



EMERALD POINTS

LIVING LIFE TO THE FULLEST

Disability, Youth and Voice

**KIRSTY LIDDIARD,
SALLY WHITNEY-MITCHELL,
KATY EVANS, LUCY WATTS MBE,
RUTH SPURR,
EMMA VOGELMANN,
KATHERINE RUNSWICK-COLE,
DAN GOODLEY**



LIVING LIFE TO THE FULLEST

This page intentionally left blank

LIVING LIFE TO THE FULLEST

Disability, Youth and Voice

BY

KIRSTY LIDDIARD

University of Sheffield, UK

SALLY WHITNEY-MITCHELL

University of Sheffield, UK

KATY EVANS

University of Sheffield, UK

LUCY WATTS MBE

University of Sheffield, UK

RUTH SPURR

University of Sheffield, UK

EMMA VOGELMANN

University of Sheffield, UK

KATHERINE RUNSWICK-COLE

University of Sheffield, UK

AND

DAN GOODLEY

University of Sheffield, UK



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

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

First edition 2022

Copyright © 2022 Kirsty Liddiard, Sally Whitney-Mitchell, Katy Evans, Lucy Watts, Ruth Spurr, Emma Vogelmann, Katherine Runswick-Cole, and Dan Goodley.
Published under exclusive licence by Emerald Publishing Limited.

Reprints and permissions service

Contact: permissions@emeraldinsight.com

No part of this book may be reproduced, stored in a retrieval system, transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise without either the prior written permission of the publisher or a licence permitting restricted copying issued in the UK by The Copyright Licensing Agency and in the USA by The Copyright Clearance Center. No responsibility is accepted for the accuracy of information contained in the text, illustrations or advertisements. The opinions expressed in these chapters are not necessarily those of the Author or the publisher.

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)



Certificate Number 1985
ISO 14001

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



INVESTOR IN PEOPLE

CONTENTS

<i>List of Illustrations</i>	vii
<i>About the Authors</i>	ix
<i>Acknowledgements</i>	xi
1. Living Life to the Fullest: Our Project <i>Sally Whitney-Mitchell and Katy Evans</i>	1
2. Theorising Disability: Towards a DisHuman Perspective <i>Dan Goodley, Katherine Runswick-Cole and Kirsty Liddiard</i>	11
3. Co-production, Participatory and Emancipatory Disability Research <i>Kirsty Liddiard and Lucy Watts MBE</i>	25
4. Posthuman Connections: Rethinking Animal–Human Relationships <i>Katy Evans, Sally Whitney-Mitchell and Ruth Spurr</i>	43
5. Disability and Faith <i>Sally Whitney-Mitchell and Katherine Runswick-Cole</i>	61
6. Rethinking Sexuality, Our Intimate Selves and Our Relationships with Others <i>Katy Evans, Sally Whitney-Mitchell and Kirsty Liddiard</i>	79
7. Labour in the Lives of Disabled Young People <i>Katy Evans, Sally Whitney-Mitchell and Katherine Runswick-Cole</i>	99
8. Making Meaningful Impact in and with Schools <i>Greenacre Co-Researchers: Jemma, Marconi, Logan, Alex, Stevie and Emily; Harry Gordon and Kirsty Liddiard</i>	115
9. Desiring Life and Living with Death <i>Katy Evans, Sally Whitney-Mitchell and Kirsty Liddiard</i>	125

References

147

Index

165

LIST OF ILLUSTRATIONS

- Illustration 1: Image Description: Designed by Harry Gordon, SEND Teacher, Greenacre School, This Diagram Shows Our Methods of How We Explored the Notion of Developing Questions for an Interview Schedule. 118
- Illustration 2: Image Description: Harry Designed an Ethics Assault Course, Set Out in the School Hall, Through Which Greenacre Co-researchers Could Play with and Learn About Ethical Considerations in Research. All of the Activities Were Made Accessible for All Children, Regardless of Disability, Impairment and/or Label. 119

This page intentionally left blank

ABOUT THE AUTHORS

Kirsty Liddiard is currently a Senior Research Fellow in the School of Education at the University of Sheffield and a theme Co-leader in iHuman. She is the author of *The Intimate Lives of Disabled People* (2018, Routledge) and the Co-editor of *The Palgrave Handbook of Disabled Children's Childhood Studies* (2018, Palgrave) with Tillie Curran and Katherine Runswick-Cole. She is also Co-editor of *Being Human in Covid-19* (in press, Bristol University Press) with Warren Pearce, Paul Martin and Stevie de Saille.

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.

Emma Vogelmann is a leading activist in the disabled community. She currently works as Lead Policy Adviser at Scope, on the children and young people team where she focusses on the issues faced by disabled children, young people and their families. Her main areas of focus are youth employment and inclusivity of disabled children.

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.