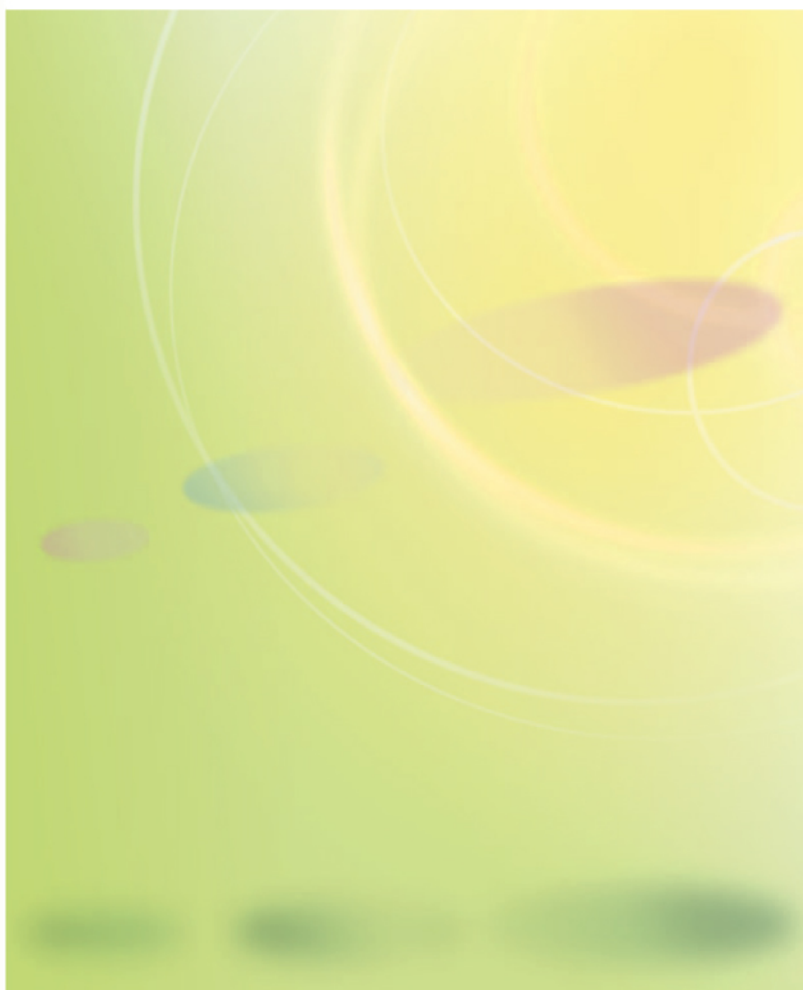


Mother-Teachers

Insights into inclusion



Barbara Ann Cole

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Preface

This book presents the stories of six women who are both mothers and teachers of children with special educational needs and/or disabilities. It sets the stories within relevant policy and sociological contexts which affect the lives of these women in their roles as mothers and teachers. It offers their experiences around a number of dichotomies, such as normality and difference, inclusion and exclusion, home and school, parent and professional, knowledge and experience.

It is not a 'how to do' book, but, rather through the stories, it seeks to offer to policy-makers and a broad range of educational, quasi-medical and even medical professionals, the lived experiences of the mother-teachers, with the intention of encouraging readers to reflect on their own professional understandings and practices in relation to children with special educational needs and disabilities. While the book acknowledges the wider policy and sociological context in relation to educational inclusion, it challenges professionals to explore the ways in which their own 'expert' processes and structures, 'knowledge' and understandings, might serve to maintain the reproduction of constructions of difference which exclude or 'other' some children and their families.

The stories draw on experiences from different sectors of education; mainstream primary and secondary; special day and residential schools and also initial teacher education. The children span a range of ages, from 3 to 24 years of age, and the experiences of the mother-teachers reflect this. Each story offers a section at the end of the chapter, which considers one aspect raised within the story for further discussion and reflection, but it is left to the reader to relate to the stories through the lens of personal experience. While the stories suggest many similarities of experience, they also challenge any notion of the women as a homogeneous group, as the discourses around them and their children might suggest. They hold different views on the meaning and nature of inclusion and special educational needs and

their experiences reflect these different understandings. But what emerges from the stories is their belief that individual professionals can make a real difference to the lives of their children. All these women have changed their professional practice as a result of being the mothers of children with special needs/disabilities. They reflect the view that 'professional knowledge' needs to be based, at least in part, on personal understanding and experience, which they maintain can develop through listening to parents who have a particular knowledge of their children. The stories demonstrate the importance of this shared understanding, if all children are to be truly valued and 'included'.

Introduction

The greater the fear, the more thinking you do. Yet she came closer to the truth than anyone else. Maybe that's how it works – that whatever is closest to the truth, you do not think about; you cannot reach it by achievement; you can only feel it ...

(Høeg 1996: 80)

The book and its context

This book is based on research with six women who are mothers of children with special educational needs/disabilities and who are also teachers of children with special educational needs (SEN). It contextualises their experiences of inclusion and exclusion against a political background of conflicting educational policies and a sociological background of powerful 'expert' discourses.

The last few years have seen the growth of policies aimed at raising the achievement of *all* children in mainstream educational settings. The most recent of these include the *Special Educational Needs Code of Practice* (DfES 2001), the Audit Commission's Report *Special Educational Needs: A Mainstream Issue* (DfES 2002), the Green Paper *Every Child Matters* (TSO 2003), and *Removing Barriers to Achievement: The Government's Strategy for SEN* (DfES 2004). All these documents state the government's commitment to safeguard and support the development and learning of all children wherever possible in mainstream educational contexts. The most recent of them (DfES 2004) commits the government to 'partnership working' to 'unlock the potential of the many children who may have difficulty learning, but whose life chances depend on a good education'. The Introduction makes clear that:

All teachers should expect to teach children with special educational needs (SEN) and all schools should play their part in educating children from their local community, whatever their background or ability. We

must reflect this in the way we train our teachers, in the way we fund our schools, and in the way we judge their achievements.

(ibid.)

In the spirit of this continuing and indeed growing commitment to a more inclusive approach to education, this book exhorts policy-makers and all those professionals involved in supporting the education of children with special educational needs/disabilities to explore outside their own professional 'boxes' and listen to the voices of those who, through their personal experiences, have particular and significant insights into issues of inclusion and exclusion. This book considers the voices of mothers and offers their insights on two levels, as mothers *and* as teachers of children with special educational needs/disabilities. I argue that while the rhetoric of policy has moved inclusion into the mainstream, in reality, for many children and their families, the experience of inclusion is very different. If the policy commitment is to translate into reality in our schools and classrooms, then I would argue that policies relating to inclusion, such as the training of teachers, the funding of schools and the assessment of achievement, must be informed by these voices of experience.

This is a book about lived experiences of inclusion and exclusion. Since the early 1980s 'inclusion' has been one of the key initiatives in education policy, internationally and in the UK, and the principal policy imperative in relation to children with special educational needs (Lindsay 2003). Emerging from the growing demand for equity and social justice, inclusion requires changes in the structures and processes of mainstream educational institutions to meet the needs of all children within an educational system which values and respects difference as diversity rather than deviance. It also requires the support and determination of parents and professionals if it is ever to become a reality for thousands of children in the UK.

Within the official discourse of inclusion, the development of home-school relations has been signalled in the official discourse as a significant way to ensure a more equal partnership between parents and professionals. Indeed, since the 1981 Education Act, numerous policy documents (e.g. DfEE 1994, 1997a, 1997b, 1997c, 1998a, 1998b, 1999, DfES 2001, 2004) have called for partnership between parents and professionals in relation to children perceived as having special educational needs. During that time a number of books and articles

exploring issues related to parent–professional partnership (e.g. Armstrong 1995, Dale 1996, Wolfendale 1997, 2002, Swain and Walker 2003) have highlighted the need for a greater understanding of how meaningful partnerships might be developed for the benefit of the children. The suggestion in the literature is that despite the legislation increasing parental rights, there remains an imbalance between parents and professionals (Fulcher 1989, Armstrong 1995, Wolfendale and Cook 1997, Todd 2003), although Armstrong (1995: 27) maintains that parents are not perceived as passive participants. Liz Todd (2003: 294) argues that current policy and practice offer a ‘complex mixture’ in which there is ‘respect for parents as equals’ but there remains a ‘continuing deficit discourse’, especially in relation to the assessment of special needs, evidenced by the renewed call for the active involvement of parents in the Code of Practice (DfES 2001).

This complexity merits further examination if we are to gain new insights into how inclusion might be moved forward. This book argues that listening to the experiences of mothers who are also professionals in a related field is an important and relevant way of gaining new understandings and exploring the perceived imbalance of power. Only by professionals setting aside the powerful and constraining discourses, which divide and boundary professionals and parents, can they really begin to give credence and significance to the voices of ‘others’. Some nine years after Derrick Armstrong’s study (1995) this book considers aspects of both power and partnership in relation to SEN. It explores experiences of inclusion and exclusion from both the professional and the personal perspective and offers the experiences of six women who are mothers of children perceived as having special needs/disabilities. These women are also involved in the education of children who in some way or other present a challenge to the education system as it stands at the beginning of the twenty-first century.

The stories of the mother-teachers span 20 years or more and cross two continents. Two of the children are now in their late teens and one is now an adult; one is just embarking on her school career; one has experience of two education systems 3,000 miles apart, and two will always need the constant support of both their parents and a range of professionals. Although there are similarities, the stories of the children and their families represent unique and singular experiences,

reflecting considerable differences in degrees of inclusion and support. They offer different perspectives on parental and professional approaches and should alert the reader to an awareness of the many differences of meaning and experience of both inclusion and exclusion. But the stories also reflect many similarities in relation to issues of power, partnership and the construction of 'knowledge' in the area of special educational needs.

Inclusion and exclusion

Inclusion and exclusion take place on many different levels within different contexts. While policy offers a macro-context, internationally, nationally and locally, experience offers insights into how that policy impacts on individual lives in both the public and the private domains. The book explores some of these experiences of SEN/disability in relation to inclusion, exclusion and parent–professional relationships through the stories of women who have experience of both sides of the personal/professional boundary. The main tenet of the book is that while a plethora of policies have been developed which support parent partnerships in SEN and educational inclusion, there still remains a 'real' gap between theory and practice. This may be an uncomfortable thought for practitioners but, far from seeking to lay blame, the book exhorts professionals to listen to parents and to examine how they, as professionals, might address some of the issues within their own practice. These stories are not written by either 'disgruntled' parents or by 'disillusioned' professionals. They are told by supportive parents who are also active practitioners working in both roles as agents for change who also have agency on behalf of 'their' children. Through a different and unique perspective, these mother-teachers have reflected on their practice, values and approaches and in many cases have redefined their own understandings of terms such as inclusion, exclusion and special educational needs.

Special educational needs and terminology

Writing a book about special educational needs, disability, inclusion and exclusion is problematic in relation to terminology. As support and funding have historically been associated with the identification and categorisation of need, parents have, not unreasonably, sought to

use SEN terminology to argue their case for educational support for their children. The 2001 SEN Code of Practice (DfES 2001: sections 7.52–7.67) redefines the categories of SEN in an attempt to engage with the complexity of categorisation and the barriers which can emerge through the labelling of children. The use of terminology to refer to the different aspects of disability and learning difficulty is in itself a challenge, for, in condensing the multiplicity of issues to a single term, there is always the danger of reductionism. In this book I will adopt the meanings and definitions offered in the 2001 DfES SEN Code of Practice which are outlined in [Figure 1.1](#).

Knowledge, experience, research

These stories are not intended as statements of ‘how things *really* are’ (Allan 1999: 1) but rather as insights into what Allan refers to as a ‘complex power/knowledge knot, which is not supposed to be unravelling’ (*ibid.*). As with the pupils’ voices in Allan’s book, the voices of these mother-teachers challenge the binaries, the related divisions used to boundary children and their families in relation to special educational needs; binaries such as inclusion/exclusion; normal/special; parent/professional; home/school; experience/expertise; powerful/powerless. What the book aims to do by presenting the stories in some of their complexity through the eyes of the parent-professionals is to reopen or at least blur the boundaries between parents and professionals; and to recreate a ‘listening space’ from which a renewed understanding might develop. Thomas and Glenny suggest that such arguments for inclusion

have to emerge less out of the kind of supposed knowledge so respected by 20th-century educators, less out of notions of success and failure (of children or of schools) and more out of ideas about social justice and human rights.

(2002: 345)

If SEN and disability are considered within this context of rights, then the question must be asked about the nature of the evidence used to make judgements on SEN, for rational enquiry and empirical studies do not always appear to support the notion of inclusion with regard to effectiveness and learning (Lindsay 2003, Thomas and Glenny 2002, Wilson 2000). But as Lindsay (2003) argues, we need to consider rights

Children have special educational needs if they have a *learning difficulty* which calls for *special educational provision* to be made for them (original emphasis).

Children have a *learning difficulty* if they:

- a) have a significantly greater difficulty in learning than the majority of children of the same age; or
- b) have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority;
- c) are under compulsory school age and fall within the definition at (a) or (b) above or would do so if special educational provision was not made for them. (DfES 2001: 6, section 1.3)

A child is disabled if he is blind, deaf or dumb or suffers from a mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed (Section 17(11), Children Act 1989, quoted in DfES 2001: 7).

A person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities. (Section 1(1), Disability Discrimination Act 1995, quoted in DfES 2001: 7)

Figure 1.1 Definition of Special Educational Needs (DfES 2001: 6–7, section 1.3)

as well as efficacy and to this end qualitative research has much to offer. This book endorses the view that there needs to be ‘a new epistemology’ around issues related to educational inclusion; a ‘reappraisal of the precepts, presumptions, tenets and methods of inquiry’ which supported the framework of SEN in the twentieth century (Thomas and Glenny 2002: 346).

There is now a growing literature which offers ‘insider perspectives’ and lived experiences around aspects of disability, SEN and learning difficulties, inclusion and exclusion (e.g. Clough and Barton 1998, Moore *et al.* 1998). The stories told here are from two very particular insider perspectives. The lived experiences reflect the range and complexity of issues and ideas; of what counts as inclusion and what matters to these mothers and teachers. It is not just about the ideology of inclusion but about the reality, experienced in different ways and on many different levels. It is interesting to compare two levels of inclusion: on the one hand there is the National Study of Inclusive Education (Lipsky and Gartner 1998), which covers 1,000 school districts and which identified seven factors contributing to inclusive schools; on the other there is the voice of Julia (see [Chapter 9](#)) celebrating the ‘inclusion’ of her son Martin as he walks across the playground, head held high with pride having been trusted to take the register back to the school office. If we are ever to achieve ‘meaningful’ inclusion surely both kinds of evidence must have their place. While the macro-level and meta-analysis offer an important overview, we must keep a space in which we can listen to the voices of individuals and their experiences. This book is about that space and some of those voices. The stories are lived within both a policy and a sociological context. Without some understanding of these contexts, the stories remain the tales of individual lives; fascinating and provoking but impossible to bring into political and sociological relief. For this they need to be considered against the broader canvass of their times.

Policy and sociological contexts

Conflicting policies? Raising standards, SEN/disability and inclusion

The last 30 years of the twentieth century saw enormous challenges to ‘traditional’ ways of understanding society. Postmodernism and feminism explored dominant, patriarchal constructions of the social order and challenged ‘the way things were’. In education policy, too, these years saw considerable changes involving the gradual and continual erosion of professional teacher autonomy and the removal of Local Education Authority control of education through policies which,

at the same time, centralised the control of education in the national government and decentralised budgets to schools. Parental choice and performance indicators such as league tables, seen as the way to raise educational standards, worked to create a quasi-market in education (Barton 1998) and from the mid-1970s onwards there was a marked shift from notions of social equity, as set out in the 1944 Education Act, to those of standards and excellence.

Alongside policies aimed at raising standards were placed those supporting the rights of children with SEN and policies which purported to promote educational inclusion for all children. Against the backcloth of league tables, parental choice and 'failing schools', policies promoting inclusion, particularly of children who present behavioural challenges to the school, are, it is argued, destined to fail (Barton 1998, Gewirtz *et al.* 1995). Many teachers feel that the government is sending out 'mixed messages' with policies of inclusion within the general context of an education market, which, they argue, creates tensions in many schools (Birkett 2000).

There is competition for funding both between schools and within individual schools, and provision for SEN can often depend on the level of parental advocacy: the more vocal the parent, the more resources the child may receive. Such competition and inequity of provision places great pressure on SEN professionals who, as well as having to work within the general education market, 'have to work within the internal market of the school to secure policy commitment and resources' (Bines 2000: 22). They have to ensure that they meet the needs of the children and their parents, for inclusion means more than 'integration' into mainstream classrooms of pupils defined as having special educational needs. It involves policies of entitlement, rights and the recognition and valuing of diversity (Barton 1998, Armstrong and Barton 1999).

Many argue that a relationship between the market ethos and inclusion is incompatible (e.g. Armstrong 1998, Barton 1998, Warnock 1996, Gewirtz *et al.* 1995) and that there will inevitably be winners and losers. It is suggested that the losers could well be children with SEN and/or disabilities (Slee 1996, Warnock 1996, Armstrong 1998). It is against the emerging tensions from this seemingly incompatible policy context that the stories are told. Within these tensions, teachers and parents have to

try to negotiate a relationship between the private space of home and the public arena of the school. For children with SEN and disabilities, this is seen as especially important and is increasingly recognised in policy documents (e.g. DfES 2001).

Home–school relations/partnership

Relations between home and school have been brought into a more formal, public arena since 1981 through the introduction of policies designed to improve home–school relations especially in the area of special educational needs. In 1978 the Warnock Report (DES 1978: 151) stated:

Parents can be effective partners only if professionals take notice of what they say and of how they express their needs, and treat their contribution as intrinsically important.

The need for partnership was also recognised in the Code of Practice (DfEE 1994: 12, section 2.28), which states:

Children's progress will be diminished if their parents are not seen as equal partners in the educational process with unique knowledge and information to impart.

Professional help can seldom be wholly effective unless it builds upon parents' capacity to be involved and unless professionals take account of what they say and treat their views and anxieties as intrinsically important.

The more recent SEN Code of Practice (DfES 2001: 12, section 2.2) offers an even stronger rationale for partnership with parents:

Parents hold key information and have a critical role to play in their children's education. They have unique strengths, knowledge and experience to contribute to the shared view of the child's needs and the best ways of supporting them. It is therefore essential that all professionals (schools, LEAs and other agencies) actively seek to work with parents and value the contribution they make. The work of professionals can be more effective when parents are involved and account is taken of their wishes, feelings and perspectives on their children's development. This is particularly so when a child has special educational needs. All parents of children with special educational needs should be treated as partners.

The next section (2.3) adds:

These partnerships can be challenging, requiring positive attitudes by all, and in some circumstances additional support and encouragement for parents.

Since 1999, the Schools Standards and Framework Act (DfEE 1998c) has required all schools in England and Wales to have signed home-school agreements which are to be drawn up in consultation with parents. There are differences in meaning, however, between the terms relationship and partnership, but I consider Pugh *et al.*'s definition of the word partnership to be a useful way of conceptualising both:

A working relationship that is characterised by a shared sense of purpose, mutual respect and the willingness to negotiate. This implies a sharing of information, responsibility, skills and decision making and accountability.
(Pugh *et al.* 1987: 5)

While the government acknowledges that the 'best results are achieved where parents, schools and LEAs work in partnership' (DfEE 1998a: 12), such relationships are not easily achieved and depend on the collaboration of both parents and professionals and the weaving together of their worries, concerns, responsibilities and priorities (Dale 1996). A number of things may contribute to the tensions and possible conflict between parents and professionals: competition for resources; greater expectations of parents; increasing legal power of parents; difference between parental expectations and professional achievements; greater division and competition among professionals; parental stress and family conflict; lack of empathy and, perhaps most notably, poor communication skills and an unwillingness to share power on the part of the professionals (Dale 1996). Hood (1999) argues that the unequal balance of power between professionals and parents is certainly a factor here. Indeed, the National Association for Special Educational Needs (NASEN 2000) expressed concern over the draft of the 2001 Code of Practice, maintaining that it still did not reflect equality in the partnership.

The power of the professional lies in the possession of a 'specialised body of knowledge and skills' which has usually been achieved after a period of prolonged training and:

although frequent rhetoric has been made of the immense importance of parenting, minimum practical recognition has been given to the validity

and usefulness of their expertise and experiences. The unpaid and unlimited hours of parenting contrast with the professional's role where there is remuneration for specific hours of employment.

(Dale 1996: 5)

Parents and professionals may have similar 'knowledge', but it is their positioning in the system that renders their perspectives and personae very different from each other. Despite the notion that parents and professionals may appear 'on the same side', i.e. that of the child, there are important differences. The parent wants what is 'right' for the child 'exclusively'; the professionals want 'what is right for him in a context' (Todd and Higgins 1998: 229). Professionals may regard parents as 'resources' in their children's education, expecting them to follow the goals of the professionals rather than act as partners with shared aims. Recent research supports the view that parents are more usually seen not as consumers or partners but rather as supporters or, even worse, as problems, and that despite the rhetoric, the home-school divide seems as wide as ever (Ouston and Hood 2000).

Armstrong (1995: 1) raises some interesting questions in relation to the role of professionals and partnership. He maintains that there is a 'contradiction in the professional-client relationship in special education assessments between benevolence and control which the concept of partnership does little to address'. From the outset, professionals 'define' the needs of others through their assessment of children with SEN, which contrasts with the 'humanitarian principles' often expressed by professionals when they theorise their own practice (ibid.). He argues that the relationship is further complicated by the vested interest of professionals in the outcomes of assessment procedures. While he is not suggesting that there is a 'conspiracy theory of professional activity' (ibid.: 147), he does maintain that professional interests, values, ethics and pressures may differ from those of other professionals and may even 'sit uneasily with an ethic of professional service governed solely by the interests of the children' (ibid.: 148). He draws on Fulcher's notion of 'entrenched professionalism' (1989: 165) by which the 'parents as partners model ... incorporates parents into the bureaucratic procedures' to illustrate how such partnerships remove the 'genuine' power of parents, allowing them merely to 'facilitate the smooth operation' of the procedures (Armstrong 1995: 144).

This is an extremely complex area where it is evident that power relations cannot easily be explained by a simple dichotomy of powerful professionals and powerless parents (Armstrong 1995, Todd and Higgins 1998). Parents are often presented as a unified group who support the aims and ethos of the school without question (Vincent 1996); but this does not appear to be the case (Hanafin and Lynch 2002). There are differences ascribed to social class, which appears to emerge as an issue in two ways: from a cultural deficit model in relation to working-class parents perceived as 'on the periphery'; and also in relation to perceptions of parental involvement as an important influence on children's learning (Hanafin and Lynch 2002: 34–5).

The discourse of home–school relations is another important factor. The separation of 'home' and 'school' puts mothers in the external environment in relation to the school and its management and therefore on the other side of the boundary from the teachers. School can be seen as representative of the divide between public and private, between professional knowledge and personal experience. For their part, mothers soon begin to perceive schools as the 'public settings' in their children's lives (Ribbens McCarthy 2000). Ribbens McCarthy maintains that there is an important and unequal power divide here between the public and the private:

In order to understand what is going on between mothers and schools we have to recognise this boundary and the various associated and extensive differences in terms of the values and concerns that are relevant on each side. I would argue, however, that the values and concerns to be found on the public side of the boundary, are manifested in very powerful social practices including the dominance of the 'psy' public discourses and ideas about 'child development' that underpin the work of schools.

(ibid.: 11)

The use of the term 'parent' in the home–school literature disguises the very gendered nature of the responsibility for schooling. Such literature on home–school relations talks about 'parental' involvement despite the evidence that it is mothers who for the most part take on that responsibility (David 1993a, 1993b, 1998, Hanafin and Lynch 2002). This responsibility affects women's roles in other areas of their lives (David 2000b: 12), as the stories in this book suggest. David argues that the mother's responsibilities in relation to school are increasing, for schools now expect children to have acquired certain