

Understanding and Promoting Access for People with Learning Difficulties

Seeing the Opportunities and Challenges of Risk



EDITED BY
JANE SEALE
AND MELANIE NIND



Understanding and Promoting Access for People with Learning Difficulties

The issue of access is at the forefront of the practical challenges facing people with learning difficulties and people working with or supporting them. This engaging text brings together evidence, narratives and discussions that question and advance our understanding of the concept of access for people with learning difficulties. Seale and Nind draw on their expertise to analyse a wide range of situations, including access to public spaces, citizenship education, community participation and employment.

Through a series of related chapters, key experts in the field of inclusion and learning difficulties enrich the access debate by:

- considering what kind of access people with learning difficulties want;
- identifying effective practice in relation to facilitating and promoting access;
- revealing the capability of people with learning difficulties to seek and achieve access to potentially exclusionary communities;
- providing a space for a wide range of people to share access stories.

With contributions from a variety of stakeholders including people with learning difficulties, *Understanding and Promoting Access for People with Learning Difficulties* clarifies the concept of access without oversimplifying what is involved. Through rigorous critique, this book provides a unique rationale for a new multidimensional model of access and ways of promoting it.

Proposing a reconceptualisation of the risk associated with promoting access for people with learning difficulties, this book will be of immense interest to students, researchers and professionals involved in inclusion and disability issues.

Jane Seale and **Melanie Nind** work in the School of Education at the University of Southampton. Both Jane and Melanie have a strong track record of publishing in the area of inclusion and learning disabilities and of publishing edited works with Routledge and other publishers.

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Foreword

It is a pleasure to provide a foreword for this important text. Reading this book has highlighted for me not only the complexity of the concept of ‘access’ but also reminded me of the smoke and mirrors of policymakers, theorists, providers, researchers and practitioners who hide the key human necessity for access behind complex philosophical questions, conflicting interests and measurable service outputs. The contributions to this book, from people with the label of intellectual disabilities and their allies, make significant inroads into the complexities and, conversely, the simple message of access. It is of course important to understand access as a troubling concept both theoretically and practically. Yet access is at its most understandable – at its most accessible – when we demand that it is viewed in the political realm. Since the 1950s, it is possible to trace a growth in potency of the disabled people’s movement, through which people with the label of intellectual disabilities are challenging their exclusion from mainstream life. The key policy imperative in the UK, *Valuing People* (Department of Health 2001), is testimony not only to the emergence of a potentially more participatory worldview developed by policymakers, service providers and professionals, but is also a consequence of the agitations and activism of people with the label of learning disabilities who have demanded access to mainstream life. This book reminds us that we must keep their activism at the foreground of all debate. Without their involvement, access withers into a limited offering of well-meaning people, rather than a crucial element of meaningful community participation.

Access, then, is about recognition, inclusion and respect. It is also about humanity and the ways in which ‘normate’ cultures continue to exclude disabled people because they are deemed as the monstrous antithesis to what the critical psychologist Edward E. Sampson (1977) termed the ‘United-Statesian’ ideal citizen of contemporary life. Access is about challenging the norms of a society that privileges certain characteristics of human beings (autonomous and hyper-capable) and opening up more exciting, inclusive, connected, different (maybe disruptive and disrupting) ways of living life. Access is not simply about accessing the ordinary. It is also about embracing the diverse. This book shows that we should not forget the simple message of access that is often lost in wider

debates of an increasingly marketised and globalised welfare system and the growing governance of families, schools, workplaces and health care systems. Access is a useful concept and term that gets right at the heart of calls for the dismantling of disabling society. It is about people, their families, their allies and advocates, their potential and their ambitions.

As Nind and Seale argue in their excellent introductory chapter, access touches upon all aspects of human and social networks including physical access, knowledge, power, relationships, advocacy and participation. The contributors to this book address these networks in a variety of exciting and novel ways. Knowledge production on the part of people with learning disabilities and their representative organisations is key to accessing wider society. When we make knowledge accessible then it can be reacted to, as in the case of accessible forms of policy and legislation, considered by Walmsley. Access allows critical appraisal of dominant knowledge (synthesis) and, when necessary, rejection of knowledge (antithesis). The contributions of Walmsley and Aspinall illuminate different sides of knowledge production of people with the label of intellectual disabilities. Access is not simply about learning about knowledge out there in the world but also about criticising it and developing alternative ideas that are more in tune with the aims and ambitions of disabled people. The role of technology has long been recognised in the social sciences. Recent philosophical work suggests that technology opens up possibilities for the flattening of social hierarchies and the extension of relationships and commonalities (Lash 2001). The impact of multimedia, described by Aspinall, is clearly being felt on the web. Voices of people, whose ideas and perspectives have often taken second place to those of experts, fill the web with new possibilities for thinking about not only accessing mainstream life but also the meaning of mainstream life. A personal favourite of mine is the spoof website set up by people who identify as neurologically atypical, which describes how one can find out if they have the diagnosis of 'neurological typicality' (<http://isnt.autistics.org/>). This site for the 'Institute of the Study of the Neurologically Typical' turns ideas of difference on their head and asks us to think about the conditions that mainstream society places on those that it *allows* access to. Related to this, Abbott and Detheridge's chapter clearly indicates that an inclusive culture is a symbolising culture. The input of resources such as Widgit, alongside the potential of the web, open up different access routes for all people including those who are labelled as having intellectual disabilities.

This book also makes some very significant points about *what* is being accessed. The inspirational chapter by members of the Bracknell self-advocacy group, Aird, Dale, Edgecombe, Jones, Rowden, Sabine, Tyler, Waight and Wornham, provides some excellent advice for readers in terms of how leisure, education, work and healthy lives can be accessed. I was particularly struck by their comment that meaningful access is associated with 'not being bored'. This is a fundamental part of life that we must keep in mind. While self-advocacy groups have added markedly to the level of interest in the lives of their

members, other areas of the community continue to create non-stimulating and boring experiences for disabled people. Being bored equates with being disengaged. And disengaging with community often results in marginalisation. A way of addressing this marginality is through opening up culture and the arts through meaningful discussions with people with learning disabilities. The chapter by Rix with The Heritage Forum discusses not only the need for meaningful processes of participation but also the importance of cultural heritage in the lives of disabled and non-disabled citizens. The meaning of citizenship tugs at the very heart of the meaning of culture and access. Access to mainstream life might also be viewed as access to cultural and civic life. The history of people with the label of learning disabilities is a history associated with a questionable relationship with the notion of citizenship. Indeed, Manion and Bersani (1987) argue that the 19th and 20th centuries marked an increasing dehumanising of people with learning difficulties, to the extent that the status of citizenship conferred on people so labelled has increasingly become owned by disabling professionals and institutions. Even in these days of anti-discriminatory legislation, disabled people remain devoid of the rights afforded to all other citizens of society. I welcome Lawson's contribution on citizenship education because it tackles a key concern for us all: if we are accessing social and civic life, we need to be aware of the rights that this gives us as citizens. Being supported in this process of getting to know one's own citizenship is difficult and requires careful, thoughtful and facilitating modes of support described eloquently by Bradley, Clayton, Grant, Royall and Taylor. I enjoyed reading this chapter and found myself wishing that their identified areas of good practice be rolled out across a whole host of contexts: in work, education and leisure.

This book is also a timely reminder of the exclusionary and uncaring nature of the communities we still live in some 20 years after the major deinstitutionalisation of many adults with the label of learning disabilities was introduced in the UK. McConkey and Collins offer a sobering account of the meaning of community participation. While their argument is not all bad news, and points to the contributions that many people with learning disabilities make to our communities, the idea that access means communities letting in some and excluding others remains a strong tension. Community exclusion or inclusion is also a matter of life and death. As Mitchell notes in his chapter, the health needs of people with learning disabilities remain misunderstood and ignored. That is why the input of experts, such as Butler who describes his contribution in Chapter 11, is more necessary now than it ever was. I was reminded of Bronach Crawley's oft-used statement in her work in the 1980s, that people with the label of learning disabilities are often a lot more useful to the empowerment of people so labelled than the most committed non-disabled advocate. The final chapter of this collection, by the editors, takes up the lessons provided by the contributors to rethink access in terms of productivity, possibility, resilience and interconnectedness. This is a brave piece of writing that not only aims for theoretical coherence and innovation but argues for a new kind of attitude around

access. Seale and Nind suggest, for example, a new model of risk that in itself takes risks, leaps of faith and tolerates serendipity. Theirs is a strong message of capacity: to view the potentiality of people with learning disabilities as they seek access to mainstream society. It is only right that all societal members start to think of how they support the access of all and to question exactly what it is that we are accessing.

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Preface

The contributions in this book cover a range of different perspectives: from researchers, to advocates, practitioners and of course self-advocates. This variety brings with it differences in style and language. Readers will therefore notice that some authors use the term ‘learning disability’, others use ‘learning difficulty’ or ‘intellectual disability’. However, rather than insist on uniformity we have decided to embrace the diversity and to interfere with the ‘voice’ of our authors as little as possible.

Introduction
