Chapter 14
Inclusivity and Research: Capturing the Lived Experiences of Young People with Disabilities

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ABSTRACT
This chapter seeks to stimulate thinking and reflection by exploring the position and place of young people with disabilities in research. In doing this, the authors contextualize the chapter within the subject area of physical education. By mapping out the research terrain of young people with disabilities they find these young people have been marginalised and often precluded from research. More recent developments around ‘inclusive research’ do signal the possibilities for research and the benefits of actively engaging with young people with disabilities. They extend discussions in this chapter by highlighting how teaching and learning in Higher Education can draw on this kind of inclusive research in order to develop ‘narratives’. These are stories based upon research data from young people with disabilities. In particular, the authors present two examples of research narratives and discuss how these can be used in teaching and learning to promote student thinking around the meaning and experiences of physical education for young people with disabilities.

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**INTRODUCTION: ‘A LIFE APART’**

In 1972 Miller and Gwynne published *A Life Apart: A pilot study of residential institutions for the physically handicapped and the young chronic sick*. This book focused on case study research in five residential establishments in Britain. The research included observations of the day-to-day activities within these institutions and interviews with staff, volunteers and residents. At the time of publication, the research discussed in this book was the first that sought to capture the experiences of living and working in residential institutions. Although written nearly forty years ago we believe this text remains a compelling read as it draws attention to a number of issues which were significant then and remain equally important to contemporary debates and discourses around disability within society. In particular, *A Life Apart* offers powerful insights around: inclusion and exclusion; the challenges of engaging in disability research; and the importance of sharing the life stories of people with disabilities. Of course, a major shift in the UK since the publication of *A Life Apart* has been the deinstitutionalization of people with disabilities and a move towards independent living and inclusion within the community. To a large extent these changes have supported a shift in thinking in which people with disabilities are becoming increasingly recognised as legitimate members of society. This is in stark contrast to the conclusions made by Miller and Gwynne (1972, p. 80) about people with disabilities within the residential establishments they researched:

> To lack any actual or potential role that confers a positive social status in the wider society is tantamount to being socially dead. To be admitted to one of these institutions is to enter a kind of limbo in which one has been written off as a member of society but is not yet physically dead. In these terms, the task that society assigns—behaviourally though never verbally—to these institutions is to cater for the socially dead during the interval between social death and physical death.

This rather poignant account portrays people with disabilities as possessing little value and having no meaningful purpose in life. In part, this analysis should serve as a powerful reminder of the ways in which people with disabilities have historically been marginalised within society. During the interim period since the publication of *A Life Apart*, the position of people with disabilities has continued to be (re)negotiated and to a large extent the catalyst has been the drive for a more inclusive society. Indeed, recent legislative and policy developments promoting inclusion and equity have gone some way to redressing inequalities (Slee, 2009). For example, the Equity Act (2010) requires public bodies to develop an equality scheme and action plan in order to demonstrate how people will be protected from discrimination and how equality and diversity will be promoted across the key equality strands, including disability. However, it should also be acknowledged that the legacy of discrimination remains ever present within contemporary society (Lakinski, 2008).

As well as providing a powerful reminder of a move from exclusionary and segregated living to more inclusive community contexts, *A Life Apart* also offers important insights into the processes and politics of doing research about the lives of people with disabilities. Indeed, since its publication, this book has provoked considerable debate about the role of researchers, power relations within research and inclusive approaches to data collection (Baker, Lynch, Cantillon, & Walsh, 2004; Mercer, 2002). Most notably, Hunt (1981) labelled the researchers, Miller and Gwynne, as ‘parasite people’, and claimed researchers were on the side of the oppressors, interested in their own research careers and consequently exploiting people with disabilities. These observations and discussions, stimulated through the *A Life Apart* research, also raise important questions about
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