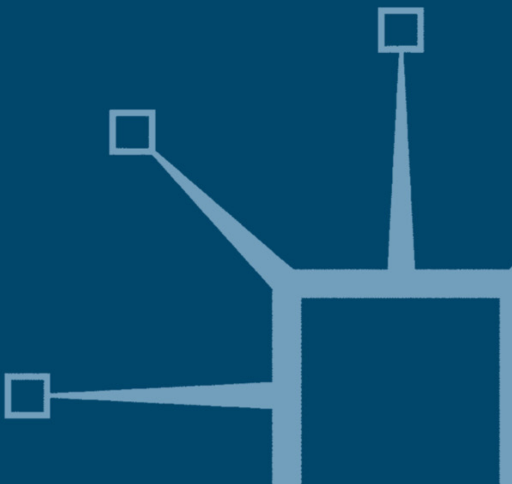
palgrave
macmillan

Parenting and Inclusive Education

Discovering Difference, Experiencing Difficulty

Chrissie Rogers



Parenting and Inclusive Education

This page intentionally left blank

Parenting and Inclusive Education

Discovering Difference, Experiencing Difficulty

Chrissie Rogers
Keele University, UK

palgrave
macmillan

Softcover reprint of the hardcover 1st edition 2007 978-0-230-01880-8

First published 2007 by
PALGRAVE MACMILLAN
Houndmills, Basingstoke, Hampshire RG21 6XS and
175 Fifth Avenue, New York, N.Y. 10010
Companies and representatives throughout the world

PALGRAVE MACMILLAN is the global academic imprint of the Palgrave Macmillan division of St. Martin’s Press, LLC and of Palgrave Macmillan Ltd. Macmillan® is a registered trademark in the United States, United Kingdom and other countries. Palgrave is a registered trademark in the European Union and other countries.

ISBN 978-1-349-28504-4 ISBN 978-0-230-59212-4 (eBook)
DOI 10.1057/9780230592124

This book is printed on paper suitable for recycling and made from fully managed and sustained forest sources. Logging, pulping and manufacturing processes are expected to conform to the environmental regulations of the country of origin.

A catalogue record for this book is available from the British Library.

A catalog record for this book is available from the Library of Congress.

10 9 8 7 6 5 4 3 2 1
16 15 14 13 12 11 10 09 08 07

For Sherrie

Contents

List of Tables and Boxes

Acknowledgements

Primarily I owe gratitude to all the parents involved in this research for sharing their private lives with me. Without this group of people the research would not have been possible, or as colourful! I would like to acknowledge the support of the Economic and Social Research Council (R42200034354) (PTA-026-27-0563). Without their support I would have been a very poor postgraduate student and postdoctoral fellow. I would also like to acknowledge that the *British Journal of Sociology of Education* has already published a paper by me and that small parts reappear here in this book.

I cannot thank Helen Lucey and David Morgan enough for their academic support and critical engagement with this work. They have been superb critics in aiding me to think through the final workings. I would like to thank both Jane Hindley and Pam Cox for their supervisory support during the PhD research, and Jackie Turton and Catherine Will for commenting on work in the early stages and listening to my insecurities. Thanks also to Ian Craib, Jane Ribbens McCarthy, Ken Plummer, Martin Richards, Nigel South and the 'Women's Workshop', who have all inspired or supported me in one way or another during the PhD and postdoctoral days.

I would also like to thank all those who have helped me to realise there's more to life than a PhD and academic research (not that I really needed much persuasion!) – to name a few; Ray Rogers (my Dad), Jacqueline Campion, Jackie and Graham Tuckwell, Helen Scott, Elaine Rogers and all my friends. However, my Mum, Shirley Rogers, has been the rock during all of this hard work.

Deepest thanks go to Eamonn Carrabine (fortunately also an academic!). He has listened to me go on about my work, my daughter and her related teenage angst. He has read and commented on earlier drafts and been there for me always. Significantly, he became my best friend, drinking partner, confidant and husband, and has supported me in all things related to my daughter and my academic life.

This research is, of course, dedicated to my daughter, Sherrie, who has been part of the narrative and listened to my never-ending, 'not now I'm working'. I hope that for a short while at least, I can now say, 'sure let's do it', before the next academic deadline kicks in!

Even with all this support, any comments I've chosen to ignore, and any mistakes that are evident in this book are of my own doing. Scarily for good, and for bad, only I can be solely responsible for the finished work.

List of Abbreviations

AD/HD	Attention deficit/hyperactivity disorder
AS	Asperger's syndrome
ASD	Autistic spectrum disorder
BSA	British Sociological Association
DES	Department of Science
DfEE	Department for Education and Employment
DfES	Department of Education and Skills
DLA	Disability living allowance
EBD	Emotional and behaviour difficulties
EP	Educational psychologist
GCSE	General Certificate of Secondary Education
IEP	Individual education plan
IQ	Intelligence quotient
LEA	Local education authority
LSA	Learning support assistant
MLD	Moderate learning difficulties
MMR	Measles, Mumps and Rubella
nasen	National association of special educational needs
NUT	National Union of Teachers
OCD	Obsessive compulsive disorder
OFSTED	Office for standards in education
OPCS	Office of population, census and surveys
PDD	Pervasive developmental disorder
PRU	Pupil referral unit
SATs	Statutory assessments tests/tasks
SEN	Special educational needs
SENCO	Special educational needs coordinator
SENT	Special educational needs tribunal
SLD	Severe learning difficulties
SPLD	Speech and language difficulties
UPIAS	Union of the physically impaired against segregation

1
Introduction

> Because I wanted it to be right this time and I suppose what it was is you have this fairy tale in your mind, where you get married and you have a baby and you push a pram around and you are going to have this beautiful baby that is gorgeous and lovely and cooing and all that, and it's just an illusion and it's just something that little girls have and then that illusion was shattered …
>
> (Kim, son with cerebral palsy)

> Maybe it [anti-depressants] would have helped me get through my depression quicker, I don't know. To me it's like no matter what drug I take I've still got the problem to deal with at the end of it. … But I've always liked to drink, but I went heavy at it … I hated coming home … I hated going to work …
>
> (Neil, son diagnosed with autistic spectrum disorder)

> I think it was so hard to be a parent of a child with special needs … you don't really know what to expect, you don't really know what to look for … and it's emotionally traumatic … you've got to *think* your child's different … I think that parents; … if their child's in mainstream school, their child's less different.
>
> (Stella, son diagnosed with a 'brain disorder', possibly on the autistic spectrum)

When we went to a birthday party a little girl got scratched on the eye, quite badly actually. He really did scratch her … the mother went absolutely berserk, and I was standing there trying to reason with her and say, 'you know I'm really sorry', and, 'my son has a speech and language problem, and he can't hear very well … and he has a problem with children around him', and she was saying things like, 'well that's not my problem that's yours'. Then I discovered I was struggling at this point trying to fight back the tears, trying to be in control, bearing in mind there were about 30 people standing around me all silent and her screaming at me.

(Kerry, two sons, one with verbal dyspraxia
and the other possibly dyspraxic)

[Speaking about mainstream education] I don't agree with it at all for children with speech and language problems, particularly with receptive disorders, because … they barely understand what the teacher is saying.

(Tina, daughter with speech and language difficulties)

As a member of the audience and a presenting delegate, I wait for the conference to begin. This particular one only happens every five years so is a big event for academics and education practitioners. The Inclusive and Supportive Education Conference (ISEC, 2005) is called 'Inclusive Education: Celebrating Diversity?' The opening ceremony begins and the room is filled with music and young people on the stage performing their interpretation of 'inclusive education'. They weave in and out, their bodies supple and mobile, their voices clear and their story profound. They sing and chant 'seize the day!' at the end of punctuated exclamations of 'individuality', 'sharing', 'creativity', 'SUCCESS!' A lump in my throat and a tear attempts to escape. I pretend I have something in my eye and look around to see if I'm the only one emotionally provoked. Either I was, or like me, everyone else was able to disguise his or her emotionality. This, after all is a serious event. I recall my daughter being on stage desperately trying to remember a

> line, and me willing her to … whatever … she was great. Back in the audience I'm sad and angry. I know that the philosophical underpinning of inclusive education is in some way right, or is it I ponder … but anyway is it not a little premature to celebrate it, when we haven't got there? I go back to my room and cry, for myself and for my daughter who will always be different and indeed difficult? I think about how the researcher and her self have merged: how I often go to conferences, as a sociologist and end up reflecting on my position as a mother.
>
> (Personal research notes, 2005)

Introduction

These windows into parents' lives capture just a snapshot of the dilemmas of becoming (and being) a mother or father with a 'disabled' child, as well as telling us something about policy discourse and practice within the context of social inclusion and, more specifically, 'inclusive' education. The stories that unfold in this book, from the very beginning, aim to capture in depth what it is like to mother a child with impairments and, more specifically, a child identified with 'special' educational needs (SEN), in a British context, with a view to contribute to debates on parenting, disability and education. What this book actually does is not only capture these sensitive parental narratives, but also create a sociological space to discuss in depth, issues about dealing with difficulty and, specifically, learning disability at both a theoretical and experiential level.

This research developed out of a desire to examine conflict and contradiction within education policy and how children identified with SEN were assessed and provided for. This concern arose from my own difficult experiences with mothering a learning disabled child, the education process and changes in education policies. While education policy and practice remained a central focus in the research, it became obvious as I carried out interviews with parents that their personal experiences of mothering were the driving force. The education process became secondary in relation to the mothers' and fathers' narratives, but it is so embedded in their experiences as their child reaches school age that it is difficult to separate the two.

With the above in mind, I have concentrated on gaining a picture of the whole experience of mothering an impaired child from pregnancy through to young adulthood. Not all the children in this study have reached adulthood yet, but listening to mothers and fathers who have been through and are going through this mothering journey has enabled me to obtain life course data. In addition to this, the actual interview process was in-depth and informal. It engaged with questions about parents' experiences, from how they felt about the birth of their child, their expectations and initial reactions to a diagnosis of impairment, to dealing with the transformation of their lives, including changing social relations and career prospects. Some of the parents in this research still have young children and are at the beginning of their mothering journey. Others, like myself, have young adults and can reflect on the education and social process so far.

Laying the foundations

Becoming a mother, or mothering (I use the term 'mothering' to describe a culturally recognised gendered role, but some fathers also take on a significant mothering role), a learning impaired child dramatically changes the expected horizon of what becoming a mother involves, her public performance and her private internal *and* external dialogues. Expectations of a certain norm – whether that is celebrating a birth, maternal bonding, returning to work, a child's healthy body, speech and language, hearing, sight, socially appropriate behaviour, academic ability, mainstream schooling, for example – means that some of the above expectations are shattered and the expectations of a normative life course are changed forever. Moreover (especially in the Western world), mothering has been explicitly associated with a private and personal life but has become publicly surveyed by health and education professionals. This process has not necessarily been driven by 'the professional', but by wider public policy and political and cultural discourses.

This book is based on the stories of 24 parents, all of whom have children identified with (or were in the process of being identified with) SEN. Definitions of SEN in England and Wales are based on a 'greater difficulty in learning than the majority of children of his age', or 'he has a disability which either prevents or hinders him from making use of educational facilities of a kind generally provided for children of his [*sic*] age in schools within the area of the local education authority' (DfEE, 1996). This book is peppered with some of my experiences in an attempt to merge my biography with the parents' stories, but what also emerges is the 'sociological imagination' that is widely referred to when discussing such matters as 'the personal troubles of milieu' and 'the public issues of social structure'. This distinction, according to Wright Mills (1959: 8), 'is an essential tool of the sociological imagination and a feature of all classic work in social science'. He suggests that the sociological imagination is brought to life by distinguishing between the personal and public, the micro world of experienced everyday life and the public issues that form part of the macro social world.

By studying the personal and private lives of individuals, questions and answers about the broader social picture – in this case, mothering, impairment, learning disability and SEN – can be asked and addressed. For example, we can address public issues about education policy and provision, social services, the medical profession and family practices. We can also address personal and private troubles about mothering, emotional angst, mental health and coping mechanisms. Importantly, concepts such as disappointment, denial and exclusion are drawn on and referred to in analysing such qualitative data and policy documents. Significantly, the two aspects of the private and public spheres experientially merge.

The private and personal narratives are the most important part of this research, as is the *telling* of intimate stories (Plummer, 1995). Certainly the stories in this book are an intimate window into lives lived. But the private world has often been mistaken for something that can only be studied psychologically or psychoanalytically, although the private world (experience) is an emotional response to the social world in relating it to the self and well-being. This is experienced both personally and in relation to the public self. My understanding of the private, personal and public has been aided not only by Wright Mills, but also by feminist researchers such as Ribbens and Edwards (1998). Women researchers have had to face criticism about their involvement and subjectivity when researching issues close to their hearts but continue to suggest, '[t]he central dilemma for us as researchers is that we are seeking to explore such privately based knowledges and personal understandings, but to then reconstitute them within publicly based disciplinary knowledge' (ibid.: 13).

Introducing disability

Throughout this book I deliberately use the word 'impaired/impairment' rather than 'disability', when referring to a child's condition, in order to stress an important analytical distinction. Impairment, as defined by the Union of the Physically Impaired Against Segregation (UPIAS) is 'the lack of a limb or part thereof or a defect of a limb, organ or mechanism of the body' (Oliver, 1996: 22). Disability is said to be 'a form of disadvantage which is imposed on top of one's impairment, that is, the disadvantage or restriction of activity caused by a contemporary social organization that takes little or no account of people with physical impairments' (ibid.).

Children's impairments are often problematised (Armstrong and Barton, 1999) and can be categorised in the Foucauldian sense (Foucault, 1973, 1980), but *experiencing* disability, according to Oliver (1996), is a result of social construction within a social model of disability. The parents I interviewed report that they experience both the actual difficulties that come with dealing with an impairment on a day-to-day basis and the disability via cultural and political spheres that feeds into these day-to-day experiences. It is an interrelated experience merging personal experiences or responses to childrearing in adversity, and the external forces of disabilism within the cultural and political spheres, based upon disadvantage and social/cultural perception. An important point to make here is that there are *actual* difficulties experienced by the parents that are directly related to their child's impairment and associated problems, *but* that the parents also experience disability as a social construction.

There are a growing number of medical and psychological terms for different kinds of impairments, such as Asperger's syndrome (AS), attention deficit/hyperactivity disorder (AD/HD), autistic spectrum disorder (ASD), cerebral palsy, Down's syndrome, dyslexia, dyspraxia and speech and language difficulties (SPLD), to name a few. Some children are classified as having low intelligence and others as having high intelligence. These labels in themselves may or may not be useful when it comes to the education of a child who has been diagnosed or identified with such impairments, but all the same, they can influence the inclusion/exclusion of the child (as too can the actual physiological/learning impairment).

The family can also be 'disabled', as a child's impairment often means the family is excluded and marginalised from certain social activities (Barnes et al., 1999; Gray, 2002). The mother, too, can become practically and emotionally 'disabled' in her new role as a mother with an impaired child (Baldwin and Carlisle, 1999). This is similar to those who have been diagnosed with a terminal illness (Sontag, 1991) or have sustained or developed a physical disability (Morris, 1991; Slack, 1999). The families in this research are a combination of single mothers or fathers, dual parents, mothers and stepfathers, siblings or only child; but all have in common a child or children with impairment in the family. However the family is formed, they are all 'disabled'.

Locating recent past and current policies

In carrying out this research and writing this book, it is important, because of the context within which the mothers and fathers who have participated in my research live – that of inclusive education policy and directives – to contextualise the policy discourse: the political sphere. 'The Warnock Report' (DES, 1978) defined SEN positively by dismissing the use of labels such as 'imbecile', 'feebleminded', 'maladjusted' and 'educationally sub-normal' and began to work on a continuum of need where children would be able to access mainstream education and work alongside their peers, with a greater involvement of the parents. (I realise 'need' is a subjective term and often dependent on the professional identifying it. However, for the present purpose I continue to use the framework of SEN as it remains within the narratives of both the parents and the professionals.)

The Warnock Report found that although only 2 per cent of school-age children had educational difficulties that affected them so severely that they could only be educated in a special school, 18 per cent were found to have some educational difficulties but were clustered in the bottom sets or placed in remedial classes within mainstream schools. The Warnock committee recommended (and it was agreed) that special help and protection was necessary for children with difficult or complex SEN. As a result of the report, it was suggested that certain children may need a statement of SEN, a formal process of identification and assessment in an attempt to highlight their difficulties and therefore make provision for those children. The Education Act 1981, which came into effect in 1983 (influenced by the Warnock Report), was based on the identification and assessment of a child's needs in order to make suitable provision for the education of all children.

The 1981 Education Act changed the whole concept of SEN. Special educational 'needs' replaced special educational 'treatment'. This was a conscious move to disregard the idea that learning difficulties and/or emotional and behavioural difficulties (EBD) were medical problems and therefore treatable. Instead, the emphasis lay on the individual needs of each child and on his or her educational potential. I would not dispute the educability of every child (in one form or other), however; this move from an impairment that is treatable to the education *potential* of a child means that education is placed above 'treatment' of an impairment such as physiotherapy, speech and language therapy or sensory therapy. A series of policy documents over the following years were introduced restructuring the education system. All mainstream schools were to provide education for children with SEN where possible. The emphasis was on 'where possible' and has been the loophole in excluding children with SEN since the 1980s.

In 1988 the Education Reform Act centralised power in the then Department of Science (DES) and invoked a national requirement for all children to reach certain academic standards at certain stages. This reform had a dramatic effect on SEN with the introduction and enforcement of the National Curriculum – which supported a homogeneous teaching structure. Children with different types of abilities would follow a similar, if not the same, curriculum nationally, and it was agreed that where possible children with SEN should have access to it. This meant that performance could then be tabled and inter- and intra-school competition encouraged. Nationally, levels of ability could be charted and a homogeneous curriculum could be followed. However, this does not allow for individuality or diverse and different abilities.

Maclure (1992: v) considers the 1988 Education Reform Act as by far the most important piece of education legislation since the Education Act of 1944. He argues that it changed the 'basic power structure of the education system'. The power that was once localised in local education authorities (LEAs) moved to central government, increasing the responsibility of the Secretary of State for Education and Science. The result was that the role of the LEAs in education had limitations in and around the whole structure of provision and they were in fact duty bound to give 'greater autonomy to schools and governing bodies' (ibid.).

Centralised power invoked a national requirement to reach certain academic standards at certain stages and ages. The 1988 Education Reform Act and the National Curriculum has encouraged

- Competition between schools and the public tabling of performances and targets.
- The charting of levels of ability.
- A homogeneous curriculum that could be followed by all children.

Since New Labour came to power in 1997 they have built on the previous government's policies. Raising educational standards has been prioritised, and this is reflected in educational policies within a discourse of high academic achievement and league tables. There are slightly less stringent requirements now for children with SEN to follow the National Curriculum rigidly. In certain cases, however, there are still fearsome debates around who should have access to it and that all children should have it available to them.

Other government directives include the *Excellence in Schools: White Paper* (DfEE, 1997b), in which raising British educational standards has been paramount. No one would dispute the aim of raising standards, but along with this are 'Oscar'-like rewards for teaching performance, zero tolerance for under-performance, league tables and the privileging of examination results. Here there is a clear conflict between inclusion and school performance. The pressure to sit and pass exams is experienced by parents via their children's experiences and education professionals' actions, as highlighted by Benjamin (2002: 43). 'Attention is focussed on the numbers and percentages of students scoring five or more passes at C grade or above, since this is the "expected level" and the benchmark for externally recognised success. It is also the measure used in compiling local league tables.' She goes on to reveal an example of this in a school staff room.

> Dave passes round the list of results from the top point-scorer to those who have scored no points at all. The room is full of exclamations – 'I knew she could do it!' 'Only three C's for Zina!' [. . .] I turn straight to the last page to see if Cassandra got any grades. She didn't get English Literature (which is no surprise) but she got an F in textiles. No one else on my row seems interested in the last page.
>
> (ibid.)

Not only are General Certificates of Secondary Education (GCSEs) grade C and above the externally recognised pass mark in England and Wales, it would seem that there are pressures to eliminate anything that may interfere with the efficient running of the education process, which has a negative impact on the inclusion of impaired children with SEN.

Furthermore, the Code of Practice (DfES, 2001a), the Education Act 1996 (DfEE) and the Special Education Needs and Disability Act (DfES, 2001b) all make up guidance or legislative directives for educating children with SEN. The last of these is supposed to bring together the SEN part of the 1996 Act and the Disability Discrimination Act 1995. Part 1 of the 2001 Act

- Strengthens the right of children with SEN to be educated in mainstream schools where parents wish it and where the interests of other children can be protected.
- Requires LEAs to ensure that parents of children with SEN are provided with advice and information and a means of resolving disputes with schools and LEAs.
- Requires LEAs to comply, within prescribed periods, with orders of the SEN tribunal (SENT), and makes other technical changes in support of the SENT appeals and statementing processes.