FROM SPECTATOR TO “SPECTACTOR”


Claire Penn, Jennifer Watermeyer, and Joanne Barratt
Health Communication Project
School of Human and Community Development
University of the Witwatersrand
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This is an unexpected, creative and delightful book filled with interesting and relevant information pertaining to living with disability. It aims to portray disability as ordinary and everyday, and through the use of challenging photographs sheds an understanding on societal and medical approaches to disability and on the human tendency to be “thrilled” by the extraordinary.

It sets out to elicit thinking and debate, and that it very effectively does. In fact we believe that at times it does more than that. The content might often be construed as controversial and often elicits discomfort even for those who are used to working with disability. The use of the terms “freak show / freakishness”, for example clearly highlights a goal to expose an intense social approach to disability. It certainly provides a novel perspective and with the aid of the beautiful photographs of Angela Buckland, tests the reader’s comfort zone continually.

The book is aimed at a wide audience and encourages from that audience, an attitude of reflexivity. While it is clear that parents and health care professionals are included in this range of readers, the content itself sometimes highlights the “us and them” interface which occurs especially in the section on encounters with the medical profession. This presentation and juxtaposition of material makes an impact and elicits powerful emotional responses.

Sometimes these responses and the quotations of parents are over-explained and the reader is almost told how to feel about the photos. Thus at times the interpretations from the academics seem less real and convincing than the interpretations of the photographer herself. There is a strong and relevant academic basis to the text, but it seems less engaging than the narratives and the photographs. Perhaps after all, this is what the experiment was all about. There are tricky topics tackled – ethics, disclosure, and stigma and it is certain that in general, the academic medium on these topics cannot possibly represent or explain these issues fully. Our role in this text thus
becomes interactive, not just the spectator but also to what Boal has described as the “spectactor”.

Stories need to be told. Sometimes they are difficult to tell, sometimes difficult to read, to see and understand. The multiple perspectives offered in this text offer insight into why these difficulties exist. The marrying of the lay perspective with the academic voice and the blend of verbal and visual material is exciting.

In short, this is a different book. It is not a neutral book. It shocks and saddens and often challenges. As a fluid and novel lens on living with and through disability, it provides insights and many opportunities for reflection and should serve as a very different platform of discovery for the public and also for health professionals in training.