

# Interventions in Disabled Childhood Studies



*Figure 1. Photo of abstract street art*

**Edited by  
Dan Goodley, Katherine Runswick-Cole and Kirsty  
Liddiard**

Sheffield: iHuman Press 2020

# Contents

Acknowledgements

Biographies

- Chapter 1 Introduction  
Dan Goodley and Katherine Runswick-Cole
- Chapter 2 How do we understand the past, present and future of disabled childhoods?  
Dan Goodley
- Chapter 3 Technologising Leadership: Virtual research contexts as spaces of disruption  
Sally Whitney and Kirsty Liddiard
- Chapter 4 The Red Helmet: A participatory approach with children in primary education:  
Silke Daelman, Elisabeth De Schauwer and Geert Van Hove
- Chapter 5 The Narrative Power of Disabled Youth: From insult and invisibility to love and  
solidarity  
Edmund Coleman-Fountain
- Chapter 6 An Ethical Responsibility  
Sharon Smith
- Chapter 7 Relational Ethics as beginning and end when doing research with (disabled)  
children  
Geert Van Hove and Elisabeth De Schauwer
- Chapter 8 Critical Disability Studies and Participatory Action Research: Antidotes to  
educational research's inherent 'othering'?  
Anna Pilson
- Chapter 9 Issues in Childhood Disability Studies: The age of anti-psychoanalysis  
Karín Lesnik-Oberstein
- Chapter 10 Transition to Where and to What? Mapping the experiences of the transition  
to adulthood for young disabled people in Scotland  
Charlotte Pearson, Nick Watson, Justine Gangneux and Ida Norberg
- Chapter 11 Theory, ethics and methods: International Disabled Children's Childhoods  
Kathryn Underwood, Marisol Moreno-Angarita, Tillie Curran, Katherine  
Runswick-Cole and Donald Wertlieb

- Chapter 12 Recognizing the Normalization Impulse: Provocations from Foucault's work for thinking about disabled children's childhoods  
Tillie Curran
- Chapter 13 Lost in Transition: Disrhythms in Ida's life  
Hanne Vandebussche, Elisabeth De Schauwer and Geert Van Hove
- Chapter 14 'Obuntu bulamu': Entangled voices in visual narratives of children with disabilities in Uganda  
Femke Bannink Mbazzi
- Chapter 15 Sami the Incredible Hulk: What Shildrick's Monster can produce  
Inge Van de Putte and Elisabeth De Schauwer
- Chapter 16 Difficult Discussions and Curious Conversations: Challenging the dominance of the medical model in global studies of childhood  
Katherine Runswick-Cole and Tillie Curran
- Chapter 17 'It's my right to play too!' Play for disabled children in Taiwan and Hong Kong  
Angharad Beckett, Pedro Encarnação, Chun-Yu Chiu and Simon T.M. Ng
- Chapter 18 The Production of The Suffering Child/Young Person with Restricted Growth: who's/whose Suffering?  
Antonios Ktenidis
- Chapter 19 Being in the room  
Jo Billington

## Acknowledgements

The editors would like to thank the Economic and Social Research Council for funding our research project Life, Death, Disability and the Human: Living Life to the Fullest (ES/P001041/1). <https://livinglifetothefullest.org/>. This project supported the original symposium on which this collection was based. We used the symposium to launch some of the key findings of the project and to connect with international researchers in the areas of childhood, youth and disability. Some of the key publications of the project include:

Liddiard, K., Whitney, S. Watts, L., Evans, K. Vogelmann, E., Spurr, R., Runswick-Cole, K. and Goodley, D. (forthcoming). *Living Life to the Fullest: Disability, Youth and Voice*. London: Emerald Publishing Ltd.

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*, 41 (8), 1473–1487.

Heah, R., Daly, A. and Mooney, J.L., and Liddiard, K. (2019) '[Vulnerable subjects and autonomous actors: The right to sexuality education for disabled under-18s](#)', *Global Studies of Childhood*. Available at SSRN: <https://ssrn.com/abstract=3303820>.

Liddiard, K., Runswick-Cole, K., Goodley, D., Whitney, S., Vogelmann, E. and Watts, L. (2018) '["I was excited by the idea of a project that focuses on those unasked questions": Co-Producing Disability Research with Disabled Young People](#)', *Children and Society*, 33 (2), 154-167.

Goodley, D, Lawthom, R, Liddiard, K. & Runswick-Cole, K. (2019) Provocations for Critical Disability Studies, *Disability & Society*, 34 (6), 972-997.

## Biographies

Femke Bannink Mbazzi is a Clinical and Educational Psychologist and Cultural Anthropologist with 20 years of research and clinical work experience in disability inclusion and mental health in Uganda. She is a FWO postdoc fellow at Ghent University and Assistant Professor at the MRC/UVRI & LSHTM Uganda Research Unit. Her passion is to find low cost, culturally relevant interventions which can improve inclusion and quality of life of children with disabilities. Femke is the principal investigator of the 'Obuntu bulamu' peer to peer support intervention for inclusion study.

Angharad Beckett is Associate Professor of Political Sociology and Joint Director of the Centre for Disability Studies, University of Leeds, UK. Her main research interests are: disability politics, human rights, inclusive education and inclusive play. She is the Programme Leader for the Masters in Disability Studies at the University of Leeds. She is Co-Chair of the newly launched (2020) *International Journal of Disability and Social Justice* and Executive Editor of the journal *Sociological Research Online*. She is currently undertaking ESRC-funded research into the impact of childhood/youth cancer on people's later life, social inclusion and wellbeing.

Jo Billington is a Doctoral Researcher in the Centre for Autism at the University of Reading. Her PhD focuses on the lived experience of autistic students in mainstream primary schools with a specific focus on the primacy of the autistic voice. In addition to her research, Jo works for *Parenting Special Children* ([www.parentingspecialchildren.co.uk](http://www.parentingspecialchildren.co.uk)) and *The Charlie Waller Memorial Trust* ([www.cwmt.org.uk](http://www.cwmt.org.uk)) to provide support to schools, families and young people with the aim of enhancing understanding and acceptance of autism and neurodiversity.

Caya (Chun-Yu) Chiu is Assistant Professor in Special Education at the National Taiwan Normal University. She is a special educator by schooling, a social scientist by profession, and a family member of an individual with intellectual disability by relation. She has been named fellow of the American Association on Intellectual and Developmental Disabilities and served on leadership teams of several professional organizations, namely, the AAIDD International Interest Network, the Sibling Leadership Network, Research and Families of Individuals with Disabilities Committee of the Division of Research at the Council for Exceptional Children, and Taiwan Society for Disability Studies.

Edmund Coleman-Fountain teaches Sociology in the Department of Social Sciences at Northumbria University. He previously worked at the at the University of York and Newcastle University. His research covers the areas of identity, disability and sexuality. He has published two books, *Understanding Narrative Identity through Lesbian and Gay Youth* (Palgrave Macmillan, 2014), and, with Janice McLaughlin and Emma Clavering, *Disabled Childhoods: Monitoring Differences and Emerging Identities* (Routledge, 2016).

Tillie Curran, PhD, Social Work, University of the West of England, has been involved in co-production research, thinking and teaching about disabled children's childhoods with a wide group of young people, families and allies and with social work students towards social justice in practice.

Silke Daelman, MA, has a background in educational studies. She is a PhD student at the Department of Special Needs Education (Faculty of Psychology and Educational Sciences, Ghent University) with the support of a Special Research Fund fellowship. As a disability studies researcher she is mainly interested in particular children's voices in educational settings and explores borders in ethics and methodology in research with children.

Elisabeth De Schauwer is guest professor at the Department of Special Needs Education at Ghent University. Using posthuman and new materialist concepts, she is mainly engaged in research on how difference works and transforms in/through (pedagogical) relationships. Working towards social justice together with disabled people and their families is a motive in activism and academia.

Pedro Encarnação is an Assistant Professor at Católica-Lisbon, Universidade Católica Portuguesa, Lisboa, Portugal, a Research Affiliate of the Glenrose Rehabilitation Hospital, Edmonton, Canada and a Visiting Professor of the Universidad del Rosario, Bogota, Colombia. His research interests include the use of robots to enable disabled children to participate in play and academic activities, as well as a means for disabled children to reveal their cognitive skills. Pedro Encarnação recently joined Albert Cook and Jan Polgar for the 5th edition of the book *Assistive Technologies. Principles and Practice*.

Justine Gangneux is currently working as a research associate at the Urban Big Data Centre at the University of Glasgow. She has worked on various research projects within the fields of digital media and communications, youth studies and sociology, and published in journals such as the *Journal of Youth Studies*, *The Sociological Review* and *Information, Communication & Society*.

Dan Goodley is Professor of Disability Studies in the School of Education and co-director of iHuman: the interdisciplinary research institute for the study of the human at the University of Sheffield. Dan has written numerous books on disability studies including *Dis/ability Studies* (2014: Routledge) and *Disability Studies* (2016, second edition: Sage). He is a proud Dad to two young women, a Nottingham Forest Football Club and Sleaford Mods fanatic.

Dr Antonios Ktenidis has recently completed an ESRC-funded PhD in the School of Education, University of Sheffield, with his thesis examining the secondary schooling experiences of young people with Restricted Growth in the United Kingdom. Prior to his PhD, Antonios completed a BEd (Hons) in Primary School Education at Aristotle University of Thessaloniki and a MA in Sociology of Education (Distinction) at the Institute of Education, University College London. He has worked in various teaching positions in primary schools in London and Sheffield and as a graduate teaching assistant for the Masters programme (Critical Psychology and Education) of the University of Sheffield. Antonios' research interests and writing focus on Critical Disability Studies in Education, Disabled Children's Childhood Studies and qualitative methodologies.

Karín Lesnik-Oberstein is Professor of Critical Theory in the Department of English Literature at the University of Reading where she is Director of the Graduate Centre for International Research in Childhood: Literature, Culture, Media (CIRCL). Her research focuses on transdisciplinary theoretical issues relating to identity, as in her monographs

*Children's Literature: Criticism and the Fictional Child* (1994) and *On Having an Own Child: Reproductive Technologies and the Cultural Construction of Childhood* (2008), her edited volumes *Children in Culture: Approaches to Childhood* (1998), *Children in Literature* (2002), *Children's Literature: New Approaches* (2004), *The Last Taboo: Women and Body Hair* (2007), *Children in Culture, Revisited: Further Approaches to Childhood* (2011) and *Rethinking Disability Theory and Practice: Challenging Essentialism* (2015), and numerous chapters and articles across a range of disciplines on childhood, gender and sexual identity.

Kirsty Liddiard is a Senior Research Fellow in the School of Education at the University of Sheffield and a co-leader of the Institute for the Study of the Human (iHuman). Kirsty is a disabled feminist and public sociologist who believes in the power and politics of co-production and arts methodologies. She is the author of *The Intimate Lives of Disabled People* (2018, Routledge) and co-editor (with Katherine Runswick-Cole and Tillie Curran) of *The Palgrave Handbook of Disabled Children's Childhood Studies* (2018, Palgrave).

Marisol Moreno-Angarita is Tenured Professor of Disability studies at The School of Medicine, at the Universidad Nacional de Colombia in Bogotá. She leads the Research Group on Disability, Policies and Social Justice. Recent publications include: *Inclusive education: Analytical Balance and State of the Art*. Universidad Nacional de Colombia, (2020); *Adapting an Education Program for Parents of Children with Autism from the United States to Colombia* (Magaña, Tejero-Hughes-Salkas). She enjoys seeing movies with her family and reflecting about life's challenges and other affairs.

Simon T M Ng is Assistant Professor and Senior Programme Director in Law at the School of Professional and Continuing Education, The University of Hong Kong (HKU SPACE). He specialises in legal theories, legal culture, constitutional jurisprudence and disability studies and is active in promoting disability equality and inclusion in the education sector. Simon founded the Workshop on Disability Rights and Equality at HKU SPACE and is founding Vice-Chairman of SEN Rights, a Hong Kong based charitable NGO. He is co-investigator of the HKU-funded project *Enhancing Learning Experience for Students with Visual Impairment in Higher Education* (2019-2021).

Ida Norberg is a sociologist interested in the impact of austerity on disabled people and the relationship between disabled people and the welfare state. Her recently completed PhD looks at the impact of austerity on disabled people in Sweden and she has also had extensive experience looking at the impact of austerity within a UK context

Charlotte Pearson is a Senior Lecturer in Social and Public Policy at the University of Glasgow. She had researched and taught extensively around themes of personalisation, welfare reform and equality in relation to their impact on disabled people.

Anna Pilson a PhD student at Durham University School of Education. Her ESRC-funded project aims to create a participatory action research model that positions visually-impaired children as knowledge producers and change agents within education and research. Outside of academia, she enjoys drag shows, gigs and seems to have a preference for bands beginning with 'S' (especially Sleaford Mods, Self Esteem and Super Furry Animals). She tweets as @pilsonanna.

Sharon Smith is a first year PhD research student within the School of Education at the University of Birmingham. She is also 'mum' to a 15 year old who has Down syndrome, and her experiences as a parent of a disabled child are at the heart of her research interests and approach. Her PhD research approaches the subjectivity of parents of disabled children to explore how this impacts on inclusion. Sharon won the inaugural BERA Doctoral Fellowship in 2019.

Kathryn Underwood is a Professor in the School of Early Childhood Studies at Ryerson University, and the IECSS Project Director. Recent publications include *Responsible for normal: The contradictory work of families*. In S. Winton, Carpenter, & G. Parekh (Eds.), *Critical Perspectives on Education Policy in Schools, Families, and Communities*. and Underwood, K., Ineese-Nash, N., & Haché, A. (2019). *Colonialism in early education, care, and intervention: A knowledge synthesis*. *Journal of Childhood Studies*

Hanne Vandebussche is connected to the field of disability studies at Ghent University. She has specific interest in the relationship between disability studies and philosophy. In her research she focusses on belonging and inclusive citizenship. Hereto she cooperates with parents, children and young adults following inclusive trajectories.

Inge Van de Putte supports children, parents, and schools in the processes of inclusive education. Support of teachers and the position of special needs coordinators were the topics in her PhD research project in the field of Disability Studies at Ghent University. In her research and publications she finds the transfer to practice very important.

Geert Van Hove is Full Professor Disability Studies and Inclusive Education at Ghent University in Belgium. As a member of a group of Disability Studies researchers at Ghent University he tries to work together with children, youngsters and adults who are members of the Flemish self-advocacy movement and with parents and families of children with disabilities.

Nick Watson is Chair of Disability Research and Director of the Centre for Disability Research at the University of Glasgow. He has written widely on a range of disability issues including disability theory, disability and technology, disabled childhoods and social support and social care.

Sally Whitney 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, Sally 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. 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 Sally's strong faith, have helped her navigate her chronic, complex illnesses and spur her passion to make the most of every situation.

Donald Wertlieb, Ph.D., is an applied developmental scientist and pediatric psychologist. He founded both the Partnership for Early Childhood Development & Disability Rights (PEDDR) and the Early Childhood Development Task Force (ECDtf). He aims to

“connect-the-dots” between the UN Convention on the Rights of the Child and the UN Convention on the Rights of People with Disability by advancing Inclusive Early Childhood Development (IECD) and Inclusive Nurturing Care (INC).

# Chapter 1: Introduction

## Dan Goodley and Katherine Runswick-Cole University of Sheffield

The 19 essays in this collection emerged out of a two-day symposium held at the University of Sheffield on the 23rd and 24th January 2020 co-organised by the Universities of Sheffield, Ghent, Glasgow, Lancaster and Leeds. Speakers included researchers and academics at varying stages of their careers; from doctoral, postdoctoral, early- and mid-career, to those contemplating their pensions. Many of these researchers work alongside disabled children and young people as co-researchers and key stakeholders. Their perspectives weave in and out of the chapters and the contributions, as you will see, raise many important problematisations, possibilities and positivities to be found in theorising the intersections of disability and childhood. And not without a good dose of alliteration.

We asked each contributor to write a thousand-word paper and most stuck quite strictly to this (others didn't; academics eh?). The papers were read by us all: the authors then presented their papers (for around five minutes), a respondent gave their thoughts (for another five minutes) after which we opened up the discussion to everyone in the room. The chapters in this collection are a collation of the revised versions of these discussions. Authors have responded to critical feedback, nuanced suggestions, and the wider sense of community that inevitably emerges over the time of a symposium such as this. We offer here some opening critical reflections and thematics that inform the background to this collection, and point to the ways that a collection such as this creates many moments in which to pause, to think, to ponder, regroup, reassess.

### Positionality

All the authors represented in this collection position themselves alongside disabled children and young people as allies and family members. In some cases, disabled young people are represented as co-authors and co-researchers. Some contributors are senior academics while others are fairly new to the process of research. Why any one of us comes to any research endeavour is a complex question. It triggers thoughts about the role of the academy, the inclinations of researchers, the personal values and politics one brings to a context of research and the intentions of anyone engaging with disability and childhood. It would be fair to say that all the chapters capture each author's commitments to bringing together disability studies and childhood studies.

But the synthesis of these interdisciplinary sites of empirical and theoretical inquiry is not without tensions. Disability studies have been accused of ignoring the specificities of childhood. Studies of childhood have been attacked for disengaging from disability. Throwing these two communities together will inevitably reveal tensions, disagreements, differing priorities and points of departure. The question of positionality then is especially important when we consider disability and childhood. What do we hope to reap from such a connection? What gaps and disconnects are we interested in addressing? How might we

adopt an approach that is not additive - simply merging the two fields - but frictional: unearthing the complexities, tensions and difficulties? Positionality demands honesty and being open about our ambitions.

## Methodology

Methodologically there is no doubt that social and educational research has moved into a more participatory framing of the research endeavour. Qualitative, digital, ethnographic and co-production approaches are no longer simply in vogue: they already constitute a growing orthodoxy associated with listening to voices, opening up the research process to a more equitable kind of practice, and working alongside disabled children and young people as partners. Being part of an academic research project lends an authoritative hand to the unfolding accounts of disabled young people: legitimizing and validating their truth claims. At the same time, the neoliberal university context is always ready to reproduce modes of research production that maintain the strategic focus of university research endeavours. Disabled children and young people risk being forever cast as the excluded subjects of university researchers who set themselves as the missionaries of inclusion. Such a methodological predisposition is not only deeply patronising but also privileges the aims of the university over the ambitions of disabled young people. The truth is that the marketised infrastructures of academic research need excluded souls (like disabled children) to be framed in terms of the rehabilitative powers of productivity, robotics, international development, digital revolutions just to name a few of the dominant research priorities of universities and external funding bodies. Our methodological grappings, fumbblings and meanderings raise real questions about human desire; some of which we will return to later. questions about desire which we will come back to below.

## Theory

Disability and childhood studies have matured theoretically. One only has to scan the contributions in this collection to find representations of historical materialism, new materialism, poststructuralism, posthumanism, psychoanalysis (and anti-psychoanalysis), post-conventionalism, phenomenology and interpretivism. Social theory bingo at its best. There are engagements with: the material, the embodied, the biopolitical, the unconscious, the psychical, the psychologised, the psychiatrised, the medicalised, the socially constituted, the resistant, the interdependent, the assembled, merged, decentred, distributed, disruptive and non-normative. This conceptual complexity mirrors a move, one might argue, from disability studies to critical disability studies. The latter is a very theoretical community and one that many of us here populate with our bodies and our writing. These are heady times. These are head-bending times. Theory swamps us, douses us, entangles us, binds us to concepts, tropes and explanatory frameworks. But where does theory lead us and leave us? Does it take us on a journey of connecting with disabled children and young people, providing analytical lines of flight that keep up with aspirations, actions and ambitions of these young people? Or does theory roll in and roll over the bodies and minds of these young people thus creating a veil that hides their aspirations, their ideas and crucially, their own theory-generation that they enact in their everyday, complex sophisticated dealings with a disabling world? Theory has to connect alongside and in parallel with the dynamic life worlds of disabled young people. But connection alone is not enough: theory should illuminate, celebrate, magnify, accompany,

follow, urge, steer and be steered by the possibilities of a life lived as a disabled young person.

## **Impact**

We might reflect smugly on our communities of disability and childhood studies: far have we travelled and much have we seen. Disability and childhood are readily plugged into a myriad of curricula across the social sciences and humanities: they are represented in classic and emerging funded projects; they have been inserted into the already crowded spaces of social justice, diversity and inclusion. But what has really changed? Are disabled children readily included in educational systems, not as after-thoughts but as already-assumed-to-be-there members of the educational class?

Data suggests that disabled young people continue to be ostracised, segregated, lost, hidden and relegated by our dominant educational systems. They are the austerity time bombs waiting to happen and the austerity victims of the last ten years. One wonders on what grounds academic researchers can sit in their /our academic communities and feel anything other than embarrassment in terms of the lack of impact of our work on the real world.

Three slivers of possibility can be offered here. First, disabled children and young people are already creating their own communities with their friends and families, communities that are resistant, responsive and connected. This is happening regardless of academia, theory and research. We, in academia need to decide where we sit in relation to - and in support of - this community building. Second, the research enterprise can be exploitative - and we mean exploitative - to include disabled young people and their representative organisations as the agents of change and possibility. Find ways to get them involved and paid and involved. Begin nascent thinking and planning of research by involving disabled young people from the start. Consider dissemination tactics that speak to and with disabled children, young people, their families and other allies. Third, and back to theory, critiquing the normative, the able, the ableist, the everyday privileging of the non-disabled opens us up to affiliations with others and other transformative ideas (say from Black, queer, working class, trans and feminist) that are equally deconstructing the neoliberal-ableist status quo.

## **What about desire?**

How do we desire disability and childhood as elements of the human condition worthy of valuing? What do we have in mind in terms of considering the predicament of disabled young people? Of course, we come here with a shared sense of the precarity of this specific group of young people who continue to be abandoned by our social worlds. But in desiring disability and childhood we might find ourselves pursuing a re-pathologisation of disabled young people through the deployment of theoretical perspectives that constitute them in terms of victim status from the very beginnings of research. Pause for a second. Consider our studies, our communities our theoretical places. Disability. Studies. Childhood. Studies. Regardless of the theories, methods or analytical approaches we throw ourselves into, we risk ending up at a final destination that reads: No Disabled Children Here. We continue to tell again and again stories of the disenfranchised. The act of desiring disability might require a new mode of desire. Starting with the intersection of disability with childhood as the entry point into our work might reconfigure this intersection

as a productive moment. This is 'crip desire': an affirmative and demanding circulation of transversal connections. As we shall see in the chapters below, this is Femke's young lad in the wheelchair, Silke's Lego boy, Inge's Sami the Incredible Hulk, Angharad's fellow keynotes at the East Asian Disability Studies forum, Nick's disabled kids in the burnt-out building, Sally as university researcher. This is not about desiring a new object but desiring anew. Desiring community, connection, relation, dependence. This might be the desire for the bio/techno/human-non-human global citizen of our contemporary times.

## Chapter 2: How do we understand the past, present and future of disabled childhoods?

**Dan Goodley**  
**University of Sheffield**

Our field of critical disability studies - at least in Britain - has been left feeling a little fragmented by a number of recent controversies. Surveying our interdisciplinary space and we find schisms and factions. Questions of disability and childhood are very much human questions. All of us already know this. When we position ourselves as allies of disabled children and their families we are, in some small ways, working to reclaim the humanities of those children (and the richness of their childhoods). Questions of disability and childhood are also, fundamentally, theoretical questions. All of the contributions to this collection share a broadly sociological or cultural perspective on disability and childhood but we may differ in the perspectives and assumptions that we hold. We might want to combine the sociological and the psychological; contemplate the play of the immaterial and material; bring back the biological into the social; tap the humanist register for political gains or entangle ourselves in a posthuman community. Collectively we represent psychology, education, sociology, social policy and social work. And we no doubt feel the presence of cultural, social, crip, critical ableist and dis/ability studies. The representation of this myriad of positionalities is but one reason to celebrate how far we have come.

And we have come far.

One only needs to think about the massive epistemological, ontological and methodological developments in disability and childhood studies - and their critical elision - that have occurred over the last two decades. Disabled Children's Childhood Studies - a paradigmatic turn defined by Katherine, Tillie and Kirsty in their recent edited volumes - is but one helpful meta-analytical description of the contemporary state of the field (Curran and Runswick-Cole, 2013, 2014; Runswick-Cole, Curran and Liddiard, 2018). But where have we come from and where are we heading? What thematics might under-gird our contemporary deliberations? And what anticipatory articulations of disability and childhood might we write when contemplating the future? These questions resonate with a number of us working at the University of Sheffield who are trying to make sense of the changing complexion of the human condition.

Our research institute - ***iHuman: the interdisciplinary research institute for the study of the Human*** (<http://ihuman.group.shef.ac.uk/work/>) - pivots around a number of key research themes which can be identified hanging around in the background of our discussions.

***Biosocial humans.*** How are the biological and cognitive sciences, as well as their application in various biotechnologies, reconstructing ideas of what it means to be human in the 21st Century? Our work covers a wide range of topics from human enhancement, the biological embedding of social inequalities, the use of neuroscience in explaining social

behaviour, and the application of new technologies in understanding health and disease. One wonders to what extent the disabled child might constitute the quintessential biosocial subject.

**Digital humans.** How are digital platforms remaking what it means to be human? Our research considers how the accelerating digitisation of society is changing what we know, who has power, and how we see our fellow humans. Issues include the changing face of online expertise, the impact of self-monitoring devices on our health and social relations, and how social media platforms enable new expressions of digital identity. While mindful of the existence of very real digital divides, I do think it is worth tracing those potentialities that are released through disabled children's participation in digital cultures.

**Future humans** – what will it mean to be human in the future? Will we live alongside robot companions and genetically edit our children? A future in which different kinds of humans can flourish together is possible, but so too is one of social and ecological breakdown. Our research considers not what will be, but how we imagine what could be, considering the future as something co-created between science and society in the here and now. One wonders about the impact of robotics and AI impinge on the life worlds of disabled children in everyday and mundane aspects of everyday life.

**Marginalised humans.** How are human kinds included or excluded by the contemporary moment? Our research pays attention to the intersections of dis/ability, age, gender, sexuality, class, race, poverty and colonialism in order to expose and challenge social processes which push some human beings to the margins. Our work is driven by a commitment to working with comrades and communities inside and outside the university to promote social justice. I am sure we would want to centralise disabled childhoods in any conceptualisation of marginalisation, but we would do this in a way doesn't make disability a master narrative, but instead, is synthesised to the intersectional constitution of disability and childhood.

iHuman draws on expertise from across the social sciences, the humanities and STEM disciplines (Science Technology Engineering and Medicine) and brings together academics, community groups and third sector organisations. We want to promote risky conversations between and across disciplines and do this primarily through our funded research projects. Now, this language plays well in discussions with senior staff, in the writing of research bids and justificatory discourses of staff promotion documents. The reality of these risky discussions is that they do not enjoy a corporate smoothness. Bringing together medics, historians, French studies scholars and sociologists - as we have done recently in the writing of a number of funding bids - has been exciting but discombobulating. We have worked hard to find a shared conceptual language (the ball has been dropped a number of times); grappled with summarising our disciplinary contexts for colleagues outside our disciplines (Ah, the pain of watching an academic explaining 20 years of research in a two minute pitch), and worried away at the dominating influence of some disciplines over others (sociologist often feel they've won the argument even though medics feel they know that they are correct). Interdisciplinarity is not only the in-thing to do (for instance, read the United Kingdom Research Research and Innovation priority funding areas) but an approach to research where we might interact with others outside of our comfort zone. I would suggest that speaking into a space occupied by the non-converted (those working outside of disability and childhood studies) remains a pressing ambition. In

this collection, perhaps we are conversing with the already converted; though the nuanced differences in our approaches, I am sure, shine through in ways that embolden our understandings of the politics of disability and childhood. Finally, we should not under-estimate the importance that the questions we ask ourselves are always human questions. And this re-humanising of our disability studies and childhood studies communities is especially important when many of us have been left feeling a little bruised by recent debates.

## References

Curran T, Runswick-Cole K (eds.). 2013. *Disabled Children's Childhood Studies: Critical Approaches in a Global Context*. Palgrave MacMillan: Basingstoke.

Curran T, Runswick-Cole K. 2014. *Disabled children's childhood studies: an emerging domain of inquiry?* *Disability & Society* 29: 1617–1630.7.

Goodley, D. (forthcoming, 2020). *Disability and Other Human Questions*. Emerald.

Runswick-Cole K, Curran T, Liddiard K. 2018. *A Handbook of Disabled Children's Childhood Studies*. Palgrave MacMillan: Basingstoke.

## Chapter 3: Technologising Leadership: Virtual Research Contexts as Spaces of Disruption

Sally Whitney\* and Kirsty Liddiard\*\*

\*Living Life to the Fullest Project, University of Sheffield

\*\* University of Sheffield

In this short provocation, we detail the politics and practicalities of co-produced disability research with disabled young people. We focus on our ESRC-funded arts-informed research project, *Living Life to the Fullest*, which has brought together a Co-Researcher Collective of disabled young women to explore the lives, hopes, desires and contributions of children and young people with what are widely known as ‘life-limiting’ or ‘life-threatening’ impairments (hereby LL/LTIs).

Sally and I have worked closely with one another – and with the wider Co-Researcher Collective – co-lead our project and have a rich and collegial working relationship. Yet, we have only ever physically been in the same space on just two occasions. We are telling you this to emphasise the creative ways in which we have made use of online spaces and new social technologies, digital methods and virtual worlds to design, formulate and conduct our research with disabled young people and their families.

Co-production is an established approach; however, our co-researchers have led us to develop inclusive research practices that engage with online social research methods in innovative ways. As we detail our experiences today, we aim to encourage disability studies researchers and others to adopt virtual environments when researching with and for the lives of disabled children and young people.

### **Disrupting the ableist, exclusive and adult-centric boundaries of research theory and practice**

To work in such ways, the Living Life to the Fullest project embodies the ethical and political principles of disabled children’s childhood studies (Curran and Runswick-Cole, 2013, 2014; Runswick-Cole and others, 2018). Disabled children’s childhood studies actively position 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 this field rightfully makes space to acknowledge disability as (positively) disruptive of the typically ableist and exclusive — and, we would add, adult-centric — boundaries of research theory and practice.

In the context of our project, then, we understand co-production as academics working together with a range of partners to produce research and outcomes not possible in isolation (Runswick-Cole and others, 2017). According to Durose et al. (2012: 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 us,

this means the research focus being led and directed by disabled young people, not just answering questions, but directing what they want to be known and explored about their own lives. For Olsen and Carter (2016: 7), the co-production of knowledge ‘can promote respectful integration of ideas’. To put it in everyday terms, then, for us research is not a process about or for disabled children and young people with LL/LTIs their families, but conducted with and by them, and again for us, led by them (see Fudge and others, 2007).

Importantly, in *Living Life to the Fullest*, participation and leadership is shaped and adapted to fit around the needs and wants of Co-Researchers. As such, much of our communication with the Co-Researcher Collective takes place online — we connect daily through a closed Facebook group, Skype, FaceTime, email and WhatsApp. Far from embodying the tokenism that can plague research with disabled people (Liddiard, 2013), the Co-Researcher Collective has made important decisions and undertaken the majority of data collection and analysis and impact planning thus far. This has ranged from designing interview schedules (which took place through a Facebook post to the group upon which Co-Researchers offered questions through ‘commenting’); to recruiting participants for interview (young disabled people and parents); carrying out online semi-structured qualitative interviews via new social technologies; growing the Co-Researcher Collective through recruiting fellow Co-Researchers; writing articles and conference papers (see Whitney et al. 2019); undertaking a collaborative and accessible analysis of narrative and artistic data; promoting the project across social media platforms; and disseminating information via co-researchers’ own networks and organisations.

### **Embodied knowledge — valuing lived experience**

In *Living Life to the Fullest*, we work on the basis that those with lived experience of disability can offer a unique ‘insider perspective’ (Kellett, 2010) that is crucial for furthering understandings of disability life and dis/ableism (ableism and disablism) (Goodley and others, 2015) — particularly the emotional labour and affective politics of what it means to be disabled and young in such dehumanising austere times (Runswick-Cole and others, 2018).

Engelsrud (2005: 281) argues that the ‘researcher’s body can be understood as both access and limitation to the acquisition of knowledge’. Co-researchers’ disabled identities and lived experiences of disability and dis/ableism have informed the research process in immeasurable ways. To give just one example, many of the questions generated through discussion and later adopted in the interview schedules emerged from a deep (lived) understanding of what it means for young people living short/er lives to live with life limiting and life threatening impairments. Much of the discussion was often self-revelatory for co-researchers. They often had lived experiences that they had never consciously considered or theorized and the process of acknowledging these experiences and incorporating them into the research was empowering (it benefited us as researchers, as well as the research itself).

As interlocutors and co-constructors of participants’ stories, co-researcher identity, subjectivity and embodiment became integral to the dialogical process of story-telling. While we acknowledge that, at times, this involves ethical considerations — both for prospective participants and Co-Researchers (and non-disabled researchers — see

Goodley and Tregaskis, 2006), and such questions have generated valuable and rich data for analysis.

### **Virtual spaces, disability research and young people**

The Co-Researcher Collective would not have benefitted the research in the ways it has without access to virtual spaces and methods. 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. Importantly, disability researchers have demarcated online or virtual research environments as being of significant value to existing and emerging disability research methodologies for a myriad of reasons (Bowker and Tuffin, 2004; Carr, 2010; Liddiard, 2013; Seymour, 2001; see Obst and Stafurik, 2010). Firstly, online and virtual environments can be malleable to different embodiments, capabilities and bodily functions (although this has its exclusions, as we explain below). Secondly, virtual arenas can offer greater accessibility and privacy: new social technologies can provide the means for disabled people to participate in research without this becoming known to social workers, personal assistants, carers, partners and parents. Thus, for disabled young people living with life-limiting and life-threatening impairments, and who face significant exclusion in multiple spaces of their lives (Abbott and Carpenter, 2014) — often aggravated by their need for complex medical and surgical care, support and interventions — online spaces can offer improved access to social, political, cultural and research worlds.

Yet we can't overlook the impacts of digital exclusion. As Seymour (2001: 148-149) reminds us, technology is far from neutral: 'old forms of social division underpin the new information age'. Thus, it's important to not homogenise the disability experience in relation to virtual technologies — digital exclusion remains a key form of oppression for many disabled people (Lane-Fox, 2010; Watling, 2011). Digital exclusion is exacerbated as more and more of our lives 'move' online in what Watling (2011: 491) calls 'visions of a digital future': banking, food shopping, community-building, activism, social communication, and finding friendship, love and intimacy and accessing sex (Liddiard, 2018). Adults with the label of learning disability, people with visual impairments and D/deaf people are routinely excluded and Othered in online and textual media: and it is likely this has contributed to the lack of diversity in the Co-Researcher Collective.

We suggest, however, that our online research relationships with one another as researchers in Living Life to the Fullest embody our egalitarian research politics as well as counter the routine dis/ableism inherent to the research process: we actively work towards generating a politicised space that welcomes and values the perspectives of young people with life-limiting and life-threatening impairments. Markedly, this is facilitated through the ways in which the Internet 'erases boundaries of time and distance' (Eysenbach, 2001: pagination unknown) and blurs public/private divides, meaning that our relationships as colleagues are not restricted to the neoliberal temporalities of 'work'. Some disability theorists have called this 'Crip time' (Kuppers, 2014), defined by Kafer (2013) as the recognition of (disabled) people's need for 'more time', and a political acknowledgement that contexts of ableism propagate timescales and temporalities to the benefit of non-impaired bodies and minds.

---

In relation to Living Life to the Fullest, then, online environments mean our project invites *flexibility* with regard to time. Through the intricacies of crip time (Zola, 1998) new temporal frameworks of research embody alternative orientations in, and to, time. For example, co-researchers will often message us at all times of the day and night - some work from their beds; we schedule meetings around the presence and time of care visits and support from personal assistants; Skype meetings involve breaks to adjust tracheostomy tubes or seat cushions; blog posts and tweets get written during the night; online interviews via Facebook Messenger are meticulously broken down into multiple sessions to minimise participants and co-researchers becoming exhausted; contributions require regular breaks due to frequent hospitalisations; we write chapters together in a 'live' time frame through the medium of Google docs; and planning a 'physical get-together' (e.g. at a conference) can take considerable time and labour due to the need to manage multiple barriers to access.

Importantly, often the social technologies employed were chosen by the co-researchers and participants according to which were most appropriate to their needs. For example, some of the co-researchers found it easier to conduct spoken interviews and used the technology of Skype, because the task of physically typing questions and responses on Facebook Messenger was a barrier. Yet for others, typing was easiest as it allowed time and space to accommodate medical needs (taking medications, carrying out care needs during the interview). Having a range of methods to carry out an interview that suited both the needs of the interviewer and participant opened up a platform so that everyone had the opportunity to contribute to inquiry.

## **Drawing Conclusions**

To sum up, we do not mention these flexibilities here as negative impacts of impairment, but as vital moments to rethink and reconsider conventional temporalities of qualitative methods and research processes. Rather, once again we suggest that these embodied experiences shape the process to the benefits of our participants — disabled young people with LL/LTIs and their families — ensuring that the materialities of disabled body-minds are centred in inquiry, rather than written out and overlooked. We have also found the added benefit of providing our co-researchers with the ability to imagine and see themselves as both valuable and the possibility of being 'in work'. In Living Life to the Fullest, then, impairment is more than an 'unwelcome presence' (Shildrick, 2009: 32), but serves to disrupt the embodied norms of inquiry, acknowledging the generative relations of alternative ways of being in the research process. In this way, our processes become more responsive to the real life worlds of disabled children and young people with LL/LTIs and their families.

## **Resources**

An open access longer version of this talk is available in the journal *Children and Society* [here](#).

To watch our short film *Living Life to the Fullest: The Co-Researcher Collective* (2018), please see [here](#).

To listen to our podcast *Co-Producing Research With Young Disabled People* please see [here](#).

To hear more about Sally's experiences of co-leading a research project, please see [here](#).

Follow our blog [here](#) and find us on Twitter at @ESRCFullLives.

## References

Abbott D, Carpenter J. 2014. 'Wasting precious time': young men with Duchenne muscular dystrophy negotiate the transition to adulthood. *Disability & Society* 29: 1192–1205.

Abell S, Ashmore J, Beart S, Brownley P, Butcher A, Clarke Z, Combes H, Francis E, Hayes S, Hemmingham I, Hicks K, Ibrahim A, Kenyon E, Lee D, McClimens A, Collins M, Newton J, Wilson D. 2007. Including everyone in research: the Burton Street Group. *British Journal of Learning Disabilities* 35: 121–124.

Bailey S, Boddy K, Briscoe S, Morris C. 2014. Involving disabled children and young people as partners in research: a systematic review. *Child: Care, Health and Development* 41: 505–514.

Bennett L, Segerberg A. 2011. Digital media and the personalization of collective action: social technology and the organization of protest against the global economic crisis. *Information, Communication and Society* 14: 770–799.

Beresford B. 2012. Working on well-being: researchers' experiences of a participative approach to understanding the subjective well-being of disabled young people. *Children & Society* 26: 234–240.

Bowker N, Tuffin K. 2004. Using the online medium for discursive research about people with disabilities. *Social Science Computer Review* 22: 228–241.

Bucknall S. 2010. Children as researchers in English primary schools: developing a model for good practice. chapter presented at the British Educational Research Association Annual Conference, University of Warwick, 1-4 September 2010

Buffel T. 2018. Social research and co-production with older people: developing age-friendly communities. *Journal of Aging Studies*, 44: 52–60.

Burch L. 2016. Tackling disability discrimination and disability hate crime: a multidisciplinary guide. *Disability & Society*. 31(10): 1408–1409.

Byrne B, Kelly B. 2015. Special issue: valuing disabled children: participation and inclusion. *Child Care in Practice* 21: 197–200.

Carr D. 2010. Constructing disability in online worlds: conceptualising disability in online research. *London Review of Education* 8: 51–61.

Carter B, Coyne I. 2018. Participatory research: does it genuinely extend the sphere of children's and young people's participation? In *Being Participatory: Researching with Children and Young People*. Coyne I Carter B (eds.). Springer: Cham; 171–178.

Clavering EK, McLaughlin J. 2010. Children's participation in health research: from objects to agents? *Child: Care, Health and Development* 36: 603–611.

Coad J, Lewis A. 2004. *Engaging children and young people in research: literature review for the national evaluation of the Children's Fund*. Online. Available at [http://www.necf.org/core\\_files/Elicitingchdrnsviewsjanecoadannlewisoct2004.doc](http://www.necf.org/core_files/Elicitingchdrnsviewsjanecoadannlewisoct2004.doc) [Accessed 21 May 2018].

Curran T, Runswick-Cole K (eds.). 2013. *Disabled Children's Childhood Studies: Critical Approaches in a Global Context*. Palgrave MacMillan: Basingstoke.

Curran T, Runswick-Cole K. 2014. *Disabled children's childhood studies: an emerging domain of inquiry?* *Disability & Society* 29: 1617–1630.7.

Durose C, Beebeejaun Y, Rees J, Richardson J, Richardson L. 2012. *Towards Coproduction in Research with Communities*. AHRC: Swindon, UK.

Engelsrud G. 2005. The lived body as experience and perspective: methodological challenges. *Qualitative Research* 5: 267–284.

Eysenbach G. 2001. Ethical issues in qualitative research on internet communities. *British Medical Journal* 323: 1103–1105.

Fargas Malet M, McSherry D, Larkin E, Robinson C. 2010. Research with children: methodological issues and innovative techniques. *Journal of Early Childhood Research* 8(2): 175–192.

Fudge N, Wolfe CDA, McKeivitt C. 2007. Involving older people in health research. *Age and Ageing* 36: 492–500.

Gibson BE, Mistry B, Smith B, Yoshida KK, Abbott D, Lindsay S, Hamdani Y. 2014. Becoming men: gender, disability, and transitioning to adulthood. *Health* 18: 95–114.

Goodley D, Tregaskis C. 2006. Storying disability and impairment: retrospective accounts of disabled family life. *Qualitative Health Research* 16(5): 630–646.

Goodley D, Runswick-Cole K, Liddiard K. 2015. The DisHuman child. *Discourse: The Cultural Politics of Education* 37: 770–784.  
<https://doi.org/10.1080/01596306.2015.1075731>.

Goodley D, Liddiard K, Runswick-Cole K. 2017. Feeling disability: theories of affect and critical disability studies. *Disability and Society* 33: 197–217.

Hallett C, Prout A (eds.). 2003. *Hearing the Voices of Children: Social Policy for a New Century*. RoutledgeFalmer: London and New York, NY.

Hewson CM. 2014. Research methods on the Internet. In *Communication and Technology. Handbooks of Communication Sciences Series [HoCS]*. Danowski JA, Cantoni L (eds.). De

Gruyter Mouton: 277–303.

Hewson CM, Yule P, Laurent D, Vogel CM (eds.). 2003. *Internet Research Methods: A Practical Guide for the Social and Behavioural Sciences*. New technologies for social research. Sage: London, UK.

Huffaker DA, Calvert SL. 2005. Gender, identity, and language use in teenage blogs. *Journal of Computer-Mediated Communication* 10: 2.

INVOLVE. 2016. *Involving Children and Young People in Research: Top Tips and Essential Key Issues for Researchers*. INVOLVE: Eastleigh, UK.

James A, Prout A. 1997. *Constructing and Reconstructing Childhood*, 2nd edn. Falmer Press: Basingstoke. Jong ST. 2017. Netnography: researching online populations. In *Handbook of Research Methods in Health Social Sciences*.

Liamputtong P (ed.). Springer: Singapore. Kafer A. 2013. *Feminist Queer Crip*. Indiana University Press: Bloomington and Indianapolis, IN.

Kay E, Tisdall M. 2017. Conceptualising children and young people's participation: examining vulnerability, social accountability and co-production. *The International Journal of Human Rights* 21: 59–75.

Kellett M. 2005a. Children as active researchers: a new research paradigm for the 21st century? ESRC National Centre for Research Methods, NCRM Methods Review chapters. ESRC: London.

Kellett M. 2005b. *How to Develop Children as Researchers: A Step-by-Step Guide to Teaching the Research Process*. Paul Chapman/Sage: London.

Kellett M. 2010. *Rethinking Children and Research: Attitudes in Contemporary Society*. Continuum: London.

Kirby P. 2004. *A Guide to Actively Involving Young People in Research: For Researchers, Research Commissioners, and Managers*. INVOLVE: Eastleigh, UK.

Kitchen R. 2000. The researched opinions on research: disabled people and disability research. *Disability & Society* 15: 25–47.

Koski K, Heyning F, Zwijnenberg R. 2016. Collaborative meaning-making in arts-based research: data interpretation with an artist, a physician, and an art historian. *Art Research International: A Transdisciplinary Journal* 1: 232–257.

Kuppers P. 2014. Crip time. *Tikkun* 29: 29–30. Lane-Fox M. 2010. Digital manifesto for a networked nation. Available at <http://raceonline2012.org/manifesto> [Accessed 5 December 2018].

- Liddiard K. 2014. The work of disabled identities in intimate relationships. *Disability and Society* 29(1): 115–128.
- Liddiard K. 2013. Reflections on the process of researching disabled people's sexual lives. *Social Research Online* 18: 10.
- Liddiard K. 2018. *The Intimate Lives of Disabled People*. Routledge: London and New York, NY.
- Littlechild R, Tanner D, Hall K. 2015. Co-research with older people: perspectives on impact. *Qualitative Social Work* 14: 18–35.
- Mitchell W. 2010. 'I know how I feel': listening to young people with life-limiting conditions who have learning and communication impairments. *Qualitative Social Work* 9: 185–203.
- Nind M. 2008. Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges. ESRC National Centre for Research Methods Review chapter. National Centre for Research Methods.
- Nind M, Wiles R, Bengry-Howell A, Crow G. 2012. Methodological innovation and research ethics: forces in tension or forces in harmony? *Qualitative Research* 13: 650–667.
- Obst PL, Stafurik J. 2010. Online we are all able bodied: online psychological sense of community and social support found through membership of disability-specific websites promotes well-being for people living with a physical disability. *Journal of Community and Applied Social Psychology* 20: 525– 531.
- Oliver M. 1992. Changing the social relations of research production. *Disability & Society* 11: 115–120.
- Olsen A, Carter C. 2016. Responding to the needs of people with learning disabilities who have been raped: co-production in action. *Tizard Learning Disability Review* 21: 1–9
- Pearson C, Trevisan F. 2015. Disability activism in the new media ecology: campaigning strategies in the digital era. *Disability and Society* 30: 924–940.
- Pluquailec J. 2018. Thinking and doing consent and advocacy in disabled children's childhood studies research. In *The Palgrave Handbook of Disabled Children's Childhood Studies*. Runswick-Cole K, Curran T Liddiard K (eds.). Palgrave Ltd: Basingstoke; 213–229.
- Rabiee P, Sloper P, Beresford B. 2005. Doing research with children and young people who do not use speech for communication. *Children & Society* 19: 385–396.
- Runswick-Cole K, Curran T, Liddiard K. 2017. The everyday worlds of disabled children. In *Disability, Normalcy and the Everyday*. Thomas G Sakellariou D (eds.). Palgrave Ltd: Basingstoke; 41–61.

Runswick-Cole K, Curran T, Liddiard K. 2018. A Handbook of Disabled Children's Childhood Studies. Palgrave MacMillan: Basingstoke.

Ryan S. 2017. Justice for Laughing Boy: Connor Sparrowhawk - A Death by Indifference. Jessica Kings- ley Publishers: London.

Save the Children. 2000. Young People as Researchers: A learning resource pack. Save the Children: London.

Seymour WS. 2001. In the flesh or online? Exploring qualitative research methodologies. *Qualitative Research* 1: 147–168.

Shildrick M. 2009. *Dangerous Discourse of Disability, Subjectivity and Sexuality*. Palgrave Macmillan: New York, NY.

Swain J, Heyman B, Gillman M. 1998. Public research, private concerns: ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability & Society* 13: 21–36.

Thomas C. 1999. *Female Forms: Experiencing and Understanding Disability*. Open University Press: Buckingham.

Tuffrey-Wijne I, Bernal J, Hollins S. 2008. Doing research on people with learning disabilities, cancer and dying: ethics, possibilities and pitfalls. *British Journal of Learning Disabilities* 36: 185–190.

United Nations. 1989. *Convention on the Rights of the Child*. HMSO: London. Walmsley J. 2004. Inclusive learning disability research: the (nondisabled) researcher's role. *British Journal of Learning Disabilities* 32: 65–71.

Watling S. 2011. Digital exclusion: coming out from behind closed doors. *Disability and Society* 26: 491–495.

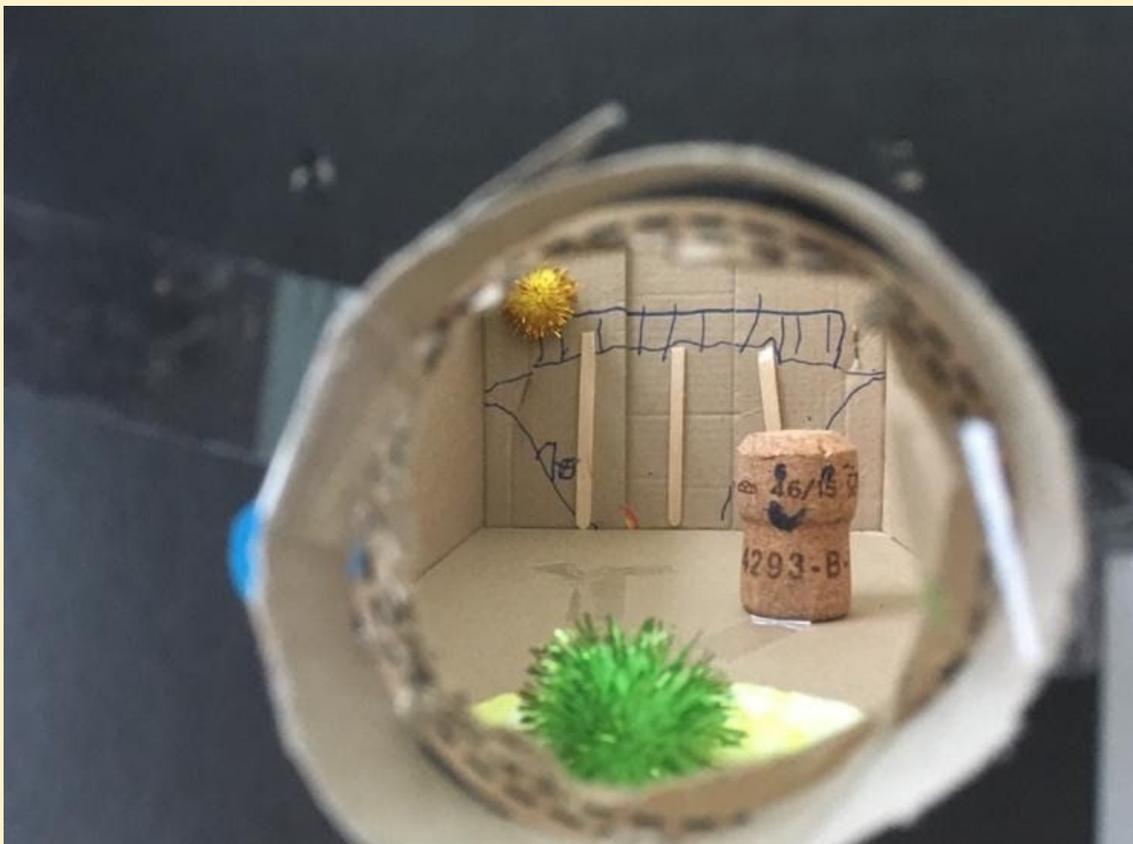
Zarb G. 1992. On the road to Damascus: first steps towards changing the relations of disability research production. *Disability, Handicap & Society* 7: 125–138.

Zola IK. 1998. The language of disability politics and practice. *Australian disability review*. Online. Available at <http://www.disabilitymuseum.org/lib/docs/813.card.htm> [Accessed 14 May 2018].

## Chapter 4: The Red Helmet: A participatory approach with children in primary education

**Silke Daelman, Elisabeth De Schauwer, Geert Van Hove  
Ghent University**

This chapter covers one narrative that emerged during the first study of the researcher's doctoral research situated in the context of the Flemish (primary) education system. It is part of a larger PhD that begins, is guided by, and will end with perspectives of children on their educational environments. It questions the dominance of (abled) adults as well as the absence of disability and children in research in education, among other research areas (Jones & Liddiard, 2018). For a long time, children have been put in a passive position and their unique voices have been overpowered and side-lined (Conner & Stalker, 2007; Allan, 2007; Holt, Bolwby & Lea, 2017).



*Figure 2. Image of model made of cardboard and a champagne cork*

In this chapter, the author takes the opportunity to focus on one small conversation with children (age 9 to 10), which can tell us a lot about the normative powers working on our ideal of the human; and about the functioning of group dynamics, identities, statuses and senses of belonging of children at school and in playgrounds.

During the course of three months, the children and the researcher worked together in workshops – using creative and participatory methods – about ‘groups’ at the playground. The children indicated the importance of ‘groups’, consisting of several children playing together in the playground under names like ‘the Sharks’, ‘the Cats’ and ‘the RubiksCubers’, among others. The children explained what you had to do to belong to a group, which social rules they followed, how belonging to particular group could add to your status and might lead to privileges. They indicated how groups seem to move within territories in the playground and how some children do not seem to belong in groups and remain in between territories, in a borderland (Anzaldúa, 1987).

### The Red Helmet



*Figure 3. Image of model made of cardboard and a champagne cork*

Imagine this situation. Four boys are sitting around a table covered with Lego with the intention of making their own stop-motion movie about the groups in class. They have brought a suitcase full of Lego equipment, weapons, clothing and other accessories in order to compose the most suitable appearance of each personage. They decide they will be the main characters of the movie; so they are turning themselves into Lego. This is when the following conversation takes place.

**Lowie:** Where is your Lego Man?

**Keanu:** Tim still has to make his. But he can't be too cool, I couldn't make it too cool either.

**Keanu:** Tim is making his Lego man already Lowie, you have to check whether it is not too cool.

**Lowie:** Yes, he has to look a little bit like you. The face has to look a little bit like yourself.

**Tim:** I am always angry so [puts on a red helmet].

[Cas & Lowie Discuss together while taking a look at the weaponry and equipment.]

**Keanu:** It can't be too cool, Tim. Oh no this is too cool already. You can only have that weapon.

**Lowie:** Show me.

**Keanu:** Look at this cool weapon.

**Lowie:** That is too cool, isn't it?

**Tim:** But I just want a shield to protect myself.

**Lowie:** But you can't, otherwise you will be too cool. I'm this Lego man. I only have one big sword.

**Tim:** You always play my bosses!

**Lowie:** I'm sorry, but it [your Lego man] has to suit [ours].

**Tim:** That is really not funny! Always playing my bosses! I already was punished today! I couldn't eat almost anything! I am still very hungry. I want to choose!

**Lowie:** But it really is not fair if he is supercool and the other ones aren't.

**Keanu:** Personally, I think Cas. is also cool actually...

**Lowie:** Yes, that is true.

**Cas:** I don't have any high-tech weapons like that. I have a bow and the other things are only the way my Lego man looks like.

**Lowie:** And I only have a big sword. But an axe and a shield...

**Cas:** No maybe an axe and a shield equal your [big sword]. Show me your man. It's just that you cannot look like you are the boss.

**Lowie:** Yes, my man does also not look like a boss [shows his Lego Man]. Alright... Maybe a little bit...

**Cas:** Show me your Lego Man. I think it might be alright...

**Lowie:** I would only remove the shield.

**Cas:** Maybe remove the cape and then it will look like... But actually, you also have a cape so...

**Lowie:** I would choose another helmet. Cause I also do not have a lot of protection.

**Cas:** Yes, maybe put on another helmet.

**Lowie:** I only have an armor.

**Cas:** Take a look at his head... I can understand that... Just put on this one [a white helmet]. Yes, like this. Do you like this one, Tim?

[...]

**Lowie:** Are you in any group? Otherwise we will put you with those ones that are not in any group.

Let's take a closer look at Tim in order to understand what matters in this conversation. When talking about places at school, Tim explains he likes to spend his time near the basketball field because it is *"a place where you can play basketball"*, *"... which is very*

*nice*". Tim also likes to visit the soccer field, which is especially nice with *"the small goals, you can play mini-soccer with it and that is a very amusing thing to do"*. Tim adores doing sport in general, recently he started boxing in his spare time: *"it is for my defence. In case someone hits me I can defend myself – but no hitting back but going directly to the teacher"*. Tim thinks things on the playground are complicated because: *"I can't join in basketball, but I can in soccer. Isn't that a little bit weird? I think it is weird."* He considers this might be because of the fact that he kicked away the ball one time when he had *"fury in his head"*.

The other children also refer to Tim when talking about the playground. *"He is always angry. I am thinking he is angry because he doesn't belong with us."* Getting to know Tim throughout his narratives of himself and his peers' narratives about him, can help us shed light on the narrative to understand how Tim is positioned to be negotiated around'. Territories seem to be closed to Tim, access is often denied; so he ends up in a borderland between territories because he cannot live up to rules applied to belonging to groups: the children highlighted how the most important rule is 'no fighting and no bullying'. The territory becomes a striated space: spaces 'which are rigidly structured and organized, and which produce particular, limited movements and relations between bodies...' (Davies, 2011, p. 6).

But making Lego Men opens a space for Tim. The boys seem to be in a flow together, collectively exploring armoury, weapons and equipment, intra-acting in a balanced way, each transcending the group they (do not) belong to. Territories seem to be in flux, borders between 'selves' become smooth, blurred and fluid (Wyatt, 2014). Within this smooth space (Davies, 2011) unexpected things become possible: positions can be reconsidered which creates a unique opportunity for the fourth boy to attach to a whole. There is an opportunity to belong. *"This is the four of us. [...] You are in the group of the main characters."* It becomes a 'space of shared deterritorialization in which they constitute one another' (Wyatt, 2014, p. 14). The territory has opened its doors.

Soon however, normalizing powers and regulations start to play out when one of the boys says... *"You have to check whether it is [his Lego man] not too cool; it can't be too cool."* And *"Show me your Lego Man, it is just that you cannot look like you are the boss."* The territory is re-structuring its borders. When the boys explain to Tim that his Lego man should look like him, Tim puts a red helmet saying *"I am always angry, so..."*. What matters when Tim puts on a red helmet? What is he telling the other children? Is he trying to warn them not to mess with him? Is he tired of covering up, immediately exposing himself? Is he trying to protect himself against possible reactions of others? Is he already expecting to be excluded?

Immediately after spotting the appearance of Tim's Lego Man, one of the boys calls: *"It can't be too cool, Tim. Oh no, this is too cool already!"*. The boys agree that something about Tim's Lego Man is not acceptable and they start to negotiate about different aspects of the Lego man's appearance. What Lego man could be accept-able? By interrogating Tim's Lego man, the other boys distance themselves and embody a superior position (Derrida, 2000; Vlad, 2014).

Tim knows what is expected of him, he knows what behaviour is accept-able. *"Playing with the others."* He also knows what behaviour is not accept-able. *"And that I do not fight."*

Clear obligatory acceptable behaviour (Goodley, 2009). Also, in the accounts of his peers 'otherness' is negatively represented which reinforces its undesirability (Goodley, 2009) and the need to be fixed. A peer states *"He has this thing which makes him angry more rapidly and the doctor said he has to take medicines, so it would happen less. That he would be angry less often. But his mother says it is better not to take the medicines. But I mean, the proof is in front of our noses that it would be better, isn't it?"*. However, Tim seems to consider himself unable to live up to these expectations when he says, *"I am not like the other children. They are never angry: I am angry sometimes. And the others are happy: I am not always happy. I think that is actually... a difference in character."* The violence and deprecating connotations are internalized (Goodley, 2009) and become a part of Tim's self-image. Territories at the playground seem to become territories within.

At the end of their negotiations, the boys decide that Tim's Lego Man is acceptable in the stop-motion movie, if it wears a white helmet instead of the red one. It was Tim's red helmet that positioned his Lego man as unacceptable. *"Take a look at his head... I can understand that [it is too cool] ... just put on this one [a white helmet] ..."*.

As the red helmet is positioning Tim's Lego man as unacceptable, so Tim's anger is also positioning him. The Lego man can participate in the movie, but not with the red helmet. Tim can belong in a group but there is no space for his anger, *"because we don't want it to become one big fight at the playground."* As long as Tim cannot accommodate to being the 'happy playing child' (Goodley & Runswick-Cole, 2011, p.612), he will remain between territories, in the borderland. Who is this 'happy playing child'? Is it the child who never kicked away a ball? Who never fights? The child who is never angry and is therefore allowed to join? Or is it the child who is never excluded and therefore never angry? Tim does not contest the alternative of the white helmet. Perhaps the white helmet easily goes together with the discourse of 'keeping it in', as he is told by his mother, teachers and behavioural therapist. *"I went to someone for my behaviour. I have to keep everything in"*. Concealing a 'secret sin' (Yarbro-Bejarano, 1994, p. 21) seems to be important if you want to make something out of your life. *"Actually, your behaviour is the most important. I want to fix my behaviour. My friend had to redo his first year because of his behaviour. That's why I say 'You also have to keep your behaviour good in order to go to fifth grade'. [...] It's for the future that you have to keep your anger inside."* He has to keep it inside if he wants to play along with the other children and gain access to their territories in the playground.

'Keeping it in', 'pushing the unacceptable parts into the shadows' (Anzaldúa, 1987: 20), risks building self-abjection and internalized oppression – quietly neglected by therapy – and might add to normalization rather than compensating for its consequences (Goodley, 2009).

I am wondering. Perhaps the borderlands and the red helmet are not devastating narratives about being an outsider? Rather, could they be the critical positions we need in order to think with children about deconstructing binaries and blurring identities created across difference (Hammad, 2010)? Does this position, as Anzaldúa (1987) suggests, offer a new consciousness that motivates us to 'eschew labels and embrace the otherness of those along the border' (Sanders, 2018)?

‘Living in the midst of the tension of a half-and-half position provides for the possibility of not only recognizing exclusion and demanding inclusion, but also uncovering and understanding how the exclusion that is identified can be included into a yet-to-be imagined world that promises something other than the same.’  
(Titchkosky, 2011: 28)

The original purpose of this study was to step away from the normative, vulnerable and passive stories about children, and to see children themselves as creative and creating in everyday experiences. However, I could not have imagined how relevant this particular battle – of stepping out of the normative – is in every child’s life at school. We need to be aware of the borderlands inhabited by our children in our educational environments. And we need to use the opportunities the borderlands offer us. It is near the borders that the movement of inclusion and exclusion can emerge.

## References

- Allan, J. (2007). *Rethinking Inclusive Education: The Philosophers of Difference in Practice*. Dordrecht, The Netherlands: Springer.
- Anzaldua, G. (1987). *Borderlands / La Frontera: The new Mestiza*. San Francisco, CA: Aunt Lute Books.
- Conners, C. & Stalker, K. (2007). Children’s experiences of disability – pointers to a social model of childhood disability. *Disability & Society*, 22 (1), 19-33. doi: 10.1080/09687590601056162
- Davies, B. (2011). Listening: A Radical Pedagogy. In S. Fahlgren (Ed.), *Challenging Gender: Normalization and beyond* (pp. 107-120). Sundsvall, Sweden: Forum for genusvetenskap.
- Derrida, J. (2000). *Of Hospitality. Anne Dufourmantelle invites Jacques Derrida to respond*. Stanford, CA: Stanford University Press.
- Goodley, D. (2009) Internalised Ableism: The Tyranny Within. In F. K. Campbell (Ed.), *Contours of Ableism. The Production of Disability and Abledness* (pp. 16-29). Retrieved from: <https://www.freelists.org/>
- Goodley, D. & Runswick-Cole, K. (2011). The violence of disablism. *Sociology of Health and Illness*, 33(4), 602-617. doi: 10.1111/j.1467-9566.2010.01302.x
- Hammad, K. L., (2010). Border Identity Politics: The New Mestiza in Borderlands. *Rupkatha Journal on Interdisciplinary Studies in Humanities*, 2 (3), 303-308.
- Holt, L., Bolwby, S. & Lea, J. (2017). “Everyone knows me... I sort of like move about”: The friendships and encounters of young people with Special Education Needs in different school settings. *Environment and Planning A*, 49 (6), 1361-1378. doi: 10.1177/0308518X17696317

Jones, L. & Liddiard, K. (2018). A Diversity of Childhoods: Considering the Looked After Childhood. In K. Runswick-Cole, K. Liddiard & T. Curran (Eds.), *The Palgrave Handbook of Disabled Children's Childhood* (pp. 389-408). London, United Kingdom: Palgrave Macmillan.

Kokaliris, G. (2015). Jacques Derrida on the Ethics of Hospitality. In E. Imafidon (Ed.), *The Ethics of Subjectivity. Perspectives since the Dawn of Modernity* (pp. 144-156). Retrieved from: <http://www.frenchphilosophy.gr/>

Sanders, S. (2018, February 14). Embracing the border: Gloria Anzaldua's Borderlands/La Frontera [Blog post]. Retrieved From: <https://womensmuseum.wordpress.com/2018/02/14/embracing-the-border-gloria-anzaldua-s-borderlands-la-frontera/>

Titchkosky, T. (2011). *The Question of Access. Disability, Space, Meaning*. Toronto, University of Toronto Press.

Vlad, A-N. V. (2014). Hospitality between commas and borders. *The Proceedings of the International Conference Globalization, Intercultural Dialogue and National Identity. Section: Language and Discourse*, 1, 471-476.

Wyatt, J. (2014). Always in Thresholds. *Departures in Critical Qualitative Research*, 3 (1), 8-17.

Yarbro-Bejarano, Y. (1994). Gloria Anzaldua's Borderlands / La Frontera: Cultural Studies, "Difference" and the Non-Unitary Subject. *Cultural Critique*, 28, 5-28.

## **Chapter 5: The Narrative Power of Disabled Youth: From insult and invisibility to love and solidarity**

**Edmund Coleman-Fountain**  
**Northumbria University**

Stories of human worth secure, and are lodged in, ‘hierarchies of credibility’ (Plummer, 2019). They are forms of meaning making that construct the value of different ways of being in the world. Bérubé (2016) addresses similar themes when he describes stories as central to how systems of sociality get legitimised. Narratives are vehicles of world-making just as much as they provide ‘insight into human hierarchies and the contingency of systems of value’ (Bérubé, 2016: 3). For example, stories of ‘hard work’, individual endeavour, or self-sacrifice give meaning and justification to a range of social practices from which systems of social and economic inequality emerge. They also provide forms of recognition in a context that values economic and material self-sufficiency (Honneth, 1995). In a world that ties human worth to self-reliance, influential ideologies bend the idea of the human in the interests of power: the self-perfecting individual of humanist philosophy is amenable to neoliberal ableist conceptions of the good (Goodley, 2014).

Hierarchies of credibility underpin what Plummer (2019) calls ‘narrative power’: a capacity to make narrative claims about the world, and to shape social and political processes by telling world-making stories. Some groups are recognised as legitimate and credible storytellers. The forms of intelligibility and understanding that powerful stories generate can structure lives into states of inequality and exclusion (Plummer, 2019). Because of this, subordinated groups can find it hard to tell stories of their own. Disability studies has long argued that depictions of impairment as ‘tragic’ have led to disabled lives being separated, symbolically and materially, from those of non-disabled people (Stiker, 2019). For Bérubé (2005), dehumanizing narratives of disability that elicit pity or horror construct the ‘Other’ of ableism. What this points to are modes of disrespect and exclusion, and the practices built around those, that have denied disabled people their humanity ‘in the eyes of the other’ (Mitchell and Snyder, 2015: 112, Watson, 2004).

The struggles of historically disrespected social groups can be understood as ‘struggles for recognition’ (Honneth, 1995). In this chapter, my focus is on the narrative power of disabled young people as similarly involved in struggles for recognition, but who can be made less visible or silent by virtue of their young age and structural social location (McLaughlin et al., 2008). I ask what disabled young people’s stories can reveal about what may ‘designate a good enough human life’ (Plummer, 2019: 64), and about the potential to imagine new forms of recognition. The visual data presented is from an ESRC funded study ‘Embodied Selves in Transition’ (PI: Prof Janice McLaughlin; for details see McLaughlin and Coleman-Fountain, 2014, 2019).

## Peripheral Bodies

Mitchell and Snyder's (2015: 14) idea of 'peripheral embodiments' – which are denied equality because of 'determinations of their excessive deviance from culturally inculcated norms' of 'bodily wholeness' and normalcy – reflects the distance between desirable 'social' bodies and physical bodies marked as other to contemporary norms. For example, heightened stigmatisation of disabled people characterised as 'undeserving of social entitlements' (Soldatic, 2018: 43) and intensification of disablement under neoliberal ableism can narrow human value to competitive individualism and undermine solidarity with people with different bodies. The way out of this, it seems, is to 'overcome' supposedly personal barriers, and 'strive' for advantage against the odds.

Peripheral embodiment reflects the misrecognition of someone's worth on the basis of their bodily difference and within a normative frame of bodily value. How bodies are 'scaled' can relate to practices of disrespect, such as denigration and insult, exclusion, denial of rights, and violence (Honneth, 1995, Young, 1990). Prejudice and stigma communicated through insult, for example, is a dominant feature in the making of unequal selves (Eribon, 2004).

In our research with disabled young people, stigmatising reactions to bodily difference – 'pulses of aversion' (Young, 1990: 123) communicated through hurtful language and stares – were seen to position disabled young people as selves of lesser worth (McLaughlin, 2017). Participants were also aware of how their bodies were made 'peripheral' through practices of exclusion or 'invisibilisation' (Herzog, 2017). One young man described his sadness at being shut off from the activities of his peers due to the lack of an inclusive space through which he could be present. Sean said:

“being disabled you can be quite left out, you can be in the background. For example, when it comes to sport and P.E at school. Sometimes you can be a bit left out or sometimes you find that you can't do things out of the blue, so that leaves you out, and sometimes, inevitably, sometime in your life you're gonna feel left out”.

Feeling left out related to not being “joined in” by others through making changes, such as to the games played, that would include him. His feeling of being 'lost in the background' reads as acknowledgement of how norms of social practice can lead to disabled young people being relegated to the side lines, an alternative to being the focus of negative attention. His representation of pain moved from the physical pain of cerebral palsy to the idea of peripheral embodiment as a factor in the making of a 'subordinated narrative self' (Plummer, 2019).



Figure 4. Pages of Book with images representing disability and inclusion

### Challenges of Recognition

Some representations reflected the desire for recognition as fully individuated selves (Honneth, 1995). These representations depicted a self 'straining against' disrespectful images (Plummer, 2019), such as of portrayals of disabled young people as damaged, helpless or pitiful. The young people's preferred self-images included showing off an alternative style of dress, a challenging attitude, involvement in or support for physically tough sports, or an ambitious imagined adulthood:

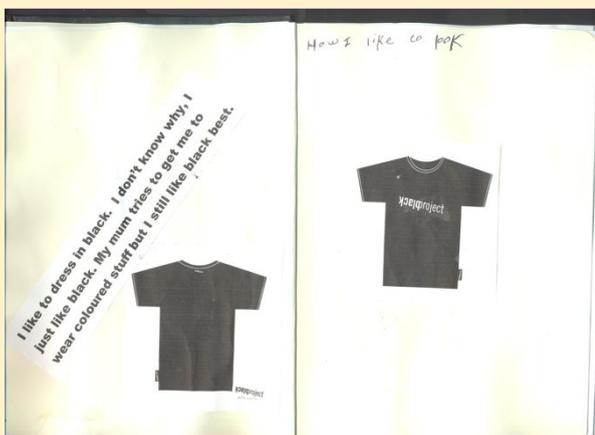


Figure 5. Image of book pages with t-shirts

Disabled young people are not outside of stratified norms of recognition, however. Their practices and stories are constructed in the context of generalised understandings about what it means to belong in the world. For example, victim-blaming aligned with neoliberal arguments about individual responsibility can intensify the regulatory gaze on disabled bodies, marking as problematic morphologies that do not appear to embody norms of self-help, and reinforce exclusion (Charmaz, 2019: 22, Sothorn, 2016). This all matters for the management of peripheral bodies. Recognition for individuated identities is shaped by the normative boundaries established by the ableist gaze, on which the normalisation of disability depends (Mitchell and Snyder, 2015).

The challenges to recognition in a context that values ‘individual responsibility, self-sufficiency, competition, efficiency, and profit’ (Charmaz, 2019: 22) affect the politics of support. For the young people, all experiencing physical disability related to cerebral palsy, it was not just a matter of getting the right support, but about balancing that with a desire for (celebrated) independence bound up in a project of becoming the ‘right kind of adult subject’ (McLaughlin, 2020: 409). Achieving a ‘normal’ standard of embodiment through bodily self-management and ‘overcoming’ disability seemed a normative goal (McLaughlin and Coleman-Fountain, 2014).

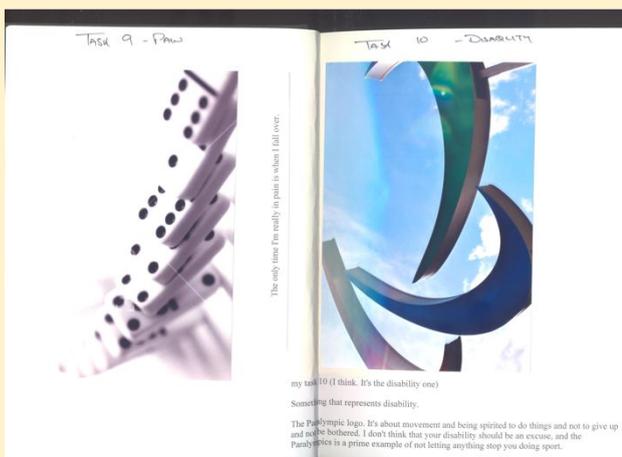


Figure 6. Image of book pages with dice on the left hand page and abstract art on the right

## The Intersubjectivities of Care

Not all recognition was sought via generalised others or a renunciation of supportive relations. Alternative values and connections, based on the material and symbolic importance of human care and interdependence provided for another form of intersubjective self-understanding (Warren and Sakellariou, 2019). Here, recognition was not just about competing in life’s game, but also about appreciating how social connection could generate feelings of human worth. In these depictions, bodies were supported physically and emotionally.



Figure 8. Series of three book pages with images of divers

The family was a primary site of recognition for our participants (Honneth, 1995). Care was represented in many ways: images of family, commentaries on love and care, and creative objects – a fabric rose head and synthetic leaves on a repaired necklace cord created to signify family ties. The storied love bonds represented in reflections on family support pointed to an alternative narrative framing of the human: less atomised, more interdependent.



Figure 9. Image of a deep pink rose with silver metallic leaves on a rope

Does this narrative have relevance for wider society and social justice – and what versions of the human does it produce? Care had a role in producing a positive sense of self. Elsewhere, McLaughlin (2019) argues for the importance of a politically-oriented ethics of care. This starts from the premise that stigmatising narratives of interdependence do not lead to greater inclusion for those with different bodies and support needs. Instead, these secure social practices that marginalise and exclude, and create conditions of disrespect that limits the scope for people with diverse bodies to achieve dignity as social persons and as people with rights. Rather, McLaughlin (2019) argues, the material and symbolic conditions for inclusion and citizenship require a narrative reframing of care practices as a social good that enables greater freedom to be, as well as solidarity and mutual recognition

across lines of difference. One aspect of doing that involves practices of interdependency being replicated in the public spheres of welfare organisations and social relations. Doing so avoids the problems of family-based solidarity equating to privatisation of care and a narrow set of concerns for 'one's own'.

## Conclusion

The stories of disabled young people can provide a way into thinking of new narratives for the social world we live in, and for imagining alternative systems of sociality and recognition. The argument here is that we can learn a lot from disabled children simply by recognising them as credible storytellers in their own right.

## References

Bérubé, M. (2005) Disability and narrative. *Pmla-Publications of the Modern Language Association of America*, 120(2): 568-576.

Bérubé, M. (2016) *The Secret Life of Stories: From Don Quixote to Harry Potter, How Understanding Intellectual Disability Transforms the Way We Read*. New York, NYU Press.

Charmaz, K. (2019) Experiencing Stigma and Exclusion: The Influence of Neoliberal Perspectives, Practices, and Policies on Living with Chronic Illness and Disability. *Symbolic Interaction*, 43(1): 21-45.

Eribon, D. (2004) *Insult and the making of the gay self*. Durham, NC, Duke University Press.

Goodley, D. (2014) *Dis/ability Studies: Theorising disablism and ableism*. London, Routledge.

Herzog, B. (2017) Invisibilization and Silencing as an Ethical and Sociological Challenge. *Social Epistemology*, 32(1): 13-23.

Honneth, A. (1995) *The struggle for recognition: the moral grammar of social conflicts*. Cambridge, Polity.

Mclaughlin, J. (2017) The medical reshaping of disabled bodies as a response to stigma and a route to normality. *Medical Humanities*, 43(4): 244-250.

Mclaughlin, J. (2019) Valuing Care and Support in an Era of Celebrating Independence: Disabled Young People's Reflections on Their Meaning and Role in Their Lives. *Sociology*, 54(2): 397-413.

Mclaughlin, J. & Coleman-Fountain, E. (2014) The unfinished body: The medical and social reshaping of disabled young bodies. *Social Science & Medicine*, 12076-84.

- Mclaughlin, J. & Coleman-Fountain, E. (2019) Visual methods and voice in disabled childhoods research: troubling narrative authenticity. *Qualitative Research*, 19(4): 363-381.
- Mclaughlin, J., Goodley, D., Clavering, E. & Fisher, P. (2008) *Families Raising Disabled Children: Enabling Care and Social Justice*. Basingstoke, Palgrave Macmillan.
- Mitchell, D. T. & Snyder, L. S. (2015) *The Biopolitics of Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment*. Ann Arbor, MI, University of Michigan Press.
- Plummer, K. (2019) "Whose Side Are We On?" Revisited: Narrative Power, Narrative Inequality, and a Politics of Narrative Humanity. *Symbolic Interaction*.
- Soldatic, K. (2018) *Disability and Neoliberal State Formations*. London, Routledge.
- Sothorn, M. (2016) You Could Truly Be Yourself If You Just Weren't You: Sexuality, Disabled Body Space, and the (Neo)Liberal Politics of Self-Help. *Environment and Planning D: Society and Space*, 25(1): 144-159.
- Stiker, H.-J. (2019) *A History of Disability*. Ann Arbor, University of Michigan Press.
- Warren, N. & Sakellariou, D. (2019) Neurodegeneration and the Intersubjectivities of Care. *Medical Anthropology*, 39(1): 1-15.
- Watson, N. (2004) The Dialectics of Disability: a social model for the 21st Century? . In: Barnes, C. & Mercer, G. (eds.) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press.
- Young, I. M. (1990) *Justice and the Politics of Difference*. Princeton, N.J., Princeton University Press.

## Chapter 6: An Ethical Responsibility

**Sharon Smith**

**University of Birmingham**

I have a daughter. She is 15 years old. She has brown hair and blue eyes. She is short in stature. She has Trisomy 21, commonly known as Down's syndrome, which means she is recognised as disabled and she struggles to learn in the same way and at the same pace as others expect her to do. She attends mainstream school. She is feisty, loud, hilarious and ever so slightly bossy, especially where her older brother is concerned. Hard as I try, though, any picture that I attempt to paint of her is a poor representation (and not just because I lack the necessary skills). Indeed, my words at the start of this introduction are completely inadequate, as she is significantly more than any impression I can give about her physical characteristics or her vibrant personality. Just being in my daughter's presence is a constant reminder to me that she defies any descriptions I can manufacture, because she soon lets me know that she is her own person, with her own perspective and her own responses to situations, often quite unpredictable and definitely unique to her. I therefore always feel both a sense of responsibility to describe her in a way that she would be happy with, whilst also recognising simultaneously that my words will never quite be good enough, as they can never fully represent her.

The same, therefore, surely applies to all other 'others', which includes any potential participants for my proposed research. My relationship with my daughter, and the sense of responsibility I feel when discussing her, are amongst the reasons I have been drawn to thinking about how the work of Emmanuel Levinas might provide an ethical framework for my research, which aims to explore the subjectivity of parents of disabled children and its impact on inclusion. By using Levinas's ethics as the guide for all my decision-making, from the outset to completion, I hope to avoid any actions that cause any form of injustice or further subjectification of either the parents who offer to take part in the study, or the disabled children and young people who could also be impacted by research about their parents.

Levinas's work is underpinned by a recognition of 'ethics as first philosophy' (Levinas, 1989: 75-87). He claims '[o]ntology as first philosophy is a philosophy of power' (Levinas, 1969: 46); therefore any discussion of what it is to be human must begin with ethics (Putnam, 2008: 70). Levinas positions ethics as 'prior to ontology or epistemology' (Gehrke, 2010: 6). He was critical of how, within Western philosophy, there is a 'primacy of the same' (Levinas, 1969: 43) and describes how every 'I think' comes down to 'an appropriation of what is, to an exploitation of reality' (p. 46). Therefore, the other person's absolute difference or otherness becomes absorbed into my 'own identity as a thinker or possessor' (p. 33). The Other becomes an object of '*my* comprehension, *my* world, *my* narrative' (Todd, 2001:73, original italics), which Levinas saw as a form of violence or negation, as it is a violation of the other's infinite difference (Garza & Landrum, 2010: 3). This violence is obviously unavoidable, as we cannot help but think about people using our own concepts and knowledge of the world. However, I can attempt to approach my research in a way that minimises the impact of this on the participants, by recognising throughout that 'both the Other and my responsibility to the Other are beyond containing or

schematising in thought' (Gehrke, 2010:8) and allowing this to be my primary ethical consideration throughout.

For Levinas, ethics must be based on a relation to people, where the response is not determined by abstract rules, but instead is simply a matter of recognising what we are 'called on' to do in the moment, in order to respect the 'alterity' of the other, the other's 'manifold difference' (Putnam, 2008: 95). Rather than a model of ethics that is based on rights and equality or universal rules to be followed, Levinas claimed that we are infinitely responsible for the Other and it is this responsibility that defines how we should act within any encounter with another person (Benson & O'Neill, 2007: 30). He rejected any suggestion that there could be universal rules for how we should behave or treat other people, because fundamentally, humans are not all the same (Putnam, 2008: 70). This approach does not offer procedures or predefined steps to take, instead, as Garza & Landrum (2010: 8) describe, 'alterity is inherent in the research situation' I have an ethical obligation to the Other, in every aspect and interaction.

Levinas attempted to conceptualise 'human subjectivity as beginning in ethical responsibility' (Strhan, 2016:334). He sees the very possibility of our subjectivity in the approach of the Other, in that we can only become an 'I' in our response to them (Gehrke, 2010: 7). For Levinas, subjectivity is a 'gift from the Other that bears with it an obligation that cannot be declined' (Gehrke, 2010: 8). I can only exist 'for the Other' (p. 8). It is therefore necessary for me to be open towards a 'genuine and open encounter with otherness' (Hibbert et al, cited in Rhodes & Carlsen, 2018: 1302). This is more than a sense of openness or a reflexivity that still reinforces my own knowledge and understanding of the world. Instead, as Rhodes & Carlsen (2018) describe, it requires an 'ethical vulnerability', where my 'own knowledge and self-understanding are themselves open to question through the research encounter' (Rhodes & Carlsen, 2018: 1297). I must allow the encounter with the Other to call both me and my understanding into constant question (Garza & Landrum, 2010: 4). I need to be willing to be personally affected and changed through my interactions with the Other, rather than attempt to classify or compare them to my own framework of knowledge (Rhodes & Carlsen, 2018: 1297). Rhodes & Carlsen describe how this does not position the researcher in a 'sacrificial position', but rather can lead to a 'heightened sense of meaning in research' as it becomes possible to pursue 'wonder' in an 'unpossessive and emphatic stretching towards the other' (Rhodes & Carlsen, 2018:1298).

My study should not attempt to generate knowledge about other people and it will not suffice simply to produce research with other people. Instead, I need to adopt a 'self-other orientation' throughout, which will allow me to be disturbed and 'personally affected, moved and changed by interactions with others' (Rhodes & Carlsen, 2018: 1297). It is my interaction with the Other, who brings me 'to an awareness of my personal responsibility', that 'creates me as a responsible person' (Dykeman, 1993: 9). As Allan (2011: 160) suggests, this requires me, as a researcher, to 'accept the inevitability of uncertainty', as it is not possible to rely on established solutions or tricks of the trade. It will be necessary to let go of methodological control (Rhodes & Carlsen, 2018:1298) and allow myself to be affected by the teaching of the Other, allowing a 'risky uncovering of oneself' (Levinas, 1998: 48). Levinas describes the ethical relation as the 'original 'After you, sir!', where we put the other person's interests before our own (Levinas, 1985: 89). Our response to the

other cannot be arrived at through abstract reason, but is something we are expected to feel (Putnam, 2008: 94). This is therefore a risky approach to take, as it cannot be planned out in advance with a reliance on existing conceptual frameworks or a pre-conceived risk assessment. Instead, ethical dilemmas will arise in the unpredictable situations that occur in the everyday practice of undertaking research, where it will be necessary to decide how best to respond in the moment. It is at this point that there is the possibility a wrong could be done (Guillemin & Gillam, 2004: 265).

For Levinas, to be a human it is necessary to obey the fundamental ethical command, which is to make ourselves available to the other, in order to meet our 'infinite' responsibility and obligation to them (Putnam, 2008: 75-6, 80). Levinas describes the Other as someone who 'haunts our ontological existence' (Levinas, cited in Dykeman, 1993:10). I can ignore them or be violent towards them but I cannot escape my ultimate responsibility to the infinite alterity of the Other. In the words of Dykeman (1993: 13) '[i]n every moment I act as a researcher, I can act either to reduce the Other to a servant of my own needs... or to empty myself and take on the Other's needs as my own'.

I therefore intend to 'approach' rather than 'understand' the subjectivity of parents in my study, with an 'intense curiosity' alongside a recognition that research participants can only remain a mystery to me (Allan, 2011: 160). It requires a recognition of the level of absolute responsibility placed on me to ensure that I do not attempt 'to contain the presence of the Other' within my written or spoken work (Garza & Landrum, 2010: 5-6). This way, I can become a 'servant for the needs of the Other', approaching my research with an 'attitude of human solidarity' (Dykeman, 1993: 14), in a way that recognises what it is to be human.

## References

Allan, J. (2011) Complicating, not explicating: Taking up philosophy in learning disability research. *Learning Disability Quarterly*, 34, (2), 153-161.

Benson, P. & O'Neill, K.L. (2007) Facing Risk: Levinas, Ethnography and Ethics. *Anthropology of Consciousness*, 18, (2), 29-55.

Dykeman, C. (1993) Encountering the Face of the Other: The Implications of the Work of Emmanuel Levinas for Research in Education. *Journal of Thought*, 28, (3/4), 5-15.

Garza, G. & Landrum, B. (2010) Ethics and the Primacy of the Other: A Levinasian Foundation for Phenomenological Research. *Indo-Pacific Journal of Phenomenology*, 10, (2), 1-12.

Gehrke, P.J. (2010) Being for the Other-to-the-Other: Justice and Communication in Levinasian Ethics. *Review of Communication*, 10, (1), 5-19.

Guillemin, M. & Gillam, L. (2004) Ethics, Reflexivity, and 'Ethically Important Moments' in Research. *Qualitative Inquiry*, 10, (2), 261-280.

Levinas, E. (1969) *Totality and Infinity: An Essay on Exteriority*. Trans. By A. Lingis. Pittsburgh: Duquesne University Press.

Levinas, E. (1985) *Ethics and Infinity: Conversations with Philippe Nemo*. Trans. By R.A. Cohen. Pittsburgh: Duquesne University Press.

Levinas, E. (1989) Ethics as First Philosophy. In: Hand, S. (ed.) *The Levinas Reader*. Oxford: Basil Blackwell Ltd, 75-87.

Levinas, E. (1998) *Otherwise Than Being: Or Beyond Essence*. Trans. By A. Lingis. Pittsburgh: Duquesne University Press.

Putnam, H. (2008) *Jewish Philosophy as a Guide to Life: Rosenzweig, Buber, Levinas, Wittgenstein*. Bloomington: Indiana University Press.

Rhodes, C. & Carlsen, A. (2018) The teaching of the other: Ethical vulnerability and generous reciprocity in the research process. *human relations*, 7, (10), 1295-1318.

Strhan, A. (2016) Levinas, Durkheim, and the Everyday Ethics of Education. *Educational Philosophy and Theory*, 48, (4), 331-345.

Todd, S. (2001) On Not Knowing the Other, or Learning from Levinas. *Philosophy of Education Yearbook*, 67-74. Available at:  
<http://mural.maynoothuniversity.ie/8538/1/1871-6695-1-PB.pdf> [Accessed 26 February 2020].

## Chapter 7: Relational Ethics as beginning and end when doing research with (disabled) children

**Geert Van Hove and Elisabeth De Schauwer  
Ghent University**

More and more researchers are convinced that disabled children's voices need to be included in research projects about them (UNCRC, art 12-13 + UNCRPD, art 7) and that children are experts about their own lives (Lundqvist, Westling Allodi & Siljehag, 2018 ; Aronsson, Hedegaard, Hojholt & Ulvik, 2012; Clark & Moss, 2001; Lundqvist, 2014; Mason & Danby, 2001). Being convinced 'of the cause' is one thing; how we translate that conviction into research practice seems to be a real challenge. In the context of these 'translation attempts', we get messages like the following by a senior researcher:

*...My name is XXX, I am the team leader for the consultation with children within the framework of an EU-funded study. The study is run by a consortium and serves the purpose of providing recommendations for the setting up of a special EU fund.*

*The study uses mixed methods.*

*The qualitative research part of the project will be carried out in the form of focus groups with children. The focus groups will have the objective of analysing the main barriers in access to basic services, such as education, nutrition, health, housing, and early childhood education for European children in four specific target groups: migrant children and refugees; children with disability; children in precarious families; and in institutions.*

*Focus groups will be organised in June in four selected countries.*

*Each country will host one focus group with 8-10 children, aged 14-17 years. One national expert per country, with experience in qualitative research is needed. The national expert will support the lead expert of the project in the development of the common guidelines for the focus groups discussions; find the institution which will support the organization of the focus group in own country (e.g. finding and gathering participant children, and providing a location, in your case in Belgium), running focus group discussions and supporting the analysis and the reporting.*

*A joint report made by the team of four experts will be developed and presented in September-October at the fact-finding workshops organized in each of the four selected countries. Unfortunately, the timeline is very short, and organization should proceed quickly.*

*In cc: The guidelines for the Focus group: with statements, informed consents, procedure to follow, ...*

### **The Holy Grail: focus groups.**

It will be clear that the holy grail for research with children is described in these kinds of messages: it is best organized in Focus Groups. Let this - organizing research with children and youngsters via focus groups - be something we ask ourselves big questions about.

Perhaps we could explain our point of view in more detail. Let's go back to a traditional definition of a focus group:

'a carefully planned discussion, designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment'. It is one form of group interview, with the distinguishing feature of group interaction (Kitzinger, 1994), used to encourage in-depth discussion (Carey, 1994).  
The aim of a focus group is not to develop consensus but to produce qualitative data that provides insight into the attitudes, perceptions, motivations, concerns and opinions of participants by generating a collective consciousness.  
Focus groups employ an interviewing technique with discussion taking place under the guidance of a moderator. The moderator facilitates discussion in a non-directive and unbiased way, using pre-determined questions (Kingry et al. 1990). A second moderator is often present, acting as note taker, observing group interactions, supervising recording equipment, but not participating in the ongoing discussion. Focus groups generate narrative data.

### **From focus group to a multi-layered dialogue.**

We take the clear view that traditional focus group work should not be used for working with (disabled) children and youngsters. This critical stance is linked to the statements in the definition that we have underlined. If we are genuinely interested in the perspectives of children who have not had opportunities to participate in research projects. In these situations, is it not always possible to plan everything in advance; one cannot work with pre-programmed questions and propositions; one cannot not participate in the discussions as a facilitator; we must give the young people opportunities to go beyond words / narratives; and sometimes extra support staff will have to be available on the spot for them.

As a logical consequence of our critical view of focus groups, we opt for a different way of working. This alternative can be described as: we don't see children and youngsters as 'focus group participants' but as partners in a real dialogue.

Building such a dialogue has some fundamental consequences. This means, for example, that we need extensive preparation preceding the research dialogue. It is good to create a safe environment in advance by offering participants some time and opportunities to: prepare their own agenda; think about the people they want to bring with them as support givers; organize their journey to the meeting, and so on.

This means also that we introduce some structure but at the same time we offer opportunities to steer the conversation: what topics are a priority, what do we skip if participants don't want to talk about certain subjects?

We also make sure we try to listen very carefully: writing words and sentences down; linking the ideas of different participants; giving time to think and speak; and making sure we understand that 'a voice' is never without connection to cultures, personal networks and personal history.

We also try to ‘animate the conversation’ - we will never work with words alone. Drawings, mind maps, photos are also seen as possibilities to open up ideas, messages and discussions.

We give a lot of attention to ‘hospitality’: cookies, coffee, juices, water, room temperature, breaks are seen as elements that can make a difference.

After the meeting - it is not finished when the meeting ends – we keep on working with our dialogue partners about the report that has to be prepared and about the way we communicate the research findings and conclusions.

We fall back on the concept of ‘visiting’ by Vinciane Despret for what we present here. Despret emphasizes that we have to try to meet each other in a horizontal way, in a process she calls ‘attunement’. Those who take this perspective start from the premises that they don’t know in advance what will come up. Those who ‘attune’ become very active in their engagement with others, active within certain encounters and open to lived experiences. Despret describes it as a way of being in the world - consisting of an individual’s whole-person act of attending to the world. ‘Visiting’, according to Despret, is not an easy practice:

It demands the ability to find others actively interesting, even or especially others most people already claim to know all too completely, to ask questions that one’s interlocutors truly find interesting, to cultivate the wild virtue of curiosity, to retune one’s ability to sense and respond – and to do all this politely! (in Haraway, 2016: 127).

Despret’s sort of politeness does the energetic work of holding open the possibility that surprises are in store, that something interesting is about to happen. They are not who/what we expected to visit and we are not who/what were anticipated either. Curiosity always leads its practitioners a bit too far off the path, and that way lies stories. “Stories are essential, but never “mere” stories. We do something, and we do it together. We become-with each other in that encounter” (Haraway, 2016:127).

### **From ‘Focus Group Guidelines’ to ‘Wise Concepts and Colleagues’ helping us to come close to working within a dialogue.**

Dialogue is of absolute importance. It is an idea of dialogue not as an exchange but as a process of transformation where you lose absolutely the possibility of controlling the final result. And it goes to infinity, it goes to the universe, you can get lost. And for human beings nowadays (...) to get lost is a possibility and a risk, you know? (Rinaldi, 2006: 184).

- We don’t go for ‘method’ first but for ‘RELATIONSHIPS’ (based on: Slife & Wiggins, 2009)

We follow MacMurray (1991) in stating that a baby is adapted to a complete dependence upon an (adult) human being... The baby's dependence provides him/her with an identity: a relational identity. In the same way, things, events, places are not primarily self-contained entities that later interact ... all things, events and places are, first of all, relationships. Humans are relational "all the way down", our being is rooted in a shared being. This way of thinking and acting brings us to the concept of belonging. Nothing and nobody can be understood without connection to the contexts we live/learn/survive in.

In our research, we really try to come as close as possible to something we could call 'thick understanding'.

- We don't go for pre-organized questions but for LISTENING (based on: Rinaldi, 2001).

For Rinaldi, listening can be understood as a metaphor for having the openness and sensitivity to listen and to be listened to – listening not just with our ears, but with all our senses.

Listening as sensitivity to the patterns that connect, to that which connects us to others; abandoning ourselves to the conviction that our understanding and our own being are but small parts of a broader, integrated knowledge that holds the universe together (Rinaldi, 2006: 65).

Listening as time, the time of listening, a time that is outside chronological time – time full of silences, long pauses, an interior time. Interior listening, listening to ourselves, as a pause, as a suspension, as an element that generates listening to others, but in turn is generated by the listening that others give us. Behind the act of listening there is often a curiosity, a desire, a doubt, an interest ... it is welcoming and being open to differences. We try to create 'a listening context' where someone feels legitimated to present their interpretations, feels free to ask questions ...

- We don't go for linearity, but for 'layers', 'complexity', 'multiplicity' (based on: Davies, 2014).

By telling, questioning, writing, animating the stories of the youngsters, we shift much more from a single story to a story with the multiplicity of every entity (human and non-human). For us, this better captures the complexity of the event. The stories we listened to could be read from different entry points, with different perceptions and possibilities of the same event. By working in layers and being very attentive to complexity, we break up our causal thinking and contra-act the singular, linear story. Through collective listening together with the young people, we create a collective understanding of that moment. We open up place for the youngsters and ourselves as researchers in understanding the emergent multiple emplacements the youngsters are part of.

- We don't go for 'autonomy' and the 'I' and 'being' but for 'BEING-WITH-ONE-ANOTHER' (based on: Nancy, 2000)

For Nancy, the 'I' is not 'prior to 'we' and existence is essentially co-existence (*être-les-uns-avec-les-autres*). In thinking about and working with others, it is clear that

others become the Other according to the mode of desire or hatred. We are less interested in this analysis of the shells that encase us, though they too are necessary, and more interested in the movement, the change involved, in cracking open.

Being open, and being vulnerable to being affected by the other, is how we accomplish our humanity; it is how the communities, of which we are part, create and re-create themselves. We are not separate from the encounters that make up the community but, rather, emergent *with* them (Davies, 2014: 10).

## References

- Carey, A. (1994) The group effect in focus groups: Planning, implementing and interpreting focus group research. In: Morse, J. M., Ed., *Critical Issues in Qualitative Research Methods*, Sage Publications, Thousand Oaks, pp. 225-241
- Clark, A. and Moss, P (2011). *Listening to young children (2nd ed.)* London: National Children's Bureau
- Davies, B. 2014. *Listening to Children: Being and Becoming*. London: Routledge
- Haraway, D. (2016). *Staying with the trouble*, Duke University Press: Durham & London.
- Højholt, C., Hedegaard, M., Aronsson, K., & Skjær Ulvik, O. (Eds.) (2012). *Children, Childhood and Everyday Life: Children's Perspectives*. USA: Information Age Publishing.
- Lundqvist, J. (2014), A review of Research in Educational Settings Involving Children's Responses, *Child Ind Res*,7 (4), 751-768: 751. <https://doi.org/10.1007/s12187-014-9253-7>
- Lundqvist, J Westling, M Allodi, A. & Siljehag, E. (2019) Values and Needs of Children With and Without Special Educational Needs in Early School Years: A Study of Young Children's Views on What Matters to Them, *Scandinavian Journal of Educational Research*, 63:6, 951-967, DOI: [10.1080/00313831.2018.1466360](https://doi.org/10.1080/00313831.2018.1466360)
- Mason, J. & Danby, S.(2011), Children as experts in their Lives: Child Inclusive Research, *Child Ind Res* ,4 (2), 185-189, : 185. <https://doi.org/10.1007/s12187-011-9108-4>
- Nancy, J.L. (2000), *Being Singular Plural*, Stanford University Press: Stanford
- Rinaldi, C. (2001), *Documentation and Assessment: What is the Relationship*, in *Project Zero and Reggio Children: Making Learning Visible*. Reggio Emilia, Italy
- Rinaldi, C. (2006). *In Dialogue with Reggio Emilia. Listening, researching and learning*. London: RoutledgeFalmer.
- Slife, B.D., & Wiggins, B. (2009). Taking relationship seriously in psychotherapy: Radical relationality. *Journal of Contemporary Psychotherapy*, 39 (1), 17-24.

## Chapter 8: Critical Disability Studies and Participatory Action Research: Antidotes to educational research's inherent 'othering'?

**Anna Pilson**

**University of Durham**

Van Hove and de Schauwer's (2020) exhortation to researchers to "fuck the focus group" is both visceral and pivotal. It provides an incitement for scholars to abandon methods that don't automatically provide opportunities to re-frame power dynamics within research. This is particularly important when working with children and young people, given that traditional paternalistic constructs of childhood undervalue both their potential to make vital contributions to knowledge generation (Lewis and Porter, 2007, p. 230) and their agentic capabilities. Children and young people are often labelled with deficit-laden terms, such as 'vulnerable' or 'incapable' – a version of 'othering' that is dressed in faux-protective coat, and which often precludes their involvement in research. When the category of 'disability' is also applied, they may find themselves further confined behind the viewing ropes, with research positioned on a pedestal of privilege, akin to a precious artefact - to be looked at but not interacted with unless in possession of accepted, and accept/able, expertise.

Hughes (2012: 17) states that "elimination and/or correction have been the primary social response to disabled people in modernity", a stance that echoes educational research's habitual dealings with disability. The views of disabled children have all but been eliminated from the genre, owing to their perpetual status as subject/object. Their under-represented experiences have been "flattened, obscured, missed, distorted and misconstrued" (Fox, 2015: 321), mirroring wider societal subjugation. Educational research has instead historically iterated a corrective, incrementalist conceptualisation of disability (Baglieri et al., 2011: 267), whilst simultaneously failing to challenge the embedded standardised and conformist structures that govern the education system. Teo (2010: 295) refers to such research, which stems from a limited acceptance of where, how and by whom knowledge can be validly produced, as constitutive of "epistemological violence": that is, the production of knowledge weaponised to perpetuate and reify systemic injustice. Therefore, this chapter asserts that we as researchers in the field of Critical Disability Studies *must* do more to subvert the orthodoxy of educational research, and ensure that we avoid (un)consciously perpetuating reductive dogmas by embedding our projects with both criticality and relational ethics (van Hove & de Schauwer, 2020).

### **Expanding engagement and expertise**

Participatory Action Research (PAR) can help us to achieve this by providing a means of democratising research, through "challenging the normative (and ableist) rubrics of research" (Liddiard et al., 2019: 164). Critical PAR is not simply a methodology, but rather an epistemological stance that ensures the research process in its entirety is viewed via a lens of equality and radical inclusion. Equally, Critical Disability Studies (CDS) should be understood "as a method, an approach, a theoretical framework and perspective—not

(exclusively) a study of disabled people” (Schalk, 2017: 1). PAR and CDS are therefore the perfect bedfellows - given their inherent aims to destabilise power structures to achieve equality of expertise in research, and to “interrogate the gap between dominant ideologies and human lives” (Torre et al., 2012: 171). In actively disrupting the prevalent societal narrative of personal responsibility, and instead addressing the ‘bigger picture’ that neatly linear research designs “by omission of the larger context, trivialize” (Fine & Torre, 2004: 19), PAR and CDS not only allow participants to “chronicle lives but also contextualise them” (Sandwick et al., 2018: 484).

Resultant “epiphanies” (Denzin, 1989: 15) arising from active participation in research can “prick...[societal] psychic amnesia” (Fine & Torre, 2004:30). In centralising under-recognised knowledge, PAR can support navigation through what Martin-Baro (1994) refers to as the schizophrenic experience of living a life that often contravenes expected official narratives, by highlighting the “wisdom, desire and tactics of subversion” (Fine, 2009: 3) present in ‘othered’ communities, and catalysing the development of critical consciousness within participants (Freire, 1972). Educational research must therefore embrace these methodologies in order to provide opportunities for disabled children and young people to “deliberate over the complexity of inclusion – practices, processes and elements of society – in ways that might lead to critical engagement” (Whitburn & Goodley, 2019: 3). It is the Academy’s obligation to expose young disabled people “to the very culture that oppresses them. That may seem paradoxical, but without the skills and knowledge of the dominant culture, students are unlikely to engage that culture to effect meaningful change” (Ladson-Billings, 2006: 36), and it has arguably never been more urgent to do so in the midst of these “revolting times” (Fine, 2016: 347).

### **Critical research during a critical time period**

The adoption of a PAR/CDS approach to educational research responds to Fine et al.’s (2000: 128) clarion call for researchers to “retreat from the stance of dispassion”). Utilising such democratising epistemologies can “reveal complex fissures and inequities in systems that represent themselves as rational, just and coherent” (Fine & Torre, 2004: 16). Thus they are the ideal means through which to invoke justice-based inquiry through which participants can engage in activist scholarship (Fox & Fine, 2012: 5), which surely constitutes an “apposite response” (Goodley et al., 2019: 989) by the Academy during this “highly contentious political moment” (Fine & Torre, 2019: 433). The contrapuntal forces of “state violence” (Appadurai, 2006: 171) and the embedment of human rights as social ideology have conspired to create a society wherein persecution has developed insidious and subtle forms. Oppression has become a wolf in sheep’s clothing, has developed many faces and facades, and is often hidden under the aegis of Trumpian/Brexitian ‘fake news’ and presently, further entrenched by political and Media responses to the Covid-19 pandemic. Poverty propaganda obfuscates the real causes of oppression in a way that is powerful, stealthy and stigmatising.

The recent transposition of a personal deficiency-centred model onto the prevailing social narrative has repositioned youth as members of the ‘precariat’ (Standing, 2011). This neoliberal notion inverts causality, and therefore (in)ability to effect resolution, onto the individual, resulting in an increasingly hostile socio-political context. Therefore, it is crucial for disabled youth who may because of (dis)ableist policy, face circuits of dispossession

(Fine & Ruglis, 2009), to develop a critical disposition and understanding of the multi-systemic structure of society. As “privilege laminates itself in denial and refuses to reflect on its own enactments of violence” (Fine, 2009: 4), the ability of our youth to “distinguish knowledge from rumour, fact from fiction, propaganda from news, and anecdote from trend, is vital for the exercise of informed citizenship” (Appadurai, 2006: 168), to avoid governmental ‘gaslighting’ and manipulation by the right hand of the State (Bourdieu, 1998).

I therefore advocate that dis/education be added to Goodley & Runswick-Cole's (2014: 6) list of "dis/human concepts", thereby challenging and reframing the normative conceptualisations of success and failure perpetuated by the education system and their impact on the journey of 'becoming' (Braidotti, 2013). PAR may be the best way to support disabled children in understanding their identities in relation to the pragmatic and political power of the norm, whilst simultaneously troubling it (Goodley & Runswick-Cole, 2014: 5), thereby educating themselves about the “dis/human reality” (Goodley, Runswick-Cole & Liddiard, 2016: 773) . PAR embraces a Braidottian "affirmative positionality" (Goodley, Lawthom & Runswick-Cole, 2014: 343) in actively seeking to undermine damaging tropes of ableism in education, and its convergence with CDS necessarily re-establishes the positionality of CDS nearer to the emancipatory extremity of the Disability Studies continuum (Goodley, 2017: 29). The time for cautious ‘navel-gazing’ (Goodley & Runswick-Cole, 2014: 1) in our discipline is over.

## Conclusion

Finally, in response to Goodley's (2020: 37) warning that ‘mainstreaming’ CDS may cause it to lose its teeth, I assert that we should not let fear of ‘conventionalising the field’, or concerns about dilution of impact and intent, prevent CDS from claiming space in the contested areas (Davis, 1997: xv) of more traditional research genres. Quite the opposite – we should make distinct and urgent attempts to do so and to reclaim its “paradigm busting” (Goodley, 2017: 40) potential. CDS must re-centre its “social transformative perspective” (Meekosha & Shuttleworth, 2009: 55) and in embracing PAR, it may find a powerful means of re-orientating itself towards co-effecting change within the normative and essentialising confines of the education system in conjunction with those marginalised by it.

CDS must be the active (and activist) agent in the solution to educational research's apparent wilful ignorance of disability. Disability has been siloed by traditional educational research, to the extent that in 2019, Critical Disability Studies in Education was referred to as an “emergent field” (Slee, Corcoran & Best, 2019: 1). This could denote at best a lack of engagement between two genres which should enjoy a symbiotic relationship, or it could, at worst, “exemplify the active erasure of disability at the ontological level” (Steinborn and Nusbaum, 2019: 489) in educational research. While it is important for CDS to delineate its ontology as distinct from the problematic invocations of disability in interdisciplinary debates (Runswick-Cole, Wechuli, & Ktenidis, 2020: 69), it must also be (come) a disruptive and central presence within educational research, rather than developing as a separate entity and a separate identity from the field as a whole. CDS is *needed* in both educational research and praxis, and it is needed *now*, to loosen the ties of embedded institutional (dis)ableism so prevalent in both, and to reposition disability “as an affirmative

phenomenon: a chance to pause, re-jig and reorient education” (Goodley et al., 2019: 988).

## References

- Appadurai, A. (2006). The Right to Research. *Globalisation, Societies and Education* 4(2), 167-177.
- Ayala, J. (2009). Split scenes, converging visions: the ethical terrains here PAR and borderlands scholarship meet. *The Urban Review*, 41(1), 66-84.
- Baglieri, S., Valle, J. W., Connor, D. J., & Gallagher, D. J. (2011). Disability Studies in Education: The need for a plurality of perspectives on disability. *Remedial and Special Education*, 32(4), 267-278.
- Bourdieu, P. (1998). *Acts of resistance*. New York: New Press.
- Braidotti, R. (2013). *The posthuman*. London: Polity.
- Davis, L. (1997). Introduction: Disability, Normality, and Power. In: L. Davis (Ed.) *The Disability Studies Reader*. (pp. 1-16). London: Routledge.
- Denzin, N. K. (1989). *Interpretive Interactionism*. London: Sage.
- Fine, M. (2009). Postcards from metro America: Reflections on youth participatory action research for urban justice. *The Urban Review*, 41(1), 1-6.
- Fine, M. (2016). Just methods in revolting times. *Qualitative Research in Psychology*, 14(3), 347-365.
- Fine, M., & Ruglis, J. (2009). Circuits and consequences of dispossession: The racialized realignment of public sphere for US youth. *Transforming Anthropology*, 17, 20-33.
- Fine, M., & Torre, M. E. (2004). Re-remembering exclusions: Participatory action research in public institutions. *Qualitative Research in Psychology*, 1(1), 15-37.
- Fine, M., & Torre, M. E. (2019). Critical Participatory Action Research: A feminist project for validity and solidarity. *Psychology of Women Quarterly*, 43(4), 433-444.
- Fox, M. (2015). Embodied Methodologies, Participation and the Art of Research. *Social and Personality Psychology Compass*, 9(7), 321-332.
- Fox, M., & Fine, M. (2012). Circulating Critical Research: Reflections on performative and moving inquiry into action. In: S. Steinberg & G. Canella (Eds.), *Critical Quantitative Research Reader*. (pp. 153-165). New York: Peter Lang.
- Freire, P. (1972). *Pedagogy of the oppressed*. London: Penguin.
- Goodley, D. (2017). *Disability Studies: An interdisciplinary introduction*. (2<sup>nd</sup> ed.). London: SAGE.
- Goodley, D. (2020). Desiring New Humanisms. In: R. Atkinson & D. Goodley (Eds.) *Humanity under duress* (pp. 31-35). Sheffield: Multitude Press.

- Goodley, D., Lawthom, R., & Runswick-Cole, K. (2014). Posthuman disability studies. *Subjectivity*, 7(4), 342-361.
- Goodley, D., Lawthom, R., Liddiard, K. & Runswick-Cole, K. (2019). Provocations for Critical Disability Studies. *Disability & Society*, 34(6), 972-997.
- Goodley, D., & Runswick-Cole, K. (2014). Becoming dishuman: thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education*, 37(1), 1-15.
- Goodley, D., Runswick-Cole, K., & Liddiard, K. (2016). The DisHuman child. *Discourse: Studies in the cultural politics of education*, 37(5), 770-784.
- Hughes, B. (2012). Civilising modernity and the ontological invalidation of disabled people. In: D. Goodley, B. Hughes & L. Davis (Eds.) *Disability and social theory: New developments and directions*. (pp. 17-32). Basingstoke: Palgrave Macmillan.
- Ladson-Billings, G. (2006). "Yes, but how do we do it?" Practicing culturally relevant pedagogy. In: J. Landsman & C. Lewis (Eds.), *White teachers/diverse classrooms*. (pp. 29-41). Stirling, VA: Stylus Publishers.
- Lewis, A., & Porter, J. (2007). Research and pupil voice. In: L. Florian (Ed.), *The Sage Handbook of Special Education*. (pp. 222-232). London: Sage.
- Liddiard, K., Runswick-Cole, K., Goodley, D., Whitney, S., Vogelmann, E., & Watts MBE, L. (2019) "I was Excited by the Idea of a Project that Focuses on those Unasked Questions" Co-Producing Disability Research with Disabled Young People. In *Children and Society*. 33: 154-167.
- Lozenski, B. D. (2016). Jazz Researchers: Riding the Dissonance of Pedagogy and Inquiry. *Critical Questions in Education*, 7(3), 268-286.
- Martin-Baro, I. (1994). *Writings for a liberatory psychology*. (A. Aron & S. Corne, Eds.) Cambridge, MA: Harvard University Press.
- Meekosha, H., & Shuttleworth, R. (2009) What's so 'critical' about Critical Disability Studies? *Australian Journal of Human Rights*, 15(1), 47-75
- Runswick-Cole, K., Wechuli, Y., & Ktenidis, A. (2020). The challenges of thinking with and through disability in interdisciplinary research. In: R. Atkinson & D. Goodley (Eds.) *Humanity Under Duress* (pp. 69-73). Sheffield: Multitude Press.
- Sandwick, T., Fine, M., Greene, A. C., Stoudt, B. G., Torre, M. E., & Patel, P. (2018). Promise and provocation: Humble reflections on critical participatory action research for social policy. *Urban Education*, 53(4), 473-502.
- Schalk, S. (2017). Critical Disability Studies as Methodology. *Lateral*, 6(1).
- Shildrick, T. (2019, September). *Youth Studies: Past, present, future*. Presentation at the British Sociological Association Youth Study Group 'Youth Intersections' Workshop, Manchester Metropolitan University.
- Slee, R., Corcoran, T., & Best, M. (2019). Disability Studies in Education - Building Platforms to Reclaim Disability and Recognise Disablement. *Journal of Disability Studies in Education*, 1, 1-11.

- Standing, G. (2011). *The Precariat: The new dangerous class*. London: Bloomsbury.
- Steinborn, M. L., & Nusbaum, E. A. (2019). Crippling Human Rights Education with Disability Studies: An Undergraduate Reading List. *Education Studies*, 55(4), 489-504.
- Teo, T. (2010). What is epistemological violence in the empirical social sciences? *Social and Personality Psychology Compass*, 4(5), 295-303.
- Torre, M. E. (2014). Participatory Action Research. In: T. Teo (Ed.), *Encyclopedia of Critical Psychology*. (pp. 1323–1327). New York, NY: Springer New York
- Torre, M. E., Fine, M., Stoudt, B. G., & Fox, M. (2012). Critical participatory action research as public science. In: H. Cooper (Ed.), *APA Handbook of Research Methods in Psychology: Vol 2. Research Designs*. (pp.171-184). New York: American Psychological Association.
- Van Hove, G. & de Schauwer, E. (2020, January). *Let us not consider children as an “exotic tribe” in research projects: relational ethics as beginning and end when doing research with disabled children*. Chapter presented at Disabled Childhood Studies International Symposium Organised by the Universities of Glasgow, Ghent, Lancaster, Leeds and Sheffield, The University of Sheffield.
- Whitburn, B., & Goodley, D. (2019). Storying disability’s potential. *International Journal of Inclusive Education*, 1-14.
- Wilkinson, R., & Pickett, K. (2009). *The spirit level: Why greater equality makes societies stronger*. New York: Bloomsbury Press.

## Chapter 9: Issues in Childhood Disability Studies: The age of anti-psychoanalysis

**Karín Lesnik-Oberstein**  
**University of Reading**

All the themes listed above continue in relation to Childhood Disability Studies to cluster around a key difficulty, which is the tension between, on the one hand, striving to see and hear the disabled child for advocacy and liberatory purposes, and on the other, the effort to resist generalising that child and subjecting it to structures of power (Curran & Runswick-Cole 2014; Tisdall 2011). In relation to this field of tension, important questions are raised about the constructions of childhood and disability, including vital problems around widely used liberatory and participatory tropes such as ‘development’ (Burman, 2007; 2016), ‘voice’, ‘agency’, and the ‘body’ (Lesnik-Oberstein et al, 2011; 2015) which are inflected by considerations of disability and childhood to reveal their inherently normalising and marginalising dynamics. For instance, the disabled child who cannot speak is then in deficit in not expressing the required ‘voice’; or the child not able to ‘act’ to the required standard is then in deficit of the required ‘agency’.

However, attempts to resolve the field of tension itself remain trapped within it, no matter how keenly the ethical and practical problems around it are felt. Several recent alternative configurations of childhood and/ or disability have not, I would argue, evaded the oppositions that ultimately still rely on known and knowable ‘identities’.

Furthermore, despite the questions already raised around these issues, the ongoing pressures of such demands seem only to be increasing in both popular and academic discourses. Significantly, there is a flood of popular and academic work focussing on self-representation and self-support or peer-support through speaking, for instance, about mental health. For instance, the mental health charity MIND and the biscuit producer McVitie’s ‘Let’s Talk’ campaign (MIND and McVitie, 2019); or the praise for a group of teenagers in the Cumbrian town of Maryport who could not access mental health services and instead formed a group, ‘We Will’, to support each other and campaign for awareness (Tickell, 2019). It is a common place to note that the prevalence of such narratives is due to the ongoing political and policy shift away from expensive and intensive professionally-trained and supported services to a cheap, de-professionalised and widely dispersed patchwork of self- and peer-support.

I argue here, however, that the casino-capitalism that is invested in dismantling the welfare state and the liberatory and advocacy concerns of childhood disability studies, while seeming to be at extreme odds with one another, in fact share an advertent or inadvertent common reliance on founding assumptions about ‘identities’ as autonomous, visible, coherent and expressive entities, and that it is this that holds in place the field of tension of childhood disability studies. McLaughlin and Coleman-Fountain (2019: 366), for instance, offer a rigorous overview of several extant arguments relating to ‘authenticity’ in childhood disability research, and offer as an alternative that ‘what we want to argue, [is] that visual

techniques, such as those associated with “auteur theory”, offer a particular insight, rather than one that is more authentic for working with children and young people.’ They are at pains to acknowledge that it is ‘important to retain an appreciation of the “socialness” of anyone’s ability to visually capture their interpretation of their life. Such individual acts are located within the broader visual and social imaginaries already present in the world.’ Yet, the implementation of these arguments then nevertheless turns out to rest on claims that:

It is therefore important to explore how disabled young people choose to represent themselves and to examine with them the relationship between their selected images and broader available representations of disability. For example, as they move through adolescence, what are the images around them, and how do these images influence how the young people represent their identities and positions in the world? (McLaughlin and Coleman-Fountain, 2019: 367)

‘Disabled young people’ are here already known as such, including to be able to ‘choose to represent themselves’ and there is a known distinction too between ‘their selected images’ and those that are ‘broader available representations’. The perspective here also knows that the ‘images’ are ‘around them’ and that ‘they’ are ‘influence[d]’ by ‘them’, therefore sustaining already known differences between the ‘social’, the ‘image’ and the ‘them’ who ‘choose to represent themselves’. Judith Butler considers these difficulties of this (advertent or inadvertent) retrieval of already known differences in the light of gender specifically.

On the surface it appears that phenomenology shares with feminist analysis a commitment to grounding theory in lived experience [...] and yet the feminist claim that the personal is political suggests, in part, that subjective experience is not only structured by existing political arrangements, but effects and structures those arrangements in turn. Feminist theory has sought to understand the way in which systemic or pervasive political and cultural structures are enacted and reproduced through individual acts and practices, and how the analysis of ostensibly personal situations is clarified through situating the issues in a broader and shared cultural context. [...] The personal is thus implicitly political inasmuch as it is conditioned by shared social structures, but the personal has also been immunized against political challenge to the extent that public/ private distinctions endure (Butler, 1988: 522-3).

Butler’s analysis of the ‘immunisation’ of ‘the personal against political challenge’, seems to me to be implicated in the ongoing pressures in both popular and academic discourses to revert to ‘lived experience’ and ‘self-representation’ despite the significant and long-standing discussion of the problems with such claims. Moreover, this reliance is, in turn, based on a common (again, advertent or inadvertent) inherently *anti-psychoanalytic* position, where the questions psychoanalysis has long since raised around the constitutions of childhood, disability, the body, voice, agency and expression, remain either unknown or forgotten or, most often, actively resisted. Key here is the work on childhood studies of Jacqueline Rose (1984), Carolyn Steedman, Cathy Urwin and Valerie Walkerdine (1985; 1990) and Erica Burman (2007; 2016 [1994]), where psychoanalysis is read radically to question childhood and ‘representation’, instead reading it as always claimed *in and through a perspective from elsewhere*. As Sigmund Freud (1920: 133)

wrote in the preface to the fourth edition of his *Three Essays on the Theory of Sexuality*: 'If mankind had been able to learn from a direct observation of children, these three essays could have remained unwritten' (1920: 133).

This psychoanalytic way of thinking, when addressed at all, has often been understood as an admission of defeat or as nihilistic: as accepting that the child (or the woman, as in Butler's arguments, or any identity) will never be sufficiently known or understood. But this understanding is not at all the claim of psychoanalysis as read by Rose, Steedman, Urwin and Walkerdine and Burman (and Butler); instead, these approaches see psychoanalysis as an 'enabling and emancipating methodology', albeit in ways very different from representational approaches. What is central here is the implication of psychoanalysis in terms of the 'splitting' of the rationalist, unitary, wholly conscious subject, not just questioning assumptions about the 'content' of such a subject, but also in terms of questioning the perspectives of researchers themselves. For the researchers too can no longer assume their own rational, unitary subjectivity in terms of a dualistic split from their object of research. The question of how and why and when researchers 'see' or 'hear' the child and disability come to the forefront in this kind of work. Literary critic and theorist Shoshana Felman (1982) makes the same argument in her account of the implications (rather than 'applications') of psychoanalysis for reading. Felman includes an epigram quoted from the French psychoanalyst and theorist Jacques Lacan at the start of her volume *Literature and Psychoanalysis. The Question of Reading Otherwise*:

This is what analytical discourse is all about: what can be read. What can be read beyond what the subject has been incited to say. [...] In analytical discourse, the signifying utterance is given another reading than what it means. (Lacan in Felman, 1982: no page number)

Lacan disrupts the ideas both of a unitary, intentional author and reader, as well as of text as a separate object of study. As Felman further elaborates:

Literature, by virtue of its ironic force, fundamentally deconstructs the fantasy of authority [...] and, for the same reasons, [...] psychoanalysis deconstructs the authority of the fantasy – its claim to belief and to power as the sole window through which we behold and perceive reality, as the sole window through which reality can indeed reach our grasp, enter into our consciousness. Psychoanalysis tells us that the fantasy is a fiction, and that consciousness is itself, in a sense, a fantasy-effect (Felman, 1982: 8).

Psychoanalysis is here the disruption of the dualities of object and subject, of viewer and viewed, and of the real and fantasy and instead pursues readings of the investments in the perspectives who see or hear the disabled child.

## References

Burman, E. (2016, third edition [1994]), *Deconstructing Developmental Psychology*. London: Routledge.

Burman, E. (2007), *Developments: Child, Image, Nation*. London. Routledge.

Butler, J. (1988), 'Performative Acts and Gender Constitution: An essay in phenomenology and feminist theory', *Theatre Journal*, 40:4, 519-531.

Curran, T. & Runswick-Cole, K. (2014), Disabled Children's Childhood Studies: a distinct approach?, *Disability & Society*, 29:10, 1617-1630, DOI: 10.1080/09687599.2014.966187

Felman, S. (ed.) (1982 [1977]), *Literature and Psychoanalysis. The Question of Reading: Otherwise*. Baltimore, MD: Johns Hopkins University Press.

Freud, S. (1920), 'Preface to the Fourth Edition' in: Sigmund Freud, 'Three Essays on the Theory of Sexuality' [1905], *S.E.*, vol. VII, London: The Hogarth Press, 123-243.

Lesnik-Oberstein, K. (ed.) (2011), *Children in Culture, Revisited: Further Approaches to Childhood*. Houndmills: Palgrave.

Lesnik-Oberstein, K. (ed.) (2015), *Rethinking Disability Practice and Theory: Challenging Essentialism*. Houndmills: Palgrave.

McLaughlin, J. & Coleman-Fountain, E. (2019), Visual Methods and Voice in Disabled Childhoods Research: troubling narrative authenticity, *Qualitative Research*, 19(4) 363–381, DOI: 10.1177/1468794118760705

MIND and McVitie, 'Let's Talk' campaign, <https://mcvities.co.uk/letstalk> [last accessed 14-12-2019]

Rose, J. (1984), *The Case of Peter Pan or the Impossibility of Children's Fiction*, London: Macmillan.

Steedman, C, Urwin, C. and Walkerdine, V. (eds) (1985), *Language, Gender and Childhood*, London: Routledge & Kegan Paul.

Tickell, L. (2019), Mental Health: The students who helped themselves when help was too slow in coming, *The Guardian*, Education section, 12-02-2019: <https://www.theguardian.com/education/2019/feb/12/mental-health-the-students-who-helped-themselves-when-help-was-too-slow-coming> (last accessed 14-12-2019).

Tisdall, K. (2011), The Challenge and Challenging of Childhood Studies? Learning from disability studies and research with disabled children, [http://scholar.google.co.uk/scholar\\_url?url=http://www.academia.edu/download/31483019/Tisdall\\_30.8.11.docx&hl=en&sa=X&scisig=AAGBfm3JN9XMTDkPhyvw8vEIGwCOF9S80A&nossl=1&oi=scholar](http://scholar.google.co.uk/scholar_url?url=http://www.academia.edu/download/31483019/Tisdall_30.8.11.docx&hl=en&sa=X&scisig=AAGBfm3JN9XMTDkPhyvw8vEIGwCOF9S80A&nossl=1&oi=scholar) [last accessed 14-12-2019]

Walkerdine, V. (1990), *Schoolgirl Fictions*, London: Verso.

# Chapter 10: Transition to Where and to What? Transitions for young disabled people and the epistemological fallacy

**Charlotte Pearson, Justine Gangneux, Ida Norberg and  
Nick Watson**  
**University of Glasgow**

The difficulties many young disabled people face as they move into adulthood has long been recognized (Morris, 2002; Stalker, 2002). The failure of this group to move from school to employment, training, further or higher education or to actively take part in the community once they have left school, has been highlighted as a major cause of their isolation and exclusion. Evidence suggests that transition arrangements are often absent, uncoordinated, young people may not always be involved in the process and suitable adult services are not always available (Kirk, 2008). Blame is often laid on the lack of co-ordination between services: while schools provide an institutional base from which to co-ordinate services, when the young people leave school, they can find themselves either 'falling through the cracks' or in a frustrating loop of continual training (Riddell et al, 2001).

This chapter aims to examine recent writings on youth transitions, particularly the work of Andy Furlong and Fred Cartmell (2007) and argue that we in disability studies need to engage with this literature if we are to improve outcomes for young disabled people.

## Disability, young people and transition theory

Youth transitions, for both disabled and non-disabled young people, have been traditionally conceptualised as a step-by-step linear process, with a predetermined end (Evans and Furlong, 1997; Furlong, 2009). Much of the focus has been on the transition from child to adult services - particularly health and social care - or grounded in traditional markers of adulthood such as securing full time work, financial independence, marriage and parenthood. These markers of 'successful' transitions have been criticised as both normative and unhelpful to in accounting for the complexity of contemporary youth experiences (Blatterer, 2007; Woodman and Wyn, 2014; Woodman and Bennett, 2015; France and Threadgold, 2015). They are particularly harmful to young disabled people, many of whom face additional and significant barriers to achieving these markers.

Adulthood is neither fixed or stable: it is not an-end point that can only be achieved after 'a completed set of transitions' (Woodman and Bennett, 2015: 6). Over the last 15 years, research on transitions has sought to explore transition to adulthood as non-linear, fragmented, multidimensional and extended, reflecting the complexity of young people's life experiences (Goodwin and O'Connor, 2005, Furlong, Cartmel and Biggart, 2006; Furlong and Cartmel, 2007; France, 2007; Cote and Bynner, 2008 Cieslik and Simpson, 2013). Changing patterns of dependency (Furlong and Cartmel, 2007), as well as the increasing period of time during which a large number of young people remain in a state of semi-dependency, have given rise to terms such as 'yo-yo', 'arrested' or delayed transitions (Cote, 2000; EGRIS, 2001; Biggart & Walter, 2006). These types of proacted

and delayed transitions have led researchers – in particular in psychological research - to try to define a new 'life phase' between youth and adulthood. Arnett (2004: 7), for example, has coined the concept of 'emerging adulthood' which he describes as a 'new' stage of life-course during which young people are able to 'explore a wide range of different possible future paths' (2004:7). His concept has since been put into question and described as a 'dangerous myth' (Cote, 2014 page no?) because it implies that young people are free to choose which direction they want to take, and over-emphasising individual choice and responsibility (Bynner, 2005; Furlong and Cartmel, 2007; Côté and Bynner 2008; Furlong, 2009, Woodman and Wyn, 2014).

This model of 'can-do' youth over-emphasises young people's individual potential and , it implies that young people are free to act as entrepreneurs who can achieve success provided they have a positive attitude and a good work ethics. It is based on a normative expectation of the type of 'adults' that young people should aim to be (Kelly, 2006: 18). It is also grounded in an idea of what young people will be rather than what they are and how they feel in the present. In other words, these conceptualisations of youth view young people 'not as complete individuals now, but as future adults, citizens and workers' (Wood, 2017: 1179).

The study of youth transitions has been embedded in broader debates about the role of individual agency and structural constraints in shaping life-chances (Evans and Furlong, 1997). To date, this approach has not been adopted in research on disability, where the focus is either on traditional markers or, more commonly, the transition from child services to adult services. Whilst disability research has not engaged with changing understandings of transition, research in youth studies has, to a large extent, ignored the experiences of disabled young people, concentrating instead on the continuing role of structural factors such as class, gender, place and ethnicity in shaping young people's transitions. Where disability has been the focus of transition, the young people have been treated as an homogenous group and the impact of these various social locations has been ignored.

Some youth research has centred on young people's individual agency and has conceptualised the enactment of their agency within specific social constraints, often beyond their control. They have, for example, focussed on how young people actively negotiate, reflect and make decisions about their lives whilst acknowledging that they do not control the circumstances under which their choices are exercised and their decisions made (Brannen and Nilsen, 2005; Furlong and Cartmel, 2007; du Bois Reymond, 2009; Furlong, 2009, 2015; Farrugia, 2013). This does not imply, however, that young people are unaware of the ways in which unequal opportunities shape their lives. On the contrary, as evidence has shown, young people tend to be fully aware of the circumstances that affect their lives (Furlong and Cartmel, 2007, Griffin, 2010, France and Haddon 2014, France and Threadgold, 2016).

Responding to the debates, Furlong and Cartmel (2007) have argued that processes of individualisation and social changes have led to an 'epistemological fallacy' in which young people are encouraged to seek individual solutions to structural issues. In other words, even though young people's life-chances and transitions remain significantly structured by social factors, subjective understandings of transitions and opportunities are increasingly

understood and experienced on an individual level. Responsibility is placed in the hands of the young people themselves to take up opportunities and live up to expectations of successful transitions. Individuals are viewed 'as being responsible for conducting themselves, in the business of life, as an enterprise, a project, a work in progress' (Kelly, 2006:18, see also Harris, 2004; Griffin, 2010; Kelly, 2013). Young women in particular have been understood and positioned as 'successful girls' (Ringrose, 2007) and 'can-do women' (Harris, 2004). Those who are successful are celebrated for their determination, resilience and confidence (Harris, 2004: 1). These narratives, feed and reinforce this epistemological fallacy by putting a great emphasis on individual responsibility, choice, independence and achievement. They overlook the social, cultural and economic constraints that shape not only life-chances, but also perceptions of these chances.

## Conclusion

This epistemological fallacy is closely linked to the widespread use of personalisation and the deployment of cash-equivalent services. This has meant that there has been a neglect of a focus on the impact of wider structural barriers over the longer term. We do not want to underplay the potential afforded to young people by the provision of funds to help them achieve their goals, and clearly cash-based models have many benefits. However, as Furlong and Cartmel's (2007) notion of an 'epistemological fallacy' (2007) makes clear, policies such as this have been framed with an over-emphasis on young people's individual capacity to secure life choices and control their destiny. They fail to address the root causes of discrimination and disadvantage; the disabling structures remain unchallenged. There is an absence of choices and services at this stage in the young peoples' lives and they are faced by an unresponsive transitions service market.

In Australia, the *National Disability Insurance Scheme* (NDIS) was set up with the expectation to 'fundamentally disrupt traditional service practice and improve disabled people's lives' (Kendrick et al, 2017: 1333-1350). The rhetoric of 'choice and control' was used by the Australian Government to promote NDIS to a wide audience. In contrast to similar schemes in Scotland, England and other European countries (Pearson and Ridley, 2016), the NDIS has received a long-term commitment to significantly increased government spending (Miller and Haywood, 2016). Yet as Kendrick et al (2017) have observed, increased funding and a reliance on the buying power of service users to stimulate creativity and innovation is unlikely to be enough on its own to transform the landscape of disability support. By making disabled people and their families *social entrepreneurs*, individuals are charged with the responsibility of negotiating access to transition services. Often in many cases, this can result in a more individually-tailored service, which matched personal interests. However, successful outcomes are reliant on the ability of young people or their parents or carers to successfully take on this role, and for local markets to have the services available.

Youth transitions for young disabled people are complicated and require a multifaceted response that can both promote individual agency whilst also tackling structural disadvantage and inequality.

## References

- Arnett, J. J. (2004). *Emerging adulthood: The winding road from the late teens through the twenties*. New York: Oxford University Press.
- Baxter, K., Glendinning, C. and Greener, I. (2011) 'The implications of personal budgets for the home care market', *Public Money and Management*, 31(2), 91-98.
- Biggart, A and Walther, A. (2006) 'Coping with Yo-yo Transitions: Young Adults' Struggle for Support-Between Family and State in Comparative Perspective', p. 41–62 in Leccardi, C. and Ruspini, E. (eds.) *A New Youth? Young People, Generations and Family Life*, Aldershot: Ashgate.
- Blatterer, H. (2007). 'Contemporary Adulthood: Reconceptualising an Uncontested Category.', *Current Sociology* 55: 771–792.
- Brannen, J., and Nilsen, A. (2007). Young People, Time Horizons and Planning: A response to Anderson et al. *Sociology*, 41(1), 153–160.
- Campbell, J. and Oliver, M. (1996) 'Disability Politics: Understanding our past, changing our future', London: Routledge.
- Cieslik, M. and Simpson, D. (2013), *Key Concepts in Youth Studies*, London: SAGE Publications.
- Côté, J (2000) *Arrested Adulthood: The changing nature of maturity and identity in the late modern world*. New York: New York University Press.
- Côté, J., and J. M. Bynner. (2008). "Changes in the Transition to Adulthood in the UK and Canada: The Role of Structure and Agency in Emerging Adulthood." *Journal of Youth Studies* 11 (3): 251–268.
- du Bois Reymond; M. (2009) Models of Navigation and Life Management in Furlong, A. (ed.) *Handbook of Youth and Young Adulthood: New perspectives and Agendas*, Routledge, London.
- Edward, S., Riddell, S. & Bee, W. (2008) *Reporting on progress towards equality of opportunity between disabled persons and other persons made by public authorities in Scotland: the Scottish Ministers' Duties. Education and Lifelong Learning*. Edinburgh: The Scottish Government.
- EGRIS (European Group for Integrated Social Research) (2001) 'Misleading Trajectories – Transition Dilemmas of Young Adults in Europe', *Journal of Youth Studies* 4(1): 101–19.
- Evans, K., and Furlong, A. (1997) Metaphors of youth transitions: Niches, pathways, trajectories or navigations. In *Youth, citizenship and social change in a European context*, ed. J. Bynner, L. Chisholm, and A. Furlong, 17–41. Aldershot: Ashgate.
- Emerson, Krnjacki, L., Llewellyn, G., Vaughan, C. and Kavanagh, A. (2016) 'Perceptions of safety and exposure to violence in public places among working age adults with disabilities or long-term health conditions in the UK: cross sectional study', *Public Health*, 135, 91-96.

- Farrugia, D (2013) Young people and structural inequality: beyond the middle ground, *Journal of Youth Studies*, 16:5, 679-693.
- France, A. (2007) *Understanding Youth in Late Modernity*. Maidenhead: Open University Press.
- France, A., and E. Haddon. (2014). "Exploring the Epistemological Fallacy: Subjectivity and Class in the Lives of Young People." *Young* 22 (4): 305–321.
- France, A., and S. Threadgold. (2015). Youth and Political Economy: Towards a Bourdieusian Approach. *Journal of Youth Studies*, 19 (5).
- Furlong, A. (2009) Revisiting transitional metaphors: reproducing social inequalities under the conditions of late modernity. *Journal of Education and Work*, 22 (5): 343- 353.
- Furlong, A. and Cartmel, F. (2007) *Young People and Social Change: New Perspectives*, Open University Press, Buckingham, Second Edition.
- Furlong, A, Cartmel, F, Biggart, A, Sweeting, H. and West, P. (2005) 'Complex transitions: linearity and labour market integration in the West of Scotland' in *Young People in Transition: Becoming Citizens?* C. Pole, J. Pilcher and J. Williams, Basingstoke:12-30.
- Goodwin, J., and O'Connor, H. (2005). Exploring Complex Transitions: Looking back at the golden age of youth transitions ', *Sociology*, 39(2), 201220.
- Griffin, C. (2004) "Representations of the Young", in: Roche, J, Tucker, S, Thomson, R and Flynn, R (eds), *Youth in Society*, London: Sage.
- Grigal, M., D. Hart, and A. Migliore. 2011. "Comparing the Transition Planning, Postsecondary Education, and Employment Outcomes of Students with Intellectual and Other Disabilities." *Career Development for Exceptional Individuals* 34 (1): 4–17. doi: 10.1177/0885728811399091.
- Harris A (2004) *Future Girl: Young Women in the Twenty-first Century*. New York: Routledge.
- Heath, S. (2008). Housing choices and issues for young people in the UK. *Joseph Rowntree Foundation, York*.
- Hetherington, S. A., L. Durant-Jones, K. Johnson, K.Nolan, E. Smith, S. Taylor-Brown, and J. Tuttle. 2010. "The Lived Experiences of Adolescents with Disabilities and Their Parents in Transition Planning." *Focus on Autism and Other Developmental Disabilities* 25 (3): 163–172. doi: 10.1177/1088357610373760.
- Howard, A., Blakemore, T., Johnston, L., Taylor, D. and Dibley, R. (2015) 'I'm not really sure but I hope it's better: early thoughts of parents and carers in a regional trial site for the Australian National Disability Insurance Scheme, *Disability and Society*, 30(9), 1365-1381.
- Kelly, P. (2013) *The Self as Enterprise: Foucault and the Spirit of the 21st century capitalism*. Gower.
- Kendrick, M., Ward, M. and Chenoweth, L. (2017) 'Australia's national disability insurance scheme: looking back to shape the future', *Disability and Society*, 32(9), 1333-1350.

Kirk S (2008) Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health and Development* 34: 567–575.

Morris, J. (2002) *Moving into Adulthood*. Joseph Rowntree Foundation, York, UK.

Pearson, C. and Ridley, J. (2017) Is personalization the right plan at the wrong time?: Re-thinking cash-for-care in an age of austerity. *Social Policy and Administration*, 51(7), 1042-1059.

Ormston, R., Eunson, J., McAteer, G., & Scotland, I. M. (2017). Improving outcomes for people with learning disabilities: Opportunities and challenges for housing.

Pearson, C. 'Money Talks?: Competing discourses in the implementation of direct payments', *Critical Social Policy*, 20(4), 459-477.

Pearson, C. (2019) 'Independent living and the failure of governments', in Watson, N. and Vehmas, S. (eds) (2019) *Routledge Handbook of Disability Studies*, London: Routledge.

Pearson, C. and Ridley, J. (2016) 'Is Personalisation the Right Plan at the Wrong time? Re-thinking Cash-for Care in an Age of Austerity', *Social Policy and Administration*, 51(7), 1042-1059.

Powel, A. (2017) *NEET: Young people not in education or training* London, House of Commons Briefing chapter Available at: [https://dera.ioe.ac.uk/30962/2/SN06705%20\\_Redacted.pdf](https://dera.ioe.ac.uk/30962/2/SN06705%20_Redacted.pdf) (Accessed 27 June 2019)

Sanderson, E. (2017) 'Youth transitions to employment: longitudinal evidence from marginalised young people in England', *Journal of Youth Studies*, [doi-org.ezproxy.lib.gla.ac.uk/10.1080/13676261.2019.1671581](https://doi-org.ezproxy.lib.gla.ac.uk/10.1080/13676261.2019.1671581)

SCLD (2016) *Learning Disability Statistics Scotland, 2015*, available at: <https://www.sclid.org.uk/evidence-and-research/statistics/> [accessed

Scottish Government (2019) *Supporting disabled children, young people and their families: guidance*, <https://www.gov.scot/publications/supporting-disabled-children-young-people-and-their-families/pages/transitions/> [accessed 11/12/19].

Scottish Government (2019) *Scottish Independent Living Fund*, <https://www2.gov.scot/Topics/Health/Support-Social-Care/Independent-Living/ScottishIndependentLivingFund> [accessed 29/5/19]. TAKE OUT?\*

Scottish Transition Forum (2016) *The Principles of Good Transition*, <https://scottishtransitions.org.uk/summary-download/>, [accessed 11/6/19].

Stalker, K. (2002) *Young disabled people moving into adulthood in Scotland*. York, Joseph Rowntree Foundation.

Woodman, D. and Bennett, A. (2015) *Youth Cultures, Transitions, and Generations, Bridging the Gap in Youth Research*, Palgrave MacMillan, New York.

## **Chapter 11: Theory, ethics and methods: International Disabled Children's Childhoods**

**Kathryn Underwood\*, Marisol Moreno-Angarita\*\*, Tillie Curran\*\*\*, Katherine Runswick-Cole\*\*\*\*, Donald Wertlieb\*\*\*\*\***

**\* Ryerson University**

**\*\* Universidad Nacional de Colombia**

**\*\*\* University of the West of England**

**\*\*\*\* The University of Sheffield**

**\*\*\*\*\* Early Childhood Development Task Force (ECDtf)  
and Tufts University**

The authors of this chapter are all members of the International Advisory Committee for the Inclusive Early Childhood Service System (IECSS: <https://iecsc.blog.ryerson.ca>) project. IECSS is a longitudinal study of interactions with institutional processes when families have a young disabled child. The IECSS international advisory committee is tasked with interpretation of the IECSS findings for an international audience across varied and geo-political contexts. As part of the work of the advisory committee, we have been contemplating the research methods of the IECSS project as a possibility for understanding systemic issues of interest to disabled children and their families across the globe, as well as for the families who are participating in the ongoing research of IECSS in Canada (Underwood et al., in press).

We are all academics who are committed to ways of thinking about disabled children that: value them as members of their communities; see their experiences and viewpoints as important for understanding the organization of all childhoods in societies; and consider disabled children to be central to discussions on international development that is focused on early childhood, education or early intervention. We agree that discussions of disabled children's lives are, too often, framed with reference to their failure to match up to the mythical norms of child development (Burman, 2008). Instead, we follow a tradition of research and scholarship that seeks to challenge representations of disabled children's childhoods as being tragic or lacking (Shakespeare and Watson, 1998; Connors and Stalker, 2007) and our explicit aim is celebrate the potential of all children's lives (Curran and Runswick-Cole, 2014).

While disability studies scholars have paid attention to the disabling barriers in children's lives (Read et al., 2006; McLaughlin et al., 2008; Greenstein, 2015; Slater, 2015), studies of childhood, too often, continue as an adult-centric area of study that has frequently ignored the lives of disabled children (Wells, 2018). We are not the first to call for a focus on the lived realities of disabled children's lives (See, for example, Watson et al, 1999) and

yet, a social oppression model of disability has struggled to make an impact on the mainstream childhood research agenda.

In trying to make sense of why this might be, it is worth paying attention to the foundational principles of the new sociology of childhood (James, Jenks and Prout, 1998). These principles depend on the image of the child as an independent, rational, autonomous, active social agent. Disabled children who fail to conform to this account of agency and autonomy trouble these principles and, as a result, disabled children have been marginalised or ignored in studies of childhood (Wells, 2018). And while childhood studies accepts that childhood as a social construction, mediated by its historical and global locations, the 'norms' of child development continue to provide a rationale for segregated or 'special' welfare and education provision in the lives of disabled children and the exclusion of disabled children from research (Burman, 2008).

In our discussions as members of the advisory board, ethics is always at the centre, and, in particular, the question of the ethics of transferring research findings from wealthy nations (including Canada, the UK and the US) to low and middle-income countries and the global south, or the global majority world. In this era of globalization, there is ongoing interest in how collective action can lead to equalization of opportunity through investment in "development". An example of this type of investment is the promotion of scientific knowledge to a global audience as the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Disabled Persons (CRPD) are implemented across global contexts. These directives are rooted in human rights frameworks but we could see that many of them were focused on rehabilitation services and research that was premised on the idea that disability is a medical condition that needs to be fixed.

In March, 2019, we attended the European Association of Childhood Disability (EACD) in Paris, France. The conference provided a venue where the majority of attendees are solidly situated in a medicalized discourse and where the goal is to "scale up" rehabilitation and intervention services and to reach the largest number of impaired children globally. We were discouraged by the lack of critical concern for the view that disabled children need to be fixed, that services needed to be clinical rather than driven by participation and community, and that the only research methods of value were those that reinforced these underlying views. We were further disheartened by the positioning of disabled children and their families on the margins of a research agenda driven by rehabilitative discourses and concerns.

We are interested in exploring approaches that break the cycle of authority that allows a small portion of the world population to determine how bodies should function, what they are capable of and which roles they should play. At the same time, we argue that there should be a renewed focus on systemic barriers in international development initiatives rather than on continuing to perpetuate approaches that entrench medical thinking about impairment.

And so, we conclude by offering a developing manifesto for change:

- Develop theories of disability that shift focus toward full, productive childhoods and futures
- Use research methods to shift the focus away from an evaluation of the child and towards an evaluation of institutions

- Re-imagine and organise policies and services to support disabled children's childhoods and their aspirations
- Listen to disabled young people and their families to understand their context and intersectional oppressions to make policy and services much more relevant and accessible

## References

- Burman, E. (2008). *Deconstructing developmental psychology*. London, UK: Routledge.
- Campbell, M. & Gregor, F. (2008). *Mapping Social Relations*. Toronto, ON: Higher Education University of Toronto Press.
- Connors, C. & Stalker, S. (2007) Children's experiences of disability: pointers to a social model of childhood disability, *Disability & Society*, 22:1, 19-33, DOI: [10.1080/09687590601056162](https://doi.org/10.1080/09687590601056162)
- Curran, T. and Runswick-Cole, R. (2014), [Disabled Children's Childhood Studies: a distinct approach?](#) *Disability and Society*, Vol. 29:10 pp1617-1630
- Greenstein, A. (2015). *Radical Inclusive Education: Disability, teaching and struggles for liberation*. London, UK: Routledge.
- McLaughlin, J., Goodley, D., Clavering, E., & Fisher, P. (2008). *Families Raising Disabled Children: Enabling Care and Social Justice*. Basingstoke, UK: Palgrave Macmillan. DOI: 10.1057/9780230583511
- Shakespeare, T & Watson N (1998) Theoretical perspectives on research with disabled children, Robinson, C & Stalker K (eds) *Growing Up with Disability*, London: Jessica Kingsley.
- Slater, J. (2015). *Youth and Disability: A Challenge to Mr Reasonable*. Surrey, UK: Ashgate.
- Underwood, K., Curran, T., Moreno-Angarita, M., Runswick-Cole, K. and Wertlieb, D. (in press) An international conversation on disabled children's childhoods: Theory, ethics and methods, *Canadian Journal of Disability Studies*.
- Watson N, Shakespeare T, Cunningham-Burley S, & Barnes, C. (1999). *Life as a Disabled Child: A Qualitative Study of Young People's Experiences and Perspectives*. Final Report. Edinburgh: Department of Nursing Studies, University of Edinburgh.
- Wells, K. (2018). *Childhood Studies: Making Young Subjects*. Cambridge, UK: Polity Press.

## Chapter 12: Recognising the Normalization Impulse: provocations from Foucault's work for thinking about disabled children's childhoods

Tillie Curran

University of the West of England

““Michel”, I [Simeon] asked, “in your life was there a specific event - say something like Rousseau on the road to Vincenne, or St Paul on his way to Damascus, even Buddha under the Bohdi tree - that afforded you the crucial insight that would determine the direction of your work?”

“Yes!”, he responded.

“When I enrolled at the Ecole Normale the headmaster demanded to learn if there was anything unusual about me. When I informed him of my homosexuality, he replied with horrified expression that such behaviour was not normal and certainly unacceptable to the reputation of the school. He then had me confined, for my own good, he said. He told me that I must be reformed, that I would be confined, examined, and treated by an array of authorities - doctors, teachers, psychology and psychiatrists, etc. At this instance I recognize in a flash how the system works. I perceived the fundamental impulse of our society: *normalization*.” (Wade, 2019: 58-59).

According to Wade, Foucault recalled his insight as happening ‘in a flash’. He knew what the headmaster was looking for and the headmaster knew to state emphatically what norms would be unacceptable for the school’s reputation. The headmaster’s claim to be acting for Foucault’s good and the practices of normalisation he invoked, were already available to him. Later, Foucault shows us how ‘problematization’ produces a solution in the same system of thought, operating not as top down or big state power, but as forms of discipline by others and discipline of the self. But these discursive practices are not inevitable and are constantly resisted. Hence, freedom is not about the mythical goal of ‘autonomy’: freedom is about ethical practices. Ethical practices concern reflection on *experience* with others and on our relationship with knowledge, and he sought ‘a form of criticism that would not judge, but bring an opening to life. It would light fires’ (Foucault, 1997:232). Speaking about ‘homosexuality’, Foucault explains that the point is not to ask ‘why’ or to normalise, but to ask ‘How, through homosexuality, are there more forms of subjectivity’; “To create gay life. To become” (Foucault 1997:163). In 2010, I suggested that the purpose of welfare should not be to ask ‘why’ disabled children, nor to aim for normalisation as ‘children first’, but to support disabled children to live a life considered by them to be enjoyable and ‘desirable’ (Curran 2010).

I have been part of the development of disabled children’s childhood studies with the emphasis on disabled children and young people’s voices, ethical practices and the questioning of norms (Curran 2013; Runswick-Cole 2018; Curran et al. 2018). I am also a social work lecturer and question social work as a system of exclusion/inclusion (Curran

2010). I'm going to back to Foucault's work here to review my research with disabled young people.

In the Imagining Young Disabled People's Transitions in a time of major societal change' research project (ImaYDIT 2018), peer researchers delivered knowledge cafes (Brown 2001) with 60 disabled young people with the aim of including disabled young people in debates about the future in a rapidly changing society. The cafes began with participants' experiences of a good life now and peer researchers facilitated conversations and art work around their hopes and dreams for their futures producing the following key messages:

Don't call us 'disabled young people' - we are just young people with the same hopes and dreams for the future as anyone else.

Support us to change the world! We want to contribute to making the world a better place.

We want the chance to make our own choices, do things for ourselves and decide on our future.

We want a chance to find out where we belong: everyone has a place where they feel they belong.

To be part of loving families, to have the chance to get married and have kids. (Jones et al, 2019:12). Do these messages reflect Foucault's notion of freedom and more desirable forms of subjectivity? We saw disabled young people creating a very different discourse to the 'transition' discourse concerned with changes to services and benefits as young people are moved to adult provision and at and after the impact events, stakeholders have said they are sharing these key messages with staff teams. The peer researchers have since run a Festival of the Future and are engaged in several community projects as a co-production group. In our analysis we supported Rice et al.'s. (2017)'s call to reject the 'future perfect' and to talk back, so that we can think about a multiple, changing future life desired in the present and see the key messages as generative narratives with multiple directions, as continuing conversations without end.

Reflecting on our research practices during and after the project, we identified five ethical hotspots:

- 1) Exclusion: peer researchers were not members of the steering group and their influence over providers was limited to the end of project impact event
- 2) The context of normalcy - nearly twice the number of young people than expected attended the cafe, and it was brought to a sudden end when the College bus arrived making our commitment to take care of participants rushed. With closer contact with the college we might have anticipated these institutional arrangements.
- 3) Identity - we discussed the need to 'think big' and had engaged advocates who had clarity about the social model of disability, but we did not discuss the meaning of 'disability' in terms of identity so the term 'disability' was seen as a label rather than a politicised or pride term.

4) Censorship - the key messages were readily accepted by the wider research team, but what if the team had disapproved of certain hopes and dreams - how much control would the peer researchers really have?

5) Exploitation - peer researchers trained and were involved throughout the research and while involvement can be seen as skill development, were we were also concerned that we could be socialising disabled young people's into a life of unpaid work

We have sought to address the ethical hot spots in Disability Rights and Robotics:.

Research team- a co-production team bringing together students from social work and robotics programmes, and experts by experience - disabled young people and adults with a diversity of lived experience in the role of co-researcher. There are therefore no 'subjects' and no steering group - co-production is research 'with not on people' (Campbell and Vanderhoven 2016:12).

Ethics - there is not need for advance (and often routine) 'ethical' approval as all involved are co-researchers (Involve 2019) and discussions about ethics are built in from the start and throughout.

Disability Rights - the main question agreed is 'how can disability rights be supported by robotics technology, now and in the future?' to generate a full view of identity and life far beyond a mechanisation of welfare discourse.

Exploitation - the main output is a bid for funded research that will seek payment for all researchers.

To finish, I don't think we will get away from the normalising impulse Foucault so eloquently depicts by aiming for a perfect research model or method, but we can aim for ethical practices. Our ethical hotspots also affirm the need for research to be led by the people with lived experience of the normalising impulse.

## References

Campbell, H. and Vanderhoven, D. 2016 Realising the Potential of Co- Production. ESRC N8/ESRC Research Programme: Knowledge That Matters

<https://www.n8research.org.uk/research-focus/urban-and-community-transformation/co-production/>

Curran, T. (2010) "Social Work and Disabled Children's Childhoods: A Foucauldian Framework for Practice Transformation", *British Journal of Social Work*, 40(3): 806-825.

Curran, T. and Runswick-Cole, K. eds. 2013, *Disabled Children's Childhood Studies - Critical Approaches in a Global Context*, Palgrave Macmillan

Foucault, M. 1997, 'Ethics: Subjectivity and truth' in Rabinow, P. (ed) *The Essential Works of Michael Foucault 1954-1984 Vol. 1*. London. Allen Lane.

Involve: Patient and public involvement in research and research ethics committee review  
[www.involve.nihr.ac.uk](http://www.involve.nihr.ac.uk)

Jones, M. , Curran, T. , Ferguson, S. , Reed, M. , Cull, N. , Lawrence, A.-J. , Stabb, M. , Bryan, B. , Buchan, F. , Coulson, A. , Fry, T. , Allen, L. , Bevins, T. , Baxter, L. , Wolfe, L. and Paterson, Z. (2018) *ImaYDiT - Imagining young disabled people's transitions in a time of major societal change: Research project report*. Project Report. University of the West of England, Bristol. Available from: <http://eprints.uwe.ac.uk/38774>

Rice, C., Chandler, E., Changfoot, N., Liddiard, K., Rinaldi, J., Mykitiuk, R. and Mundel, I., 2017. 'Imagining Disability Futurities', *Hypatia: A Journal of Feminist Philosophy*, 32:2, 213-229,.

Runswick-Cole, K. Curran, T. and Liddiard, K. (eds.) 2018, *The Palgrave Handbook of Disabled Children's Childhood Studies*. Basingstoke: Palgrave Ltd

Wade, S., 2019, *Foucault in California A true story wherein the great French Philosopher Drops Acid in the Valley of Death*, Heyday, Berekeley, California.

## Chapter 13: Lost in Transition: disrhythms in Ida's life

**Hanne Vandebussche, Elisabeth De Schauwer & Geert Van Hove**  
**Ghent University**

*Tina (Ida's mother): We went to the Ardennes on holiday. Sometimes we just lose her... Also there... we were walking with the six of us and suddenly we realised she was gone (again).*

*Alex (Ida's father): We know by now how she moves and how she thinks. So, we decided to follow the road going down, not up. We also know she chooses the way with the least resistance.*

*(Laughing)*

*Tina: Yes. That means she will walk with the wind in her back.*

*Jane (Ida's sister): Another big possibility is that she is going into a shop, as she adores shopping.*

*Tina: Or into a tea-room, drinking a hot choco.*

*Alex: We also know she walks tremendously slowly. It is quite shocking that we manage to lose her, even though she walks so slowly. It is just... when you walk, you get in your rhythm. Sometimes you forget her rhythm is so different.*

*Tina: It is also reassuring to know she will not panic. She's going to make use of the opportunity to go for what she wants.*

Ida is a young woman with an intellectual disability. She has followed inclusive education during her whole school career. A very intensive stage of new adventures and complicated searches continues (What will she do? What does she want to do? What is possible? where will she work? Will she be able to live apart from her parents?), after a long period with ups and downs, experiencing resistance against her presence in a regular school by teachers and others. She was challenged to colour outside the lines in her inclusive school trajectory. She needs to invent a life on the threshold of becoming adult, continuing her inclusive life course and taking into account (and using) normative conceptions about how life develops in multiple domains like work, housing, leisure time, intimate relations, sexuality, encounters with friends and family, etc. She and her family weaved a group of people around her whom she meets regularly to discuss these difficult life issues. In this network her parents, sister, support workers, neighbour and a family friend are involved, the first author was asked to attend these network moments also. Walking with her and this network, makes us question the time(s) and speed of transition.

Transition can bring young people in the idea of being 'off-time' (Langøy and Kvalsund 2018). As Woodman & Wyn (2013) state, successful transitions to adulthood are seen to be linear, involving fixed steps at prescribed time. This means that in the transition after secondary school normative conceptions require young people to fulfil the markers of a happy and successful adulthood, i.e. full-time work; independent living; long-term relationships (France and Treadgold, 2016: 618). In some critical approaches to transition,

the dominance of this norm of adulthood is questioned, taking into account the challenges these transition processes pose for some young people (e.g. Furlong, 2009; France and Treadgold 2016; Nguyen, Stewart and Gorter, 2017; Watson 2020). We draw on these ideas that bring to light difficulties in tempo; challenges posed by the structural organisation of society; the need for support to go to work or to live independently; precarious financial situations, etc; and want to keep them in mind when looking at *time* specifically.

Thinking time and being time bring up the kind of big questions contemplated by many philosophers over history. Time appears to work in a multitude of manners. We do not intend to, and are not able to, unravel all its secrets and complexities. We do, however, want to draw attention to how time works and shows itself to be very concrete in the situation of Ida: we touch time in her particular situation.

Ida, very tentative, thinks about what directions she would really like to follow in her life, entering pauses and thresholds of slowness and reflection together with her support worker and others. This is noticeable in how she handles the questions about work, living alone, etc., and in the way we work together in our research. If we reflect about her doings, it is as participant in a research project and as compaignon with the privilege to be part of an intensive search in her and her parents life course. She makes us wander about several rhythms, tempo, being and doing time. The slowness of Ida confronts us with many rhythms at play. Her being in time is not only slow, but it also appears to be very fast, often unexpectedly. There is no stable and steady rhythm we can connect her with. She is *in time* in many ways. The rhythm of her walking is not always the same, the rhythm of her doing is sometimes surprising, leaving her parents and siblings with new quests to try to find her. They illustrate the many ideas and options they have to think with her, as her, *becoming-her* (Deleuze and Guattari 1987). They need to find her rhythms. The same challenges arise when Ida is connected with her school, when she dances and when she goes to work.

Ida needs more time to figure out what she wants to do, what she can do, and to learn the things she would like to do. In the request of Ida to pause, to hold - a request she shows in many situations in her life and we discuss together with her family - , we become more self-conscious about how a structured and linear way of looking at time is keeping her, but also others, in a corset. Slowing down is helpful in (re)thinking (about) our own being in time.

Philosophy and disability studies both pay attention to the complexity and many workings of time. Bringing them together is helpful to see how to disrupt the normative and dominant linear way of doing and being in time inherent to our neoliberal society. But we do not only wish to disrupt and resist linear time, we also try to imagine different ways of being and becoming in time. Ida and her way of handling being lost, inspires us and opens up new ways to think about life. Kuppers (2014) talks about 'crip time': referring to the works of Margaret Price (2011), she reflects on the need for more flexibility in how time works in becoming and staying part of productive society. Limited time makes us look for alternative and creative ways of being part of what matters (Whitney and Liddiard 2020). Crippling time asks us to respect other way of being and the need for flexibility.

Bergson's (2018 [1907]) idea of 'duration' is very close to the processual way of looking at how human lives develop and change. Limitless time is flowing and knows no milestones that would define when you should be ready to study, to live alone, to go to work, etc.; that is, as in the norms connected with transition. In piling up all these expectations, there is little room for experimentation, for failure, for slowing down and taking little steps. Either you can meet these expectations, or you cannot. Ida and her network think about all these different domains, but they need time in order to make them accessible and possible. The first priority for Ida is being able to learn and develop her passions: dancing, acting, going away from her hometown to the big city, and arranging the necessary support to do this.

Lefebvre (2004) on the other hand, shows the many rhythms at play, focusing on the eurhythmic harmony and polyrhythms at stake. We would like to add a disrhythmic time. In this disrhythmic time, there is eye for the many rhythms at work, for limited and limitless time. Ida is confronted with limited time because of her 'slowness', for failing to fulfil the requirements of 'adulthood'. But she is also in limitless time, taking time to fulfil a life she wants to live. This life is not there at once, nor is it there all by herself. It goes together with taking risks - calculated risks most of the time - but without knowing where she will end up. Ida, in close connection with her network, keeps going on, realizing that her transition to adulthood will take a lot of time: such transition asks for slow learning together.

Ida connects with the struggles of disabled people when uttering the need for crip time and simultaneously draws attention to the more self-conscious way of living all people need. We argue that in crippling time, people learn to resonate (Hartmutt 2016) with the rhythms and rhymes of life. It brings to the foreground how time is not (only) linear. The realisation of the difference of time makes us aware of the control a certain chronological conception of time imposes on us and that in questioning this, we are letting several speeds crisscross. We claim that crip time is not only teaching us how exclusionary dominant linear time is - it is not only about the *impossibility of fitting into this* system. Rather, disrhythmic time is also an attempt to question the system, arguing for a slower way of living and being more attentive for the many rhythms in space-time-matterings (Barad 2014).

Ida illustrates this within a complex web of desires. Together with her family and network, she focuses on opportunities to dance, to become a professional performer or actress, to develop her abilities to make things or others pretty. In her speaking, in her dancing, in repetition, at home with her network, we listen to the polyrhythms of her entangled body. We hear her careful walks and silent presences; her heartbeat and breathing; her slow way of getting up in the morning; her dancing at speed; her living together in a warm family of six; her movements when she gets lost in the city. Connecting with her through all these rhythms brings us closer to the life she is striving for, her limited and limitless time.

### **Acknowledgements**

Special thanks to Sally Whitney and Dan Goodley for the inspirational conversation and feedback on this text.

## References

- Barad, K. (2014). Diffracting Diffraction: Cutting Together-Apart. *Parallax*, 20:3, 168-187, DOI: 10.1080/13534645.2014.927623
- Bergson, H. (2018 [1907]). De creatieve evolutie. [The creative evolution] Vertaald door Joke van Zijl. Oorspronkelijke titel: L'évolution créatrice: Paris: Félix Alcan.
- Deleuze, G., & Guattari, F. (1987). A Thousand plateaus: Capitalism and schizophrenia. London, England: Athlone Press.
- France A.& Treadgold, S. (2016). Youth and political economy: towards a Bourdieusian approach. *Journal of Youth Studies*, 19, 5, 612-628, DOI:10.1080/13676261.2015.1098779
- Furlong, A. (2009) Revisiting transitional metaphors: reproducing inequalities under the conditions of late modernity. *Journal of Education and Work*, 22 5, 343-353.
- Hartmut, R. (2016 [2013]). Leven in tijden van versnelling, een pleidooi voor resonantie. [Living in times of acceleration, pleading for resonance]. Vertaling: Huub Stegeman. Amsterdam: Boom.
- Kirk, S. (2008). Transitions in the lives of young people with complex healthcare needs, *Child: care, health and development*, 34, 5, pp.567-575. doi:10.1111/j.1365-2214.2008.00862.x
- Kuppers P. (2014). Crip time. *Tikkun* 29: 29–30.
- Langøy & Kvalsund Langøy, E. E. & Kvalsund R. (2018). Vulnerable Youth – Dependency or Independence? School Experiences, Transitions and Adaptation to and within Adult Life. *Scandinavian Journal of Disability Research*, 20(1), pp. 296–305. DOI: <https://doi.org/10.16993/sjdr.34>
- Lefebvre, H. (2004). Rhythmanalysis: Space, Time and Everyday Life. London: Continuum, 2004.
- Nguyen, T., Stewart, D. & Gorter, J. W. (2017). Looking back to move forward: Reflections and lessons learned about transitions to adulthood for youth with disabilities. *Child Care health Dev.*, 44, 83-88. DOI: 10.1111/cch.12534
- Price, M. (2011). *Mad at school: Rhetorics of mental disability and academic life*, University of Michigan Press.
- Watson, N. (2020). Transition to where and to what? Mapping the experiences of the transition to adulthood for young disabled people in Scotland, *Disabled Childhood Studies International Symposium organized by the Universities of Glasgow, Ghent, Lancaster, Leeds and Sheffield*, 23<sup>rd</sup>-24<sup>th</sup> January 2020.

Whitney, S. & Liddiard, K. (2020). Technologising Leadership - Virtual Research Contexts as Spaces of Disruption.pdf. [Accessed January 15<sup>th</sup> 2020].

Woodman, D. & Wyn, J. (2013). Youth Policy and Generations: Why Youth Policy Needs to 'Rethink Youth', *Social Policy & Society*, 12, 2, pp. 265-275.

# **Chapter 14: ‘Obuntu bulamu’: Entangled voices in visual narratives of children with disabilities in Uganda**

**Femke Bannink Mbazzi**

**MRC/UVRI & LSHTM Uganda Research Unit, Entebbe, Uganda and Ghent University, Faculty of Psychology and Educational Sciences, Ghent, Belgium**

## **Introduction**

Disability studies have been dominated by scholars from high income countries and predominantly use disability language from normative frameworks such as the Convention of the Rights for Persons with Disabilities (CRPD) (UN, 2006), and the Sustainable Development Goals (SDG) (UN, 2015). In studying disability and inclusion in low income countries there is need to learn from indigenous frameworks (Grech, 2016; Ingstad & Whyte, 1995; Seligman & Darling, 2009) and participate in ‘intellectual decolonisation’ (Meekosha, 2011). South African scholars suggest looking at family, poverty, cultural conceptions of disability, and the notion of ‘ubuntu’ (I am because we are) as an alternative disability discourse (Chataika & McKenzie, 2013; Oppenheim, 2012).

Existing childhood disability frameworks and interventions in Uganda are mostly based on international conventions and funded and implemented by private not-for-profit agencies (Alliansen, 2017; AusAID, 2015; DFID, 2013; GIZ, 2014; USAID, 2017). To offer an alternative discourse, a multidisciplinary Ugandan research team explored the narratives of children and related these to the central Ugandan concept of ‘Obuntu bulamu’ (Bannink, Nalugya, et al., 2020; Bannink, Nalugya, & Van Hove, 2019): an accepted and consistent behaviour that signifies a shared set of values, which promote well-being, togetherness and unity (Karlström, 1996; Otiso, 2006).

## **Methods**

Thirty-two children with disabilities aged between 8 and 14 years, who are part of a larger cohort study on inclusive education in Central Uganda, were asked to describe their daily life experiences through oral narratives, drawings, photos, and video scripts. The children had different disabilities which allowed representation of different impairments including (in terminology from the Global North) visual and hearing impairments, neuro-disabilities, intellectual disabilities, and autistic spectrum disorder. Each child was matched with a peer of their choice. The children, peers, and at least one parent or older sibling participated in four workshops between August 2018 and July 2019. Home and school visits by a member of the research team and the filmmaker took place in between the workshops. Audio and film recordings of the discussions during the workshops were made and data was transcribed and analysed using thematic analysis.

Children and their parents and siblings were invited to participate in a first workshop in which they described their daily life through drawings and oral narratives. In a second workshop, training on the use of photo and video cameras was given. Children were given instant cameras to take photos and were followed up at home and in school by a member of the research team. The children received instructions for taking photos of their daily lives: what is important to them, what they enjoy, and what they dislike or find difficult. The photos were discussed in a third workshop.

Each child then developed an idea for a video script together with a peer (they selected their peer themselves from their class or community), their parents, and members of the research team. From the initial films, the research team selected three stories in discussion with the children, parents, and teachers, and asked a professional filmmaker to film their narratives. The narratives became three detailed case studies (which are described elsewhere (Bannink, Kawesa, Nalugya, Van Hove, & Seeley, 2020). The films were shared in a fourth workshop in which children, parents, teachers, local leaders, government representatives and academics gave feedback which was taken into account in drafting the final versions. The final versions were shared with the participants and were made accessible online with the consent of all involved:

<https://www.ugent.be/pp/orthopedagogiek/en/news-events/news/obuntubulamu.htm>.

## Findings

Themes identified in the narratives, drawings, and photos were: friendship; play; belonging to a family; parents' (mostly mothers') care and perseverance in looking after and loving their child with a disability despite negative attitudes from relatives and community members; poverty; lack of services; and inaccessibility of schools and other public places. Whilst some themes were disability or impairment specific, such as social stigma of persons with disabilities, as well as difficulties in access to buildings for children with mobility difficulties (Figure 1), the majority of narratives focused on relationships with family and friends. These themes were similar for children with disabilities and their non-disabled peers: the importance of play (Figure 2); having a friend; and having someone who cares for you and supports you (Figure 3). The wider themes of poverty and lack of health and social services for all (and sometimes more pronounced for children with disabilities) were identified through descriptions of daily challenges and desires. These were rarely mentioned as direct challenges, but literally appeared as background in some of the photos and films.

The process of creating the films itself was a process in which a web of connections was made visible. From the start, children included their peers, parents, teachers, and community members. The film scripts were focused on telling 'their' story in the plural: children asked parent(s) to talk about their early years, their experiences with hospitals and schools, and asked their teachers and peers to talk about school. The voices were entangled, children described their lives from a perspective of 'we', our home, our school, our church. When speaking about 'I' they shifted to individual achievements in school, and what they would like to do in future. Each child returned to the 'we', describing how in future they would take care of their parents, and be part of their community. In all photos and videos interdependence rather than autonomy dominated the narratives, and was interlinked with 'Obuntu bulamu'.



Figure 10. Photo voice, themes 'inaccessibility' and 'friendship'



Figure 11. Drawing, themes 'I like to play' and 'friendship'



Figure 12. Photo voice, themes 'friendship' and 'supporting each other'

## Conclusion

In this explorative study of daily life narratives of children with disabilities, a ‘child-friendly participatory research method’ was used. The children’s oral, drawn, photographic, and video narratives showed how ‘Obuntu bulamu’ makes it inherently impossible to produce individual voices: rather, ‘Obuntu bulamu’ considers the forces producing voice in a complex web of interdependent relationships. This follows Mazzei’s (2016: 153) suggestion to think of distributed voices and ‘look at voice as a process of connections [...] and the forces at work producing voice as an entanglement’ (Mazzei, 2016).

The development of the photo and video narratives had many layers. Whilst the four workshops and the activities in between can be described as a linear process in time, adjacent layers of influence of the research team, the filmmaker, and all participating were added in each phase of the project. All research team members are Ugandan or have been resident in Uganda for over 20 years, but were taught in education systems in or based on the Global North’s human rights framework, and were trained to use ‘international’ definitions and interpretations of disability and inclusion. The use of photo and video narratives helped to give more weight to interpretations of non-verbal narratives and reduce the use of imported terminology and language.

None of the children’s narratives directly used words from a human rights discourse. The children instead focused on the importance of belonging to a family, having a parent who cares, changing negative attitudes: they communicated how friendship and interdependence make life worthwhile amidst poverty and absence of health and social services.

Interaction between different subjects in creating the ‘research outcome’ was a chaotic, and complex process, influenced by colonial paradigms, historicity of society, and power relations (Grech, 2011; Meekosha, 2011). When conducting ‘participatory research’ there is need to critically reflect on these factors and accept that methods, including film, have an element of ethnocentrism (Ogunyemi, 2014). Rather than taking the narratives themselves as the main output, we argue that the process of their creation is valuable in itself and can incite critical discussions on disability, childhood, ethnocentrism and post colonialism in the Global South.

Whilst ‘participatory research’ and the use of various ‘child friendly methodologies’ in research with children has become the norm in the Global North (Hill, Davis, Prout, & Tisdall, 2004; Horgan, 2017; Veale, 2005), involvement of children with disabilities in research in the Global South is still limited (Wickenden & Kembhavi-Tam, 2014). This study shows, together with a few others (Chappell, Rule, Dlamini, & Nkala, 2014; Walton, 2011), that it is feasible and indeed, required – even if complicated due to ethical considerations and power relations - to involve children with disabilities if we want to develop more in-depth knowledge of childhood disability in the Global South.

## Acknowledgements

The Obuntu bulamu study team and partners: Ruth Nalugya, Elizabeth Kawesa, Harriet Nambejja, and Janet Seeley, MRC/UVRI & LSHTM Uganda Research Unit; Patrick Ojok and Pamela Nizeyimana, Kyambogo University and Department of Special Needs and Inclusive Education, Ministry of Education and Sports; Bongole Wamala, Wakiso District Education Office; Olive Nabiryo, Katalemwa Cheshire Home; Kitsha and team, Magic

Films; Geert van Hove, Ghent University. We thank all the children, parents, teachers, and schools who participated in this study. This study was funded by the Flemish Interuniversity Council – University Cooperation for Development (VLIR-UOS) and the International Federation for Spina Bifida and Hydrocephalus. The author receives a postdoc grant from the Research Foundation – Flanders (FWO).

## References

Alliansen, A. (2017). Tracking Inclusion in Norwegian Development Support to Global Education. Norway: Fafo / Atlas Alliansen.

AusAID. (2015). *Development for All: Towards a disability-inclusive Australian aid program 2009-2014*. Australia: Australian Government.

Bannink, F., Kawesa, E. S., Nalugya, R., Van Hove, G., & Seeley, J. (2020). 'You are welcome our dear visitors' - video narratives by children with disabilities in Uganda. *In draft*.

Bannink, F., Nalugya, R., Kawesa, E. S., Nambejja, H., Nizeyimana, P., Ojok, P., . . . Seeley, J. (2020). 'Obuntu bulamu' – development of an indigenous intervention for disability inclusion in Uganda. *Under review*.

Bannink, F., Nalugya, R., & Van Hove, G. (2019). 'They Give Him a Chance'-Parents' Perspectives on Disability and Inclusive Primary Education in Uganda. *International Journal of Disability, Development and Education*, 1-19.

Chappell, P., Rule, P., Dlamini, M., & Nkala, N. (2014). Troubling power dynamics: Youth with disabilities as co-researchers in sexuality research in South Africa. *Childhood*, 21(3), 385-399.

Chataika, T., & McKenzie, J. A. (2013). Considerations of an African Childhood Disability Studies. In T. a. K. R.-C. Curran (Ed.), *Disabled Children's Childhood Studies: Critical Approaches in a Global Context* (pp. 152–163). Basingstoke: Palgrave.

DFID. (2013). *Education for children with disabilities: Improving access and quality (Guidance note: A DFID practice paper)*. United Kingdom: Department For International Development.

GIZ. (2014). *Inclusive Education: Applied Research for more Evidence in Education*. GIZ.

Grech, S. (2011). Recolonising debates or perpetuated coloniality? Decentring the spaces of disability, development and community in the global South. *International Journal of Inclusive Education*, 15(1), 87-100. doi: 10.1080/13603116.2010.496198

Grech, S. (2016). Disability and development: Critical connections, gaps and contradictions *Disability in the Global South* (pp. 3-19): Springer.

Hill, M., Davis, J., Prout, A., & Tisdall, K. (2004). Moving the participation agenda forward. *Children & Society*, 18(2), 77-96.

- Horgan, D. (2017). Child participatory research methods: Attempts to go 'deeper'. *Childhood*, 24(2), 245-259.
- Ingstad, B., & Whyte, S. R. (1995). *Disability and Culture*. Berkeley: University of California Press.
- Karlström, M. (1996). Imagining democracy: political culture and democratisation in Buganda. *Africa*, 66(4), 485-505. doi: 10.2307/1160933
- Mazzei, L. A. (2016). Voice Without a Subject. *Cultural Studies ↔ Critical Methodologies*, 16(2), 151-161. doi: 10.1177/1532708616636893
- Meekosha, H. (2011). Decolonising disability: thinking and acting globally. *Disability & Society*, 26(6), 667-682. doi: 10.1080/09687599.2011.602860
- Ogunyemi, O. (2014). The impact of ethnocentric news values on the framing of Africa: A case study of African diasporic press in the United Kingdom. *Ecquid Novi: African Journalism Studies*, 35(1), 9-24. doi: 10.1080/02560054.2014.886658
- Oppenheim, C. E. (2012). Nelson Mandela and the power of Ubuntu. *Religions*, 3(2), 369-388.
- Otiso, K. M. (2006). *Culture and customs of Uganda*: Greenwood Publishing Group.
- Seligman, M., & Darling, R. B. (2009). *Ordinary families, special children: A systems approach to childhood disability*: Guilford Press.
- UN (2006). *Convention on the Rights of Persons with Disabilities*. New York: United Nations.
- UN (2015). *Sustainable Development Goals*. United Nations.
- USAID (2017). *Disability Rights and Inclusive Development*. United States of America: US Agency for International Development.
- Veale, A. (2005). Creative methodologies in participatory research with children. *Researching children's experience: Approaches and methods*, 253-272.
- Walton, E. (2011). " They discluded me": possibilities and limitations of children's participation in inclusion research in South Africa. *Perspectives in Education*, 29(1), 83-92.
- Wickenden, M., & Kembhavi-Tam, G. (2014). Ask us too! Doing participatory research with disabled children in the global south. *Childhood*, 21(3), 400-417.

## Chapter 15: Sami the Incredible Hulk: what Shildrick's Monster can produce

**Inge Van de Putte and Elisabeth De Schauwer**  
**Ghent University**

To understand our local context - Flanders (Belgium) - it's important to understand that we have a long history of segregation. And we have the highest number of children in special education in the whole of Europe, with an over-presentation of children with social and behavioural needs (De Schauwer, 2017). The enrolment in special education is not mandatory: rather, it's a normative choice, it's seen as the best choice for children. As a result, segregation is embedded in our system.

Over last four years, we have been involved in a research project -'Potential' - the goal of which is to support the competence of teachers in creating inclusive education. The voices of children and their parents are too often neglected, in practice as in research (Goodley & Runswick-Cole, 2014). Together with Ellen Vermeulen, we made a documentary about these 'missing voices', presenting the narrative of four children and their parents which in a wider professional development with teachers. these teachers are undertaking collaborative action research in their school with a team of six - 10 colleagues. In one of the sessions, we use the documentary to provoke a dialogue between teachers. Normally, we let the reactions stand as they are, and have faith that the documentary will affect viewers and maybe change minds towards a more inclusive way of thinking.

In some groups, we experimented with working differently to bring in new thoughts. We asked ourselves: 'How can we think critically?' And answered the question: 'By not pathologizing the problem, but looking for the line of forces in relation to one of the children, Sami'.

For several years, as researchers we learned how new materialist methodologies enrich our disability studies framework. We worked on a collective biography, drawing on Margaret Shildrick's (2002) concept of 'Monster'. Working with this concept of Monster felt provocative: but it has expanded our thinking. Shildrick provides a fascinating insight into the way that the onto-epistemological construction of normalised identities involves the normalised subject in abjecting difference/disability. Shildrick invites those who identify themselves as normal, not only to make visible the processes whereby they *abject* the so-called monstrous other, but also to find ways to *re-claim* that monstrosity as *integral to their own humanity*. That re-claiming is not a revaluing of the different others, but a rethinking of the human (De Schauwer et al.2016). We plugged the concept of monster into different scenes in the documentary.

For instance, in the dialogue with teachers we reflect on the question: 'What does the concept of monster produce?'



Figure 13. Image of child wearing a cap and writing with other children around them

*Sami's class is on a three-day farm trip: they are looking at the sheep, the goats and the chickens. The smell of mown grass hangs in the air, the sun shines on their cheeks and mosquitoes are everywhere. When the teacher calls, the children gather together to listen to the teacher's explanation and to do a fill-in exercise. They all receive a form with empty boxes where they can fill in the answers which can be found on a plate next to the henhouse. The children are close together, each with their form close to the teacher. The teacher makes it a competition to fill in the answer as quickly as possible. Sami circulates on the edge of the group, looking around, his eyes are searching for what he has to do. The teacher tells him to start. He grabs his pen and writes with hard pressure on top of his form: 'I hate this'.*

Sami refuses to be silent and he writes the words "I hate this". At that moment he doesn't pass the test of the normative subject. Sami doesn't manage to cover up that he doesn't know what to do or that he doesn't want to do his exercise. He uses strong words, 'I hate this'. It is because of these strong words and actions that the teachers abject him. He's not the nice, friendly, docile student. For a lot of teachers in the professional development groups, he is undermining their authority. As Shildrick (2002) says: the monster is disrupting normalcy. Sami's response points out how meaningless this activity - filling in a form when you are outdoors - is. But by excluding him, the teachers don't have to listen to his words.

His voice is a material-discursive practice that is inseparable from all elements (human and non-human) in an assemblage. The form that needs to be filled out has a strong force: it materializes the system that there is one right answer, and one kind of student that fits in the normative school. The agential forces of human and non-humans are entangled and intra-act. If we look carefully, we can see that there are also children who don't know what to do, but they have strategies to cover up - they copy the answer of their classmates, or they look around without being noticed. They can act as a normative subject and that's why they earn access.

But Sami doesn't do that: he is intense, unpredictable, not reliable; his presence produces fear. Teachers participating in the professional development groups ask questions like: 'How do we respond to him?' 'What is the 'right' reaction?' The expert discourse is working on and through the teachers. They are experts in teaching, in didactics, in management: audit strategies will measure their expertise or compare their performance. Sami's

responses generate the fear that they, as individuals, are not good enough (Bansel, & Davies, 2014). His resistance is not seen as an ability, as a capacity to tell something.

But we can also look at the words 'I hate this' from a different angle, and then it's intriguing what Sami brings in. He underlines that this kind of activity is pointless: 'What will children learn about animals and their lives through reading a text and searching for the right answer?' His resistance makes us think about what we are creating in schools. He's questioning the grammar of schooling, the things we take for granted. His response gives the possibility of seeing the school as a smooth space.

At the same time, teachers also desire to do outdoor activities, creative projects that inspire students: activities that are not always clearly defined, not always focused on a product with evaluation and value the desire to work differently, to work collaboratively. Sami makes these different discourses visible, he opens up ways of seeing how we are always intra-acting with each other. He brings a new understanding of what it means to feel connected and makes the relational work in an inclusive classroom visible (Van de Putte et al. 2017).

Teachers think in terms of making sure the deficit or disturbance is gone, but rather, we could think in terms of connections and reciprocity. We all need connections with others, with the space, with the animals on the farm, etc. Sami calls for connection and makes us think in terms of connections and shared responsibility - the teacher is not solely responsible for making inclusion work, Sami alone is not responsible for becoming an able subject, inclusion is not the job of one person. It requires partnership with colleagues, parents and other children.

## Conclusion

Instead of searching for one hegemonic truth as a result of seeing the documentary, we set up a community of inquiry. We plugged in Shildrick's (2002) concept of 'monstrosity' to make visible the ambivalent processes through which difference is abjected and at the same time reclaimed. The collective work of watching the film, employing the concept of monster and reflecting upon its mutual entanglement with other agents, helped us to become aware of our own thinking and acting. Sami the Incredible Hulk: on one hand, we abject him to keep our idea of the normalized self, but at the same time, he gives us the opportunity to think about 'What does it mean to become human?' The monster makes it possible to re-think new ways of being in the world. The monster calls us and invites recognition. The attention shifts from disability to connections, desire, intra-action.

In this way we refuse the 'inclusion phobia' (Goodley, 2017) about children with emotional and behaviour needs and open up the responsibility of teachers for the question: 'What is needed to see the human in all his entanglements? Are we in the position to humanize Sami to see differently to Sami?' In this way, inclusion is not only about having the competence to differentiate, to use strength-based approaches, but also about reflecting on our own positions and encounters with 'monsters'. It's about creating an environment of openness, of listening, truly seeing the other and intra-acting with each other;

## References

Bansel, P., and Davies, B. (2014). Assembling Oscar, Assembling South Africa, Assembling Affects. *Emotion, Space and Society* 13.40–45.

- De Schauwer, E., Van de Putte, I. & de Beco, G. (2017). Inclusive Education in Flanders, Belgium: a Country with a Long History of Segregation. In G. de Beco, S. Quinlivan & J. Lord (EDS). *The Right to Inclusive Education in International Human Rights Law*. Cambridge, UK: Cambridge University Press.
- De Schauwer, E., Van de Putte, I., Claes, L., Verstichele, M. and Davies, B.( 2016). 'Shildrick's Monster: Exploring a New Approach to Difference/disability Through Collective Biography.' *Disability & Society*, 31 (8), 1098-1111
- Goodley, D. & Runswick-Cole, K. (2014). Becoming dis/human: Thinking about the human through disability. *Discourse: Studies in the Cultural Politics of Education*, DOI: 10.1080/01596306.2014.930021
- Goodley, D. (2017). *Disability Studies. An interdisciplinary introduction*. Sage: Los Angeles.
- Shildrick, M. (2002) *Embodying the Monster. Encounters with the Vulnerable Self*. London: Sage Publications.
- Van de Putte, I., De Schauwer, E, Van Hove, G. Davies, B. (2017). Rethinking agency as an assemblage. From change management to collaborative work. *International Journal of Inclusive Education*. <https://doi.org/10.1080/13603116.2017.1412514>

## **Chapter 16: Difficult Discussions and Curious Conversations: Challenging the dominance of the medical model in global studies of childhood**

**Katherine Runswick-Cole\* and Tillie Curran\*\***

**\*The University of Sheffield**

**\*\*The University of the West of England**

In this short chapter, we reflect on the persistence of the medical model of disability in framing the lives of disabled children, and on our attempts to disrupt the dominant narrative in the context of conferences about childhood. We see the medical model as a frame through which the lives of disabled children are individualized, pathologised and constructed as ‘a problem’ in need of a solution. A solution, by the way, that can only be offered by a psy-professional (medic, social worker, teacher, psychologist) (Oliver, 1991).

We argue that, despite interventions from critical disability studies into the debates about children’s lives, there has been a lack of critical engagement with a host of (negative) assumptions about the lives of disabled children, which permeate every day talk about, and policy and practice for, disabled children.

Finally, we reflect on our experiences of attempting to disrupt the dominant medicalised discourses of childhood in the specific context of conferences ‘about childhood and disability’. We conclude by calling for research alliances that pay attention to the lived experience of disabled children and young people in order for them to meet their aspirations to live full lives (Liddiard et al. 2019).

### **The persistence of the medical model**

As academics working within and from a critical disability studies perspective (Goodley, 2014), we view disability as a form of social oppression. We resist the view that disabled children are ‘not quite like’ other children (Goodley et al. 2015) and we take an affirmative approach that values difference and diversity in childhood as a many splendored thing.

We follow a long history of scholarship that has rejected pathologised and individualized models of childhood disability that locate the ‘problem’ of disability within individual bodies and minds (Oliver, 1991). We embrace the view that disability is ‘a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being’ (Thomas, 2007, p. 73). We note that as early as 1999, Shakespeare et al (1999: 2) exposed the damaging effects of studies that focus on impairment, vulnerability and service use in research ‘about’ disabled children that constructed ‘them’ as ‘passive’, and ‘dependent.’ For many readers of this volume, who are familiar with the scholarship and politics of critical disability studies, this approach is familiar and accepted.

And yet, once when we step outside of these critical disability studies informed spaces, we are quickly reminded that progress towards the application of social models and critical theories of disability in the lives of disabled children has been slow. Out there, in the 'real world' of 'mainstream' childhood research, things feel very different. At a number of different childhood conferences hosted by both inter/national universities and by supra-national organisations engaged in promoting the global rights of the child, we have found ourselves confronted by a lack of critical engagement with a host of negative assumptions about disabled children. These include:

- An unquestioned assumption that the aim of 'innovative' research focused on childhood and disability is to develop, and then to 'scale-up', rehabilitation and interventions services (guided by Global North understandings of disability and development);
- Clinicians, who present such research, are themselves as best placed to identify what the 'problem' is and how to develop solutions that they regard as beneficial;
- 'Participation' in decision-making is a 'good thing' and is promised to disabled children, young people and families. However, it should be professional-led and is, therefore, enacted in ways that continue to ensure that the voices of disabled children and their families remain marginal in a research agenda, which is still driven by rehabilitative discourses and concerns (Curran and Runswick-Cole, 2014).

The medical model continues to maintain a vice-like grip on research funding and discussions of disabled children's lives across the globe. These practices and relationships act in concert, repeatedly over decades, to produce a disabled child a broken object - a 'something', there to be observed and, if possible, repaired by experts. The impact of this type of research is to construct disabled children as vulnerable and undesirable.

### **Why does the medical model persist?**

Given the tradition of scholarship that has challenged medical and individualized models of disability and their colonizing tendencies (Grech 2013; Chataika and McKenzie 2013), we want to reflect on why the medical model persists in being the dominant frame through which the lives of disabled children, young people and their families are read in research and scholarship about childhood. We think that there are two broad factors at play. First, the problem of disability for the sociology of childhood and second, the neglect of disability in social constructionist research.

Disability continues to be a problem for the sociology of childhood (James, Jenks and Prout, 1998) which continue to labour under the misapprehension that individual autonomy exists – it does not (McLaughlin 2020). Despite the new materialist and posthuman turn in studies of childhood (Goodley 2014; Osgood et al. 2015; Moxnes & Osgood, 2019) which has troubled conventional understandings of individual action and agency, childhood studies are still haunted by the reified image of the child as a bounded, independent, active social agent interacting with their social worlds. Disabled children, and others, who do not conform to this account of agency have become a 'problem' for childhood studies which has led to disabled children being marginalised or ignored within its theory and research practices (Wells, 2018).

Second, while the field of childhood studies has accepted that childhood is socially constructed in its historical and geographical location, disability has been excluded from the social constructionist turn, and the 'norms' of child development continue to provide a rationale for segregated or 'special' welfare and education provision in the lives of disabled children and the exclusion of disabled children from research (Burman, 2008). A new materialist childhood studies has re-asserted that matter matters (Barad, 2003) without attending fully to a political history in which some bodies and minds matter more, or less, than others.

## Stepping out of our comfort zone

At the 'childhood' conferences described above, we have found ourselves in venues where, typically, one of two things happen:

1. Disability is seemingly missing. Childhood is discussed in relation to age, gender, race, class and ethnicity, but, inevitably, dis/ability is the absent presence in the room (Davis, 2006);
2. Disability is present – as deficit, lack and disorder. In these venues, the majority of presentations are solidly situated in a medicalized discourse and the discussions serve to illustrate the extent to which the negative assumptions about disabled children's lives we list above are internalised. Disabled children are present as broken objects and without age, gender, race, class and ethnicity or status as siblings, grandchildren and friends (Curran and Runswick-Cole, 2014).

As we sit in conference sessions we are, on the face of it, presented with two choices. The first is to feign happiness, nod along and comply with the cultural expectations of these spaces and leave the dominant narrative intact (Ahmed, 2017). The second is to refuse to play along and to challenge both the absence of disability and the fantasy of the 'typically developing child'. And in these moments, we inevitably become 'crip killjoys' puncturing the 'reasonable' consensus that disabled children are in need of fixing (Ahmed, 2017; Johnson and McCruer, 2014).

And yet, in our experience, the 'choice' to remain silent is never really open to us because, as Ahmed (2017) reminds us, even in the moment of hesitation ('Shall I say something or stay silent?'), social justice work is already being done and *saying something* becomes the only option.

The moment of challenge is always difficult. In our interventions we are trying to bring the "the disabled child" out from under the shadow of the norm while our interlocutors are simultaneously holding onto "the normative child" with all their strength. We experience a range of responses to criticism of the biomedical model (Jones and Wilsdon, 2018). Sometimes the response is dismissive; sometimes there is open hostility and defensiveness; at other times, there are concerted attempts to re-inscribe the act of resistance back into the dominant narrative ('We all want the same thing, really, don't we?') in order to neutralize the challenge. When we and others, including parents, speak of oppressive practices, they are re-storied in front of us – parental anger at social injustice is represented as a symptom of their need for sleep as they carry the 'burden' of care for

their 'disordered' child. Discourses of kindness, empathy and expertise, are, perhaps unintentionally but, effectively employed to smother any nascent dissent.

Despite these difficult discussions, our experiences have not been entirely negative ones. We have found that when we present in sessions at conferences where the medical model dominates, we can often draw a crowd - extra chairs are smuggled in by attendees curious to find out more about a presentation that begins with disabled children's potential. These moments of curiosity are simultaneously moments for conversations about the lives of disabled children. The set of conditions we have described are not static or immutable, neither are they necessary or inevitable. At the same time, we have to acknowledge that challenging the dominant narrative is often risky and demanding in terms of emotional labour.

At the conferences we attended, and we are constantly reminded that the voices of children, young people and their families must be front and centre. Their direct experiences are vital if research and theory are to have an impact that really does matter. And we continue gathering together in our spaces to develop our questions. We share our projects such as Living Life to the Fullest ([livinglifetothefullest.org](http://livinglifetothefullest.org)). We will explore what it means to be human and call out the practices that dehumanise and normalize which continue in everyday life (<http://iHuman.group.shef.ac.uk>). We will share strategies for securing redress and full lives ([humanactivism.org](http://humanactivism.org)). And we will continue to seek out difficult discussions, in uncomfortable spaces, in the hope that these curious conversations will, in their small ways, enable disabled children and young people to meet their aspirations to live full lives.

## References

Ahmed, S. (2017) *Living a Feminist Life*, Georgia: Duke University Press.

Barad, K. (2003) Posthumanist performativity: Toward and understanding of how matter comes to matter [Signs Journal of Women in Culture and Society](#) 28(3):801-831

Burman, E. (2008). *Deconstructing Developmental Psychology* (2nd ed.). East Sussex: Routledge

Chataika, T. and McKenzie, J. (2013), 'Considerations of an African Childhood Disability Studies' in *Disabled Children's Childhood Studies: critical approaches in a global context*, edited by T. Curran and K. Runswick-Cole, 89-104, Basingstoke: Palgrave MacMillan

Curran, T. and Runswick-Cole, K. (2014), 'Disabled Children's Childhood Studies: a distinct approach?' *Disability and Society* 29:10 1617-1630

Davis, L. J. (2006) 'Constructing normalcy: The bell curve, the novel, and the invention of the disabled body in the Nineteenth Century' in Davis, L. J. (ed) *The Disability Studies Reader* (2<sup>nd</sup> Edition), New York: Routledge, pp. 3-16.

Goodley, D. (2014) *Dis/ability Studies: Theorising disablism and ableism*. London: Routledge.

- Goodley, D., Runswick-Cole, K. and Liddiard, K. (2015) *The DisHuman Child in Discourse: The Cultural Politics of Education* DOI: 10.1080/01596306.2015.1075731#.Vh-V2844RDE.
- Grech, S. (2013), 'Disability, Childhood and Poverty: Critical Perspectives on Guatemala' in *Disabled Children's Childhood Studies: critical approaches in a global context*, edited by T. Curran and K. Runswick-Cole, 89-104, Basingstoke: Palgrave MacMillan
- James, A., Jenks, C. and Prout, A., (1998) *Theorising Childhood*, Cambridge: Polity Press.
- Johnson, M. L., & McRuer, R. (2014). Cripistemologies: Introduction. *Journal of Literary & Cultural Disability Studies*, 8(2), 127-147,242. Retrieved from <https://search-proquest-com.sheffield.idm.oclc.org/docview/1545106235?accountid=13828>
- Jones, R. and Wilsdon, J. (2018) *The Biomedical Bubble: why UK research and innovation needs a greater diversity of priorities, politics, places and people*. Available online at: <https://www.nesta.org.uk/report/biomedical-bubble/> Accessed on: 2<sup>nd</sup> February, 2020
- Liddiard, K., Whitney, S., Evans, K., Watts, L., Vogelmann, E., Spurr, R., Aimes, C., Runswick-Cole, K. and Goodley, D. (2019) Working the edges of Posthuman disability studies: theorising with disabled young people with life-limiting impairments, *Journal of Sociology of Health and Illness*. <https://onlinelibrary.wiley.com/doi/epdf/10.1111/1467-9566.12962>
- Moxnes, A. and Osgood, Jayne (2019) Storying diffractive pedagogy: reconfiguring groupwork in early childhood teacher education. *Reconceptualizing Educational Research Methodology* , 10 (1). pp. 1-13. ISSN 1892-042X
- Oliver, M. (1991). *The Politics of Disablement*, Basingstoke: MacMillan Press
- Osgood J, Scarlet RR and Giugni M (2015) Reconfiguring quality: Beyond discourses and subjectivities to matter, bodies and becomings in early childhood education. In: Cannella GS, Salazar Perez M and Lee I (eds) *Critical Examinations of Quality in Early Education and Care*. New York: Peter Lang, pp. 139–156.
- McLaughlin, J. (2020) *Relational Autonomy as a Way to Recognise and Enhance Children's Capacity and Agency to be Participatory Research Actors*, *Ethics and Social Welfare*, DOI: [10.1080/17496535.2020.1714689](https://doi.org/10.1080/17496535.2020.1714689)
- Shakespeare, T., Priestley, M. and Barnes, C. (1999) *Life as a Disabled Child: a qualitative study of young people's experiences and perspectives* Online at: <http://disability-studies.leeds.ac.uk/research/life-as-a-disabled-child/>
- Thomas, C. (2007). *Sociologies of disability, 'impairment', and chronic illness: Ideas in disability studies and medical sociology*. London: Palgrave.
- Wells, K. (2018) *Childhood Studies: Making Young Subjects*, Cambridge: Polity Press

## Chapter 17: 'It's my right to play too!' Play for disabled children in Taiwan and Hong Kong

Angharad E. Beckett\*, Pedro Encarnação\*\*, Chun-Yu Chiu\*\*\* and Simon T.M. Ng\*\*\*\*

\*University of Leeds, UK

\*\* Católica Lisbon School of Business & Economics

\*\*\* National Taiwan Normal University

\*\*\*\* Hong Kong University

There are many knowledge-gaps surrounding disabled childhoods, globally (UNICEF 2013). Whether and how disabled children's experiences of play are affected by cultural constructions of disability and childhood, plus varied social, economic and family structures around the world, is one such lacuna. This contribution has two objectives. First, to summarise findings from a study exploring play for disabled children living in Taiwan and Hong Kong. Second, to invite the reader to join us in considering how a new materialist approach might provide a useful new way to explore the local formations of disabled children's play 'events'.

Disabled children's right to play is enshrined within the United Nations (UN) Convention on the Rights of the Child (CRC Article 31) and UN Convention on the Rights of Persons with Disabilities (CRPD Article 30). This right is not being realised for all disabled children and they are at more risk of experiencing play-deprivation and exclusion from a full play experience (Hughes 2003).

Impairment-effects (Thomas 2014) may present certain challenges to children in/to their play. These may be overcome, however, if those practicing 'allyship' (families, friends, professionals) use imagination and follow the lead of disabled children, who often navigate impairment-effects creatively. The truly *disabling* barriers lie beyond the minds and bodies of children. The International Play Association (2015: np) has neatly summarised the barriers thus: '(1) inaccessible facilities and environments, negative attitudes and inappropriate social policies and programmes; and (2) the imposition of activities determined by adults' onto disabled children's play.

For a detailed narrative review of research (and useful bibliography) into barriers to play for disabled children within the social environment, we recommend Barron et al. (2017). Here we provide a list of the main disabling barriers identified in international literatures:

- (a) Inaccessible physical environments and exclusionary design e.g. of playgrounds, with insufficient consultation with disabled children and their families;
- (b) A difficult journey to play spaces (e.g. lack of affordable and accessible public transport);
- (c) Noise and overcrowding at playgrounds;
- (d) Insufficient play-space at home and/or late or no adaptations e.g. absence of a stair-lift reducing children's independent mobility;

- (e) Lack of toys suitable for children with different abilities and those matched to children's abilities not being age-appropriate;
- (f) Disabled children being more likely to be bullied by peers;
- (g) Exaggerated perceptions of 'risk' amongst staff at play-sites; some parents and teachers limiting disabled children's opportunities to make choices, take risks, embrace challenges and make friends;
- (h) Adults considering play to be 'frivolous or disposable' if their focus is on making sure that disabled children participate in therapeutic or educative regimes.

One response to (h) has been to make such regimes *playful* or *play-like*, but this has led to much 'play-adulteration' (Else & Sturrock 1998; Hughes 2012) - the contamination of play by adult agendas. Play theorist Sutton-Smith (1997) provided a deconstructive account of major 'play rhetorics' and concluded that the dominant play rhetoric of the 20th Century (clearly continuing into the 21st) was 'play-as-progress', a work-ethic repurposing of play. Whilst not dismissing all work in this vein, he was concerned that the rhetoric is problematic when it serves 'adult needs rather than the needs of children' ( p. 42). Whilst this rhetoric impacts on the play lives of most children (especially in the West), Disability Studies researchers have found that it has been overly present in the lives of disabled children, where it has operated as part of a quest for 'normalisation' of children towards a neoliberal-ableist 'ideal' (Goodley & Runswick-Cole 2010).

Existing research thus shows that disabled children face economic, physical, attitudinal and ideological barriers to free play. A final point is that these barriers are known to operate in assemblage (Feely 2016) and with more enabling factors – resulting in inclusion in, or exclusion from, play. Addressing one type of barrier without addressing all that are in operation in any given play event, is unlikely to ensure disabled children's right to play.

### **Disabled Children's Play: Taiwan and Hong Kong**

In 2018 we conducted an online survey, using Qualtrics®, of parents of disabled children living in Taiwan and Hong Kong. For full discussion of the methodology, sampling technique, response rate and mode of analysis please see Becket et al. (*forthcoming*). We did not consider parents' views to be 'proxies' for those of their children. Parents and disabled children do not always perceive things similarly. Previous studies have revealed that parents often consider the lives of their disabled children more negatively than children themselves (see Connors and Stalker 2003; 2007). As we develop further lines of research we will strive for disabled children's deep level of engagement (Tisdall 2012), to capture their experiences of, and aspirations for, play, and establish if there are any differences between their accounts and those of their parents.

Insights from parents gained via our study revealed the following (NB where we mention only one location, Taiwan or Hong Kong, this is because the finding was particularly noteworthy):

- (1) Most parents believe it is important that their child has the opportunity to play;
- (2) Most parents recognise that play has multiple benefits for their children, including for emotional wellbeing;
- (3) Most parents said they preferred inclusive play-spaces (for children of all abilities), so that their child could have opportunities for inclusion, would not feel stigmatised and because such spaces are less boring;

- (4) Less than a third of parents said that their child enjoys playing in a community playground;
- (5) 38% of Taiwanese parents felt community playgrounds were inaccessible and 63.6% were not satisfied that those playgrounds were safe;
- (6) Only around a third of parents from Hong Kong reported that their child plays with other children 'every day or a few times a week';
- (7) Almost 70% of parents said that the negative attitudes or lack of understanding of other children were a barrier to their child's play;
- (8) 40% of Taiwanese and 54% of Hong Kong parents were not satisfied with space at home for their child's play;
- (9) Over a third of parents stated that their child's other commitments (e.g. educational, rehabilitative, otherwise therapeutic) limited their play time;
- (10) Over half of parents stated that they did not have enough time to support their child's play. Most respondents were mothers. Taiwanese parents identified as impediments: 'housekeeping' (80.8%), 'taking care of other children and family members' (67.4%) and 'work' (48.1%); Hong Kong parents identified work (64.9%) and 'housekeeping' (54.1%);
- (11) 52.3% of Taiwanese parents and 44.3% of Hong Kong parents reported that they were not satisfied with their own level of knowledge/skill regarding how to support their child's play.

In the qualitative responses, Taiwanese parents were more likely to identify developmental 'functions' of play e.g.: '*rehabilitation in games*', '*motivation and development*', '*comprehension and focus*'. There was a suggestion here of the 'play-as-progress' rhetoric (Sutton-Smith 1997) and concern for 'normalisation' through play (Goodley & Runswick-Cole 2010). Taiwan has a well-established, Americanized self-help industry, with books on parenting regularly appearing in the top rankings for sales in this field (Hendriks 2016). Without further discussion with parents we can do no more than speculate that the popular science of parenting may be influencing these parents' perceptions.

Parents also reflected on the impact on children and parents of living in societies that prioritise academic achievement (Shek & Chan 1999). This was a particular concern amongst Hong Kong parents, as their 'free text' responses indicated (quotes from different parents):

*The child has high study pressure. Parents feel troubled. Relationship is affected and so is the child's self-esteem and self-confidence. Through play, children can release some of the pressure. Hope that the government can adjust the aims of education and let children have real time to play.*

*Children of the same age have great study pressure. Other parents have arranged too little play time, therefore it's difficult to find playmates.*

## Discussion

To date we have adopted a rights-based, barrier-mapping and individual-barrier-understanding approach to this study and its findings. We have worked to

develop a nuanced interpretation of these findings in relation to *local context*. Figure 1 provides a flavour of our analysis. We have sought to understand:

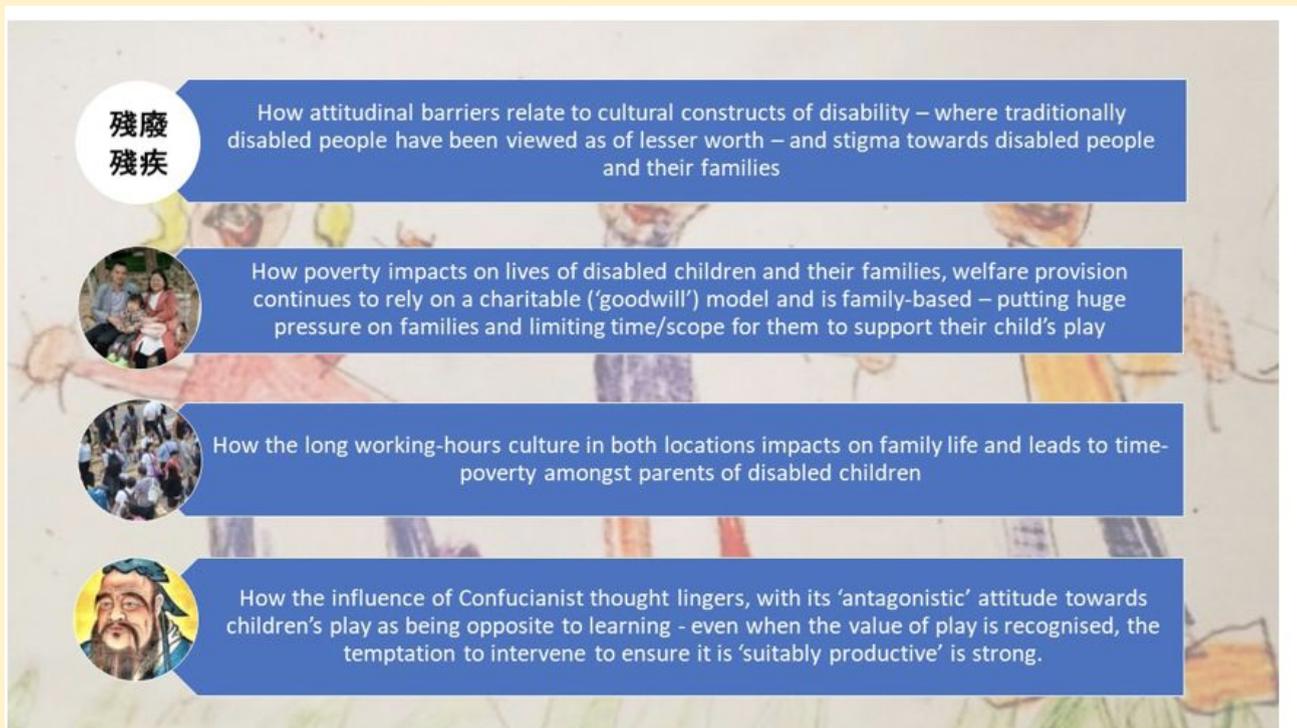


Figure 14. Summary of lines of analysis

Having explored potential explanations for parental responses and the experiences they report, we have outlined implications for further research or policy/practical change in order to realise disabled children's right to play.

Herein, however, we want to invite the reader to join us in considering how a new materialist perspective might allow us to advance/further our analysis. We are inspired by Game Studies research (Taylor 2009) which proposes that the Deleuzo-Guattarian concept of the 'assemblage' offers a helpful (ontological) framework for the study of play, since play comprises 'a number of parts interwoven in complex ways at particular historical moments' (p. 332). Such parts will always include the child, but may also include playmates, artefacts (e.g. toys/objects), the time of/for play, assistive technologies, play-spaces, rules of a game, attitudes and practices of parents or others, relevant institutional, policy/legal structures and cultures. Each part, or component of a given play event has 'properties' (qualities) which emerge from the interactions between the parts.

Is there potential utility to employing Deleuze and Guattari's (1988) sociology of associations in our research? We believe so. Their ontology allows us to consider how 'human bodies and all other material, social and abstract entities' might be viewed as 'relational', gaining 'shape and substance' as they are drawn into 'arrangement' (Fox & Alldred 2017: 17). Assemblages are held together by the capacities of assembled relations to affect or be affected – a force that achieves a change of state or capabilities. Such change may be physical, biological, psychological, social, political or emotional.

Assemblages are like machines that do and produce things. We believe that in order to realise disabled children's right to play, it is important to recognise the complex entanglements of material and non-material factors that produce either *playful* or *non-playful* events, or to put that in a more 'conventional' way: *enable* or *disable* play for disabled children.

To date, what we have done is begin the process of identifying at least *some* of the components 'at play' in disabled children's play events and lives in Taiwan and Hong Kong. Our next steps must be to explore how these components operate together, understand what they produce and then consider how to create new arrangements, assemblages, that allow for the production of playful events. Of course, Deleuze and Guattari also provide us with a wonderful vocabulary with which to describe such events - as occurring when 'power flows', involving an opening of the possibility of 'becoming-different', of disabled children 'becoming otherwise', following their own desires rather than following adult-determined pathways. Exploring play for disabled children in Taiwan and Hong Kong in this way will, we hope, prove fruitful - not only in terms of helping us to refine and develop our recommendations for enhancing access to and inclusion in play for disabled children living in these locations; but also allowing us to develop a methodology that can be applied elsewhere, by other researchers concerned with disabled children's right to play and advancing our understanding of disabled childhoods, globally.

## References

Barron, C., A.E. Beckett, M. Coussens, A. Desoete, N. Cannon Jones, H. Lynch, M. Prellwitz, D. Fenney Salkeld (2017) *Barriers to Play and Recreation for Children and Young People with Disabilities: Exploring Environmental Factors*. Warsaw/Berlin: De Gruyter.

Beckett, A.E., P. Encarnação, C-Y. Chiu and S.T.M. Ng (forthcoming 2020) 'Play for disabled children in Taiwan and Hong Kong: parent perspectives', in *Disability Studies in Education*.

Connors, C. and K. Stalker (2003) *The Views and Experiences of Disabled Children and Their Siblings: A Positive Outlook*. London: Jessica Kingsley Publishers.

Connors, C. and K. Stalker (2007) 'Children's experiences of disability: pointers to a social model of childhood disability', *Disability & Society*, 22 (1), pp. 19-33.

Deleuze, G. and F. Guattari. (1988) *A Thousand Plateaus*. London: Athlone.

Else, P. and G. Sturrock. (1998) 'The playground as therapeutic space: playwork as healing', chapter presented at Play in a Changing Society: Research, Design and Application, IPA/USA National Conference, Longmont, CO, 17–21 June. Online: <https://ipaewni.files.wordpress.com/2016/05/colorado-chapter.pdf> (18/03/19).

Feely, M. (2016) 'Disability studies after the ontological turn: a return to the material world and material bodies without a return to essentialism', *Disability & Society*, 31 (7), pp. 863-883.

- Fox, N. and P. Alldred (2017) *Sociology and the New Materialism. Theory, Research, Action*. London: Sage.
- Goodley, D. and K. Runswick-Cole. (2010) 'Emancipating Play: Dis/abled Children, Development and Deconstruction.', *Disability & Society*, 25 (4), pp. 499-512.
- Henricks, T. (2008) 'The nature of play: an overview', *American Journal of Play*, 1 (2), pp.157-180.
- Hughes, B. (2003) 'Play Deprivation, Play Bias and Playwork Practice', in F. Brown (Ed) *Playwork Theory and Practice*. Maidenhead: Open University Press.
- Hughes, R. (2012) *Evolutionary Playwork*. 2nd Edition. Abingdon: Routledge.
- International Play Association (IPA) (2015) *Position Statement on the Play Rights of Disabled Children*. Online:  
<http://ipaworld.org/ipa-position-statement-on-the-play-rights-of-disabled-children/>  
(03/01/17).
- Shek, D.T.L. and L. K. Chan (1999) 'Hong Kong Chinese Parents' Perceptions of the Ideal Child', *The Journal of Psychology*, 133 (3), pp. 291-302.
- Sutton-Smith, B. (1997) *The Ambiguity of Play*. Cambridge, Massachusetts: Harvard University Press.
- Taylor, T.L. (2009) 'The Assemblage of Play.', *Games and Culture*, 4 (4), pp.331-339.
- Thomas, C. (2014) 'Disability and Impairment', in J. Swain, S. French, C. Barnes and C. Thomas (Eds) *Disabling Barriers – Enabling Environments*, 3rd Edition. London: Sage, pp. 9-16.
- Tisdall, E.K.M. (2012) 'The Challenge and Challenging of Childhood Studies? Lessons from disability studies and research with disabled children.', *Children & Society*, 26(3), pp.181-191.
- UNICEF (2013) *The State of the World's Children 2013. Children with Disabilities*. Online:  
[https://www.unicef.org/sowc2013/files/SWCR2013\\_ENG\\_Lo\\_res\\_24\\_Apr\\_2013.pdf](https://www.unicef.org/sowc2013/files/SWCR2013_ENG_Lo_res_24_Apr_2013.pdf)  
(15/10/17).

# Chapter 18: The Production of the Suffering Child/Young Person with Restricted Growth: who's/whose suffering?<sup>1</sup>

**Antonios Ktenidis**  
**University of Sheffield**

## Restricted growth<sup>2</sup> as a cause of individual suffering

Disabled children's and young people's bodies are caught in a process of medical reshaping, with medical interventions aiming to align them 'with norms of how bodies should be' (McLaughlin and Coleman-Fountain, 2014: 76). One group that has been exposed to the medical and psychological gaze (Foucault, 1989) has been those with Restricted Growth (herein after RG). Kruse (2003) refers to how the positive mystical social constructions of RG people as sacred figures (see also Adelson, 2005a) were superseded by the medicalisation of RG, through which they were constructed as abnormal (medical) subjects, or, to put it simply, how 'wonder becomes error' (Thomson, 1996:3).

Children and young people with RG have been the research subjects/objects of medical and psychological research since the end of the 19<sup>th</sup> century (Medeiros, 2016; Thompson et al., 2008). These studies focused on (but were not limited to) their 'abnormal' development, proposing that these children presented a range of deficits: cognitive (Dowdney et al., 1987; Wilson et al., 1986), social (Stabler et al., 1980; Stace and Danks, 1981), behavioural (Abbott et al., 1982; Money and Pollitt, 1966) and self-esteem (Gordon et al., 1982; Rotnem et al. 1977). The same studies were also drawn upon to make a case for the need for the early detection of 'poor' growth:

The significance of timely detection of poor growth in early life resides in its association with adverse functional consequences, including poor cognition and educational performance, low adult wages, lost productivity... (de Onis et al., 2012: 1).

Poor growth, then, was understood as a source of suffering<sup>3</sup> due to its adverse consequences not only during childhood, but during adulthood too, constructing RG children, young people and adults as suffering subjects. As Medeiros (2016: 116) maintains, '[t]he psychological literature concerning short-statured children is remarkable in that, with few exceptions, the conclusion is that shortness is a handicapping<sup>4</sup> condition'.

---

<sup>1</sup> This research was funded by an ESRC White Rose Social Science DTP scholarship.

<sup>2</sup> Restricted Growth (or dwarfism) refers to a medical condition characterised by an adult stature of 4ft10" and below (Adelson, 2005a).

<sup>3</sup> It is important here to clarify that by suffering I do not refer to the physical pain resulting from the impairment.

<sup>4</sup> This is the author's wording, which perpetuates a perspective of disability as tragedy (Oliver, 1990).

## The human growth hormone as the panacea to the problem of suffering

The vast majority of biomedical techniques of bodily alteration gain both their justification and *raison d'être* from suffering (Cadwallader, 2007: 376).

From the beginning of the 20<sup>th</sup> century and prior to the 1980s<sup>5</sup>, children and young people with RG conditions were treated with different forms of growth hormone, most often sourced from animals (Medeiros, 2016; Morrison, 2015). However, with the production of the synthetic form of hGH in the 1980s and its 'advantages' –the product's safety, its increased quantity and its low cost - this treatment became more widely used (Conrad and Potter, 2004). According to Cutler et al. (1996) and Morrison (2019), the prescription of hGH treatment depended on the paediatric endocrinologist's beliefs about the effects of short stature on the well-being of children and the effectiveness of the treatment.

Besides increasing height, the hGH was also considered to compensate for other deficits – behavioural, self-esteem - triggered by RG. For instance, the National Cooperative Growth Study (Stabler et al., 1998) suggested that the behaviour of the children with Growth Hormone Deficiency (GHD) and those with Idiopathic Short Stature (ISS) was improved after being treated with hGH. Similar findings were proposed by Chaplin et al.'s (2011) study which recruited 99 short-statured children (32 with GHD and 67 with ISS). The authors argued that the behaviour and the self-esteem of these children were improved post-treatment. Nevertheless, such findings were contested by other studies. For example, the Wessex Growth Study (Downie et al., 1996) and other studies (Theunissen et al., 2002; Visser-van-Ballen et al., 2007; Colman et al., 2005) found no difference in short children's behaviour, psycho-social functioning or self-esteem after the treatment.

Some of the above studies (e.g. the Cooperative Growth Study) which discussed the positive contribution of hGH were funded by the company manufacturing hGH. Medeiros (2016: 134) spoke of the 'synergy between child psychologists' research and pharmaceutical companies' financial endeavours', indicating how studies in favour of treatment with hGH were beneficial to the pharmaceutical companies for the promotion of their product.

The bodies of children and young people with RG became sites for pharmaceutical intervention (Morrison, 2015)<sup>6</sup>, with the purpose of alleviating their suffering. Not only did the hGH treatment reinforce the narrative that these children were suffering because of their bodies, but it was depicted as the panacea to the problem of RG (Allen & Frost, 1990).

### A critical reading of the problem of suffering: who's/whose suffering?

Suffering is all too often treated as a neutral, natural response to a wrong; as such, it is often taken as the grounding for, rather than the object of, critique (Cadwallader, 2007: 375).

The word 'suffering' has already been used a number of times in this paper. There has been a reference to the *suffering subject* – the child or young person with RG-, the

---

<sup>5</sup> It is beyond the scope of this paper to provide a history of the development of the hGH industry (for this see Medeiros, 2016).

<sup>6</sup> Morrison (2015: 305) refers to the 'pharmaceuticalisation of short stature'.

*source/cause of suffering* –the body with RG- and the *means to alleviate the suffering* –the hGH treatment. Here I take a pause to think of how the suffering subject is produced, where the problem of suffering lies (is the body the ‘real’ source of suffering?) and what the implications of the means used to alleviate suffering are. To think these questions through, I engage with Cadwallader’s (2007: 389) work, who proposes an understanding of suffering ‘as fundamentally political experience’<sup>7</sup>.

Cadwallader (2007: 375) critically interrogates the suffering ‘experienced by subjects who deviate too far from a culturally defined norm’, considering ‘the relation’ suffering ‘bears to normalcy’. For Cadwallader, ‘to understand this suffering simply as natural, neutral response to something that is neutrally, naturally “wrong”, ignores the way that suffering and happiness are intimately bound up, conceptually, discursively and experientially with abnormalcy and normalcy’ (p. 389). She identifies two major functions of suffering: ‘first, it individualises subjects, and reinforces this through making the problem of suffering their own responsibility; and second, it operates as a motivation for subjects to seek (techniques of) normalisation’ (p. 389). Not only is the problem of suffering located on the individual(’s) body, but the responsibility for doing something about it also lies on them as ‘responsible’ individuals (or their parents in the case of children and young people).

The invention of normalising treatments also played a key role in the individualisation and normalisation of suffering. With the availability of normalising treatments, suffering operated as the perfect motivation or even compulsion for individuals to normalise. Individual normalising treatments are a quicker and surer fix for suffering than cultural change, and normalisation becomes practically the only responsible choice a sufferer can make, especially given that the refusal to normalise is characterised as even more deviant (ibid: 391).

Such a treatment for children and young people with RG was the hGH (Morrison, 2015), which was supposed to align their short body with what was (and still is) deemed by the physician as ‘normal’: that is, to achieve the ‘normal abnormal’ (Mallet and Runswick-Cole, 2016). What the treatment with hGH did was to conceal the social structures and dominant ideologies of, for instance, heightism and ableism, that (re)produced the body with RG as a problem and as a suffering subject in the first place (Allen and Frost, 1990). As Adelson (2005b: 146) proposes, ‘“fixing” the stigmatized individual rather than mending society’s attitudes becomes legitimized as the best way of avoiding society’s rebuff’.

## Conclusion

This paper had two aims: firstly, to interrogate the construction of the suffering child/young person with RG through medicalised, psychologised, deficit discourses; and secondly, to consider critically the medicalised responses to this construction and their implications. I argued that by locating the problem of present (and future) suffering on children’s bodies -or as Hughes and Paterson (1997: 336) put it, ‘disability as oppression becoming embodied as suffering’ - pharmaceutical interventions on their bodies became a legitimate means to alleviate such suffering.

However, I am left wondering to what extent such responses are not the solution, but are actually part of the problem, as they obscure the social roots of such suffering and,

---

<sup>7</sup> On that matter, see also Clare (2017).

therefore, hinder the necessary structural and cultural changes. Finally, this paper has demonstrated non-disabled people's fixation with fixing what they (have) construct(ed) as the abnormal body. As Curran and Runswick-Cole (2014: 1625) propose, it might be worth 'turning the gaze away from scrutinising the lives of disabled children and to analyse instead the reactions of non-disabled people to disabled children's lives or 'to pathologise 'the normals' among us' (Goodley and Lawthom 2013, 176)'.

## References

- Abbott D, Rotnem D, Genel D, Cohen D. (1982) Cognitive and emotional functioning in hypopituitary short-statured children. *Schizophrenia Bulletin*, 8, 310-319.
- Adelson, B. (2005a). Dwarfs: The changing lives of archetypal 'curiosities'—and echoes of the past. *Disability Studies Quarterly*, 25(3).
- Adelson, B. M. (2005b). *Dwarfism: medical and psychosocial aspects of profound short stature*. JHU Press.
- Allen, D. B., & Fost, N. C. (1990). Growth hormone therapy for short stature: panacea or Pandora's box?. *The Journal of Pediatrics*, 117(1), 16-21.
- Cadwallader, J. (2007). Suffering difference: Normalisation and power. *Social Semiotics*, 17(3), 375-394.
- Chaplin, J. E., Kriström, B., Jonsson, B., Hägglöf, B., Tuvemo, T., Aronson, A. S., Dahlgren, J. & Albertsson-Wikland, K. (2011). Improvements in behaviour and self-esteem following growth hormone treatment in short prepubertal children. *Hormone Research in Paediatrics*, 75(4), 291-303.
- Claire, E. (2017). *Brilliant Imperfection: Grappling with Cure*. Duke University Press, Durham.
- Conrad, P., & Potter, D. (2004). Human growth hormone and the temptations of biomedical enhancement. *Sociology of health & illness*, 26(2), 184-215.
- Curran, T., & Runswick-Cole, K. (2014). Disabled children's childhood studies: a distinct approach? *Disability & Society*, 29(10), 1617-1630.
- Cutler, L., Silvers J. B., Singh, J., Marrero, U., Finkelstein, B, Tannin, G. and Neuhauser, D (1996). Short Stature and Growth Hormone Therapy: A National Study of Physician Recommendation Patterns. *JAMA*, 276 (7), 531–537.
- Dowdney, L., Skuse, D., Heptinstall, E., Puckering, C., & Zur-Szpiro, S. (1987). Growth retardation and developmental delay amongst inner-city children. *Journal of Child Psychology and Psychiatry*, 28(4), 529-541.
- Downie, A. B., Mulligan, J., McCaughey, E. S., Stratford, R. J., Betts, P. R., & Voss, L. D. (1996). Psychological response to growth hormone treatment in short normal children. *Archives of disease in childhood*, 75(1), 32-35.
- Foucault, M. (1975). *The Birth of The Clinic*. Vintage Books, New York.

- Gordon M., Crouthamel C., Post E.M., Richman R.A. (1982). Psychosocial aspects of constitutional short stature: Social competence, behaviour problems, self-esteem, and family functioning. *Journal of Pediatrics*, 101, 477–480.
- Hughes, B. & Paterson, K. (1997) The social model of disability and the disappearing body, *Disability & Society*, 15(4), 555–568.
- Kruse, II, R. J. (2003). Narrating intersections of gender and dwarfism in everyday spaces. *Canadian Geographer/Le Géographe canadien*, 47(4), 494-508.
- McLaughlin, J., & Coleman-Fountain, E. (2014). The unfinished body: The medical and social reshaping of disabled young bodies. *Social Science & Medicine*, 120, 76-84.
- Medeiros, A. (2016). *Heightened expectations: The rise of the human growth hormone industry in America*. University of Alabama Press, Alabama.
- Money, J., & Pollitt, E. (1966). Studies in the psychology of dwarfism: II. Personality maturation and response to growth hormone treatment in hypopituitary dwarfs. *The Journal of Pediatrics*, 68(3), 381-390.
- Morrison, M. (2015). Growth hormone, enhancement and the pharmaceuticalisation of short stature. *Social Science & Medicine*, 131, 305-312.
- Morrison, M. (2019). Valuing height: diagnosis, valuation and the case of idiopathic short stature. *Sociology of health & illness*, 41(3), 502-516.
- Oliver, M. (1990). *The Politics of Disablement*. London: Macmillan.
- Rotnem, D., Genel, M., Hintz, R. L., & Cohen, D. J. (1977). Personality development in children with growth hormone deficiency. *Journal of the American Academy of Child Psychiatry*, 16(3), 412-426.
- Stabler, B., Whitt, J. K., Moreault, D. M., D'ercole, A. J., & Underwood, L. E. (1980). Social judgments by children of short stature. *Psychological reports*, 46(3), 743-746.
- Stabler, B., Siegel, P.T., Clopper, R. R., Stoppani, C.E., Compton P. G. & Underwood L. E. (1998). Behavior Change after Growth Hormone Treatment of Children with Short Stature. *The Journal of Pediatrics*, 133 (3), 366–373.
- Stace, L., & Danks, D. M. (1981). A social study of dwarfing conditions I. The reactions and questions of parents of children with bone dysplasias. *Journal of Paediatrics and Child Health*, 17(3), 167-171.
- Theunissen, N. C., Kamp, G. A., Koopman, H. M., Zwinderman, K. A., Vogels, T., & Wit, J. M. (2002). Quality of life and self-esteem in children treated for idiopathic short stature. *The Journal of Pediatrics*, 140(5), 507-515.
- Thompson, S., Shakespeare, T., & Wright, M. J. (2008). Medical and social aspects of the life course for adults with a skeletal dysplasia: a review of current knowledge. *Disability and rehabilitation*, 30(1), 1-12.
- Thomson, R. (1996). Introduction: from wonder to error—genealogy of freak discourse in modernity. In *Freakery* (ed R. Thomson). New York: New York University Press, 1–19

Visser-van Balen, H., Geenen, R., Kamp, G. A., Huisman, J., Wit, J. M., & Sinnema, G. (2007). Long-term psychosocial consequences of hormone treatment for short stature. *Acta Paediatrica*, 96(5), 715-719.

Wilson, D.M., L.D. Hammer, P.M. Duncan, S.M. Dornbusch, PL. Ritter, R.L. Hintz, R.T. Gross, and R.G. Rosenfeld. (1986). Growth and intellectual development. *Pediatrics*, 78, 646-650.

## Chapter 19: Being in the room

### Jo Billington University of Reading

As an autism researcher who is highly critical of the medical model of disability that historically dominated the field of psychology in which I work, I was delighted to be invited to the Disabled Childhood Studies International Symposium hosted by iHuman and ESRC Living Life to the Fullest Project at the University of Sheffield in January 2020. The presentations and lively dialogue among the attendees allowed me to engage with a broad range of perspectives not commonly discussed within my own academic field. My research focuses on the lived experience of autistic children in mainstream schools and seeks to place children at the heart of the research process. My work is predicated on the primacy of the autistic voice and as such, I felt much more at home with the ontological and epistemological foundations of the symposium than with the positivist principles that have tended to underpin psychological autism research.

During her summing up of the symposium, Professor Katherine Runswick-Cole took time to thank to the people who had 'been in the room' - those who were physically present, those who had contributed virtually such as Sally Whitney, and scholars such as Kirsty Liddiard who, although unable to attend, had been very much present in the ideas and themes discussed across the two days. However, for me, Katherine's comment had a different significance. It prompted me to reflect on my own feelings about being in the room. It connected with the sense I have always had about being an outsider in matters relating to the lives of disabled children despite being parent to two disabled children myself. As Ryan and Runswick-Cole (2019: 1126) have observed, non-disabled mothers of disabled children can find themselves in "a liminal space betwixt and between 'proper' motherhood and 'proper' disability activism, and this has been evident in the struggles I have experienced while trying to establish myself as a legitimate voice in matters relating to the lives of my children. I need to stress that my outsider status isn't something I think I intrinsically have: it's not something I have created for myself. Rather, it has been constructed through my experience of years of not being taken seriously.

Please allow me to explain. I am not a 'typical academic' in similar ways to which my children are not 'typical children'. Of course, 'typicality' is a problematic concept - just one the threads in the tapestry of the symposium - but I see myself as 'other' in academia as I do in much of the rest of my life. Rather than this being a long-held career plan, I came to academia in middle-age looking for a way to legitimise (that word again) my anger and outrage at the injustices my children have faced throughout their lives. At the start of my PhD, I remember thinking, 'If I can just channel this anger into something productive, maybe I can get through this'.

And what is 'this'? Well, for me, it's largely about fighting for justice. It's about arguing that the truth that has been presented about my children is not their truth, is not our truth. It started with trying to persuade our GP that the difficulties my child was facing and the distress he was experiencing were cause for concern and not dismissal. We needed care and support, not blame and derision. It then became about gathering 'evidence' of various

sorts in order to add support for what I knew to be true because my testimony wasn't evidence enough. It was about having to fight for validity. It was also about a lot of closed doors. Getting to be in the room is a struggle for many families like mine and continues to dominate the narrative around the support autistic children receive, or don't receive (e.g. Crane et al., 2016; National Autistic Society, 2017; Ryan & Runswick-Cole, 2009; Siklos & Kerns, 2006).

There is no doubt in my mind that one of the driving forces behind applying to do a PhD was the need to establish myself as an 'expert' in a system in which professional knowledge is privileged over parental knowledge (Hodge & Runswick-Cole, 2008). After so many years of being dismissed as someone who lacks credibility, my PhD is in some way an attempt to address the power inequalities I have experienced in my role as a parent. It is a response to the years of not being taken seriously and not being allowed in the room.

The rooms I have had to fight to get into: the clinics of paediatricians, speech and language therapists, occupational therapists, psychologists, the offices of headteachers, special educational needs co-ordinators, learning support specialists, outreach workers, social workers, primary mental health workers, local authority commissioners ... the list goes on. Of course, there have been times when, once in the room, the sense of disappointment and futility has been overwhelming. But there have also been times when it has been life-changing. The feelings of frustration are still there though. Why did it take so many years to get this meeting/this outcome/this person to listen to me?

Yet here I was, in a room of deep thinkers, agitators and agenda-setters. A room I didn't have to fight to get into. A room to which I had been specifically invited and warmly welcomed. A room where my relative lack of discipline-specific knowledge was celebrated rather than maligned. Where I could contemplate what was known and unknown to me without fear of ridicule or embarrassment. A room where diversity of thinking was not only encouraged but expected.

The papers presented during the symposium touched on ethics, consent, co-production and the importance of placing the lived experience of the child at the heart of research. Every paper presented underlined the importance of access and participation. Central questions related to what it means to be human featured large in the conversations. Again, this resonated with me in interesting ways when framed against the dehumanising consequences of the education and social care system which play out daily in my home. I felt emotional at times because the scholars in the room were promoting the very basic human dignities I have not often experienced in my advocacy for my children but which I strive for in my research. Their consideration and careful contemplation of what it means to be human for disabled children and their families is something that moved me deeply and will stay with me.

## References

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism, 20*(2), 153-162.

Hodge, N., & Runswick-Cole, K. (2008). Problematizing parent–professional partnerships in education. *Disability & Society*, 23(6), 637-647.

National Autistic Society, (2017). All Party Parliamentary Group report, Autism and Education in England. Retrieved on 11/03/20 from <https://www.autism.org.uk/~media/nas/documents/get-involved/held-back/appga-autism-and-education-report>

Runswick-Cole, K., & Ryan, S. (2019). Liminal still? Unmothering disabled children. *Disability & Society*, 34(7-8), 1125-1139.

Ryan, S., & Runswick-Cole, K. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 43-53.

Siklos, S., & Kerns, K. A. (2006). Assessing need for social support in parents of children with autism and Down syndrome. *Journal of autism and developmental disorders*, 36(7), 921-933.