARCHER COLLECTIVE: NEW WAYS OF WORKING

The entire project, including the writing of this book, involved us all working together as a Collective and adopting new ways of working. As mentioned above, the project was co-led by disabled young people via The Co-Researcher Collective and three university-based academics, each who themselves have lived experience of disability in different ways – as disabled people, carers and allies. We sought to use anti-ableist and anti-disablist approaches that often involved being creative in how we approached research tasks. This included using virtual spaces and methods for research; creating an environment in which we could be open about and identify each other's differences and needs; understanding the importance of taking our time, and incorporating this understanding into our working practices (see Chapters 3 and 7). The creativity elicited from these ways of working as a Collective highlighted the possibilities of what disability can bring to everyday life, as well as research practices and inquiry. As a Collective, we understood the value of disability and difference and that, by their very nature, these unique ways of being can be positively disruptive to normative ways of working (see Chapter 7).

Initially The Co-Researcher Collective came together as a group of relative strangers but over the course of this project our relationships with one another have evolved into something none of us predicted. For us, as disabled young people exploring the life experiences of our peers, it was inevitable that we were going to be personally touched by the data and broader material. For many of us it was the first time we saw our own experiences reflected back at us and our collaborative discussions enabled us to challenge our internalised ableism. One of the few times we met in a physical space was at the project's residential Analysis Retreat where we analysed our data together, immersing ourselves in participants' stories and sharing our own experiences as part of the analytical process (see Chapter 3). This was a very impactful time for those involved and we believe that being together in a safe space allowed a greater emotionality into the process as we examined our own lives. In fact, each one of us shed a tear during this time. We feel the mutual understanding and friendships that have developed through our meetings and WhatsApp conversations have led to increased intimacies, facilitating a richer content for this book. The Co-researcher Collective became a force of its own and our relationships became deeper than a team simply collecting and analysing data together. We have both commiserated and celebrated with each other through life events from moving locations and struggling to recruit personal assistants to finally being successful in winning 'fights' for funding. Throughout, there has been an innate understanding of the challenges these things pose and it has become a safe space to voice these frustrations within the group where so often these experiences are silenced. In many ways, we created a solidarity between us which Ahmed (2004, p. 189) notes:

> *Solidarity does not assume that our struggles are the same struggles, or that our pain is the same pain, or that our hope is for the same future. Solidarity involves commitment, and work, as well as the recognition that even if we do not have the same feelings, or the same lives, or the same bodies, we do live on common ground.*

Furthermore, the 'access intimacy' that Mia Mingus (2011) discusses in her blog about crip solidarity was at the heart of the project and strengthened the bonds within The Co-Researcher Collective and broader team. To clarify our use of the word crip, we follow Hamraie and Fritsch (2019, p. 2) and reify it as 'the non-compliant, anti-assimilationist position that disability is a desirable part of the world'. Mingus (2011, n.p.) explains:

> *[...] access intimacy is that elusive, hard to describe feeling when someone else 'gets' your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level.*

This access intimacy that we enact together as a team denotes closeness, friendship and solidarity in our project as ways to extend thinking about the affective politics and emotionality of inquiry. We note this here, because despite these intimacies, in nearly four years of working closely together, we have seldom ever been in the same room, or shared physical space. Our point here, then, is to counter normative ideas of face-to-face work as a point of superiority in qualitative research and to affirm technologies as spaces ripe for human and affective connection, nurture and care, especially for marginalised people who experience barriers in the physical and social world.

Co-researcher Sally summarises [and writes] what crip solidarity has meant to her: Joining The Co-Researcher Collective has benefitted me personally in addition to being a group doing fab quality research into the lives of young, disabled people. This is because it is a group formed 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.

Everyone involved in The Living Life to the Fullest Project has been keen for its impact to reach beyond inquiry and the words you will read in this book. It is our wish that this inspires a shift in how research with disabled young people is conducted and truly embeds the principles of co-production, as opposed to the often tokenist efforts to include disabled young people in research (Whitney et al., 2019; Liddiard et al., 2018). In our project, disabled young co-researchers had the flexibility and influence to steer the direction of this project. Arguably, the final result is something which likely would not have had the chance to materialise had it been led only by academics based in universities. As a way to encourage this kind of co-production to take place within other settings and across projects we have developed a co-production toolkit that we titled *Why Can't We Dream?* as one of the key legacies of this project (https://whycantwedream.co.uk/). We discuss the toolkit and its application in Chapter 8.

## WHAT FOLLOWS IN THIS BOOK?

Whilst we have tried to capture and portray the wide range of topics that disabled young people discussed in our research, a book such as this could not reflect the vastness and depth of issues raised. This book serves to highlight some of the key themes that emerged from our collaborative analysis that we have deemed pertinent to representing the realities of our disabled young participants living with LL/LTIs. However, every disabled young person experiences life differently and will always have different stories to tell. We hope this book introduces the reader to this rich and much needed area of study.

It was our intention all along to make this book as accessible as possible to ensure that a diverse range of people could take something from it, whether that be social workers, academics, students, young people or families. We were particularly keen for it to be accessible to disabled young people themselves. Although the life experiences and the paths that led us to working together as a Co-Researcher Collective were diverse, what united us was a sense of loneliness some of us had all experienced at various points in our lives as disabled young people. We therefore wanted the book to represent the solidarity of disabled young people in living their lives despite the challenges often involved in living within and through ableist contexts that often exclude us (see Chapter 2). It is our hope that disabled young people will feel reassured that they are not alone in their experiences, in the same ways we all did when we came together as a Collective. For many co-researchers, this book became a personal legacy, a way to leave a mark on the world and carry our messages forward when we are no longer here. We will talk more about the importance of our legacies in Chapter 9.