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Brief Final Thoughts…

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In writing this book, I set the authors an almost impossible challenge. Not only were they tasked to condense their vast knowledge and subject expertise into chapters of no more than 6000 words, but the time frame to completion was relatively short. You may appreciate that this has not been easy. As a consequence, within our department (we work together within the Division of Children, Young People and Education at the University of Suffolk) there has been much low-volume grumbling about stifling word count, ridiculously short deadlines, and the impact that teaching, marking and research priorities have on editorial deadlines. For this, I apologise. However, the professionalism and dedication of my colleagues has made my job as editor relatively easy and very enjoyable. I, for one, think we have done an incredible job and am very proud of the outcome.

In our endeavour to seek an understanding of dis/abled childhoods, we have produced a discursive text that challenges the norm. It crosses disciplinary boundaries and troubles ideas that have been taken for granted. This was our intention. We set out to widen our understanding of disabled

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children's childhoods, not close them down. Indeed, we railed against compartmentalising debates by deliberately opening them up for discussion and debate. In doing so, we have challenged the orthodoxies fixed within the fields of disability and childhood studies. Through emphasising inter-connectedness both within and across disciplines, and refusing to prioritise one set of ideas over another, we hope that we have unsettled the more traditional conception of childhood. Drawing on Goodley and Runswick-Cole's (2016:2) theoretical ideas of being human, we have extended and expanded what childhood means by 'dissing' (or disrespecting) the 'normative, rational, independent, autonomous subject'.

Our journey into childhood and disability within this volume has been an interesting and insightful one. We have critically analysed and evaluated key issues and different perspectives relating to both disciplines for, as suggested within the Introductory chapter, we believe that they are established enough to withstand robust criticism. For example, in Chap. 2 Sarah Richards emphasises the relevance of social policy to critical disability and childhood studies. Tracing the significant historical policy shifts in the care of disabled children, she uses value-laden concepts purposefully to interrogate the ways in which welfare is produced and to whom it is given. She argues that good intentions for support and inclusion often lead to practices which exclude and marginalise. Disrupting ideological and conceptual frameworks that emphasise individualised definitions of agency, independence and inclusion, Sarah suggests that a more effective way to pursue inclusion is to encourage practices that have an ethic of care and an ethos of social justice at their core. Through discussion and debate, she advocates that this, alongside their need for political advocacy and rights movements to further highlight social injustices will encourage and enrich social relatedness and interdependency between children and parents, professionals and individual, families and the state.

Building on the rights perspective introduced by Sarah, Pere Ayling argues that despite decades of national and international attempts to protect the rights of children and adults, disabled people do not yet enjoy full citizenship and are still perceived as not having equal worth as their non-disabled counterparts. In Chap. 3, Pere disrupts the idealised notion of equality by interrogating the complex and inter-connected concepts of diversity and rights, applying them to dis/abled childhoods. Arguing for an equal outcome approach that correlates with human rights principles of enablement, social justice and human dignity, Pere contends that understandings of disability and childhood should be further examined through human rights lens. More specifically, however, she suggests that looking at disability through a human rights framework will shift the debate from individual pathology (medical model) to the social construction (social model) of disability. Rather than seeing disability as arising from alleged 'deficiencies', Pere frames it within a human rights perspective, revealing how disability is actually a by-product of the interactions between people with impairments and unfavourable socio-economic and environmental factors.

Placing the individual at the centre of discussions, Cristian Dogaru draws on the interactional model of disability to focus on the effects that impairments may have on children and their childhoods. In Chap. 4, he debates and discusses the definitions and classification systems of impairment, and whilst acknowledging the value laden use of language when describing impairment and disability, Cristian argues that the context of impairment cannot be divorced from disability. Steering away from the 'deficiency' model and aligning himself with an interactionist view, he has carefully and respectfully navigated through what Bhaskar and Danermark (2006, p. 280) suggest is a 'necessarily laminated system' that represents the complex reality of disability.

Ferran Marsa-Sambola continues the theme of the individual in Chap. 5 where he explores the ways in which disability impacts on self-identity. Drawing on qualitative and quantitative research, Ferran examines the main factors associated with the development of what he terms as 'disability identity', arguing that communal attachment, affirmation of disability, disability identity politics and activism, and personal meaning of disability are formed and maintained through childhood and adolescence. He concludes that further investigation as to how sociodemographic and clinical factors impact on personal and social development is needed, suggesting that reframing negative aspects of impairment into positive characteristics is necessary to develop adequate ways to empower disability identity.

Utilising a framework based on popular culture to support the discussions in Chap. 6, Jessica Clark considers some of the foremost ways in which the figure of the disabled body circulates both challenging and reifying dominant imagery of disability. Here, she reconnects with the body and emphasises the importance of the corporeal for theorising about disability and for understanding the experiences of individuals. Contributing to the resurgence of interest in the bodies of children, and acknowledging that cultural and mediatised images are influential in shaping young people's identities, she examines how disabled children and young people are represented through popular culture. Jessica argues that traditionally the media have dis/represented disabled children and young people as malevolent, villains, scroungers and the subjects of charitable benefaction for so long that they are now perceived as having natural rather than cultural origins. She also suggests that the images of immorality, pity and dependency play a significant role in marginalising and excluding disabled children and young people. Taking time to rethink cultural dis/representation, Jess suggests refashioning popular culture in such a way that new technologies, new programming formats and content and greater participation of disabled people themselves in cultural production is the way forward to place greater emphasis on disability as part of a continuum of the embodied experience of childhood.

The theme of dis/representation continues in Chap. 7, where the editor, Allison Boggis argues that attitudes and belief systems of disability and childhood impact on the social dis/positioning of disabled children to such an extent that it renders them more at risk of being abused. Building on Jess's observation that popular culture embodies disability and impairment mostly in a negative way, she suggests that this discourse is so deeply embedded in historical, social and political practices that the dominance of abled bodies over disabled bodies is maintained. It is this that is at the very centre of the abuse and violence directed towards disabled children and young people. However, as childhoods continue to be ‘dissed’ through abuse and violence, and little is known about what happens to disabled children that have been abused, Allison advocates that disabled children should be a central part of the safeguarding process of change by empowering them to voice their opinions and exercise their rights to feel fully and safely included within their communities.

Garfield Hunt then takes up the mantle in Chap. 8 where he explores key debates in relation to the concept of early interventions. Drawing on arguments posed by both Sarah Richards (Chap. 2 this volume) and Pere Ayling (Chap. 3 this volume) Garfield uses an ecological lens to examine the complexity and diversity of family lives, emphasising the notion of rights and negotiation to bring about self-advocacy and empowerment.

Educating our children has been a central notion of cultural importance in the UK for centuries. Nurturing our successors to become fully fledged, financially independent citizens is synonymous of what has become known as a 'good' education. However, it would seem that a 'good' education is prioritised for some and not for others. Vanessa Rawlings reflects on what she terms as a 'healthy' debate and constructive criticism of the education system in the UK within Chap. 9. Whilst not doubting professional's engagement, commitment and passion for upholding all children's rights to an appropriate education, Vanessa illustrates the somewhat chequered history of the provision of Special Education, critically evaluating the 'one-size-fits-all' approach to inclusion. Vanessa's thoughts on current education policy and provision are disruptive, for she highlights the need for significant changes to be made within the education system and advocates a more social justice-based approach. This, she argues, will support educational attainment for all (not just some) and ensure that educational content, support and interventions are effective, appropriate and regularly evaluated for meeting individual educational needs.

A common thread that weaves throughout this volume is the marginalisation (and sometimes exclusion) of disabled children's voices. All authors agree that further research into disabled children and young people's lives and lived experiences is clearly needed. The penultimate chapter, written jointly by Sarah Richards and Jessica Clark, examines the trajectory of disability research in relation to children and childhoods. Through discussion and debate, they critically reflect on the ways that imposed passivity of disabled children and young people have impacted on their agentic participation within research. Whilst celebrating that greater prominence is now given to the voices of disabled children and young people within participatory research, they point out that rarely is the subject matter outside of disability and into the realm of childhood more generally, or topics not related to childhood at all. Sarah and Jess advocate that children should be included in research as a matter of course and it will only be then that we can claim that children are actively involved in research, and the rhetoric of inclusivity is realised.

The choice of title for this book *Dis/abled Childhoods? A Transdisciplinary Approach* has ruffled a few feathers within the academy. It appears that the transdisciplinary part is acceptable, but that the use of the term dis/abled childhoods are not. Childhoods are not disabled, we have been told. We dis/respectfully dis/agree. Whilst childhoods are fascinating and offer an insight into what it is to be human, they are diverse and impacted on by a variety of influences. As authors and scholars, we cannot collectively agree on what childhood is, but one thing we do agree on is that phenomenologically, it should never become normative, rational, rigid and narrow. Including disability within our discussions and conversations about childhood will be disruptive and challenging but will help us not only to think critically about what it means to be a child but also more about childhood as a whole.

Of course we acknowledge that disabled children's childhoods are not all disabled. We also understand that suggesting that childhoods are dis/abled is not particularly comforting. None the less, in support of our potentially controversial position, we turn to the academic literature which illustrates the ways in which individuals, institutions, organisations, and debates marginalise, disregard or disempower disabled children and young people. Clearly, disabled children's inclusion, opportunities and life chances are impacted upon by societal attitudes and physical barriers. Arguably, if one is living in such circumstances, how can the 'hood' in which they are living, not be disabled?

References

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