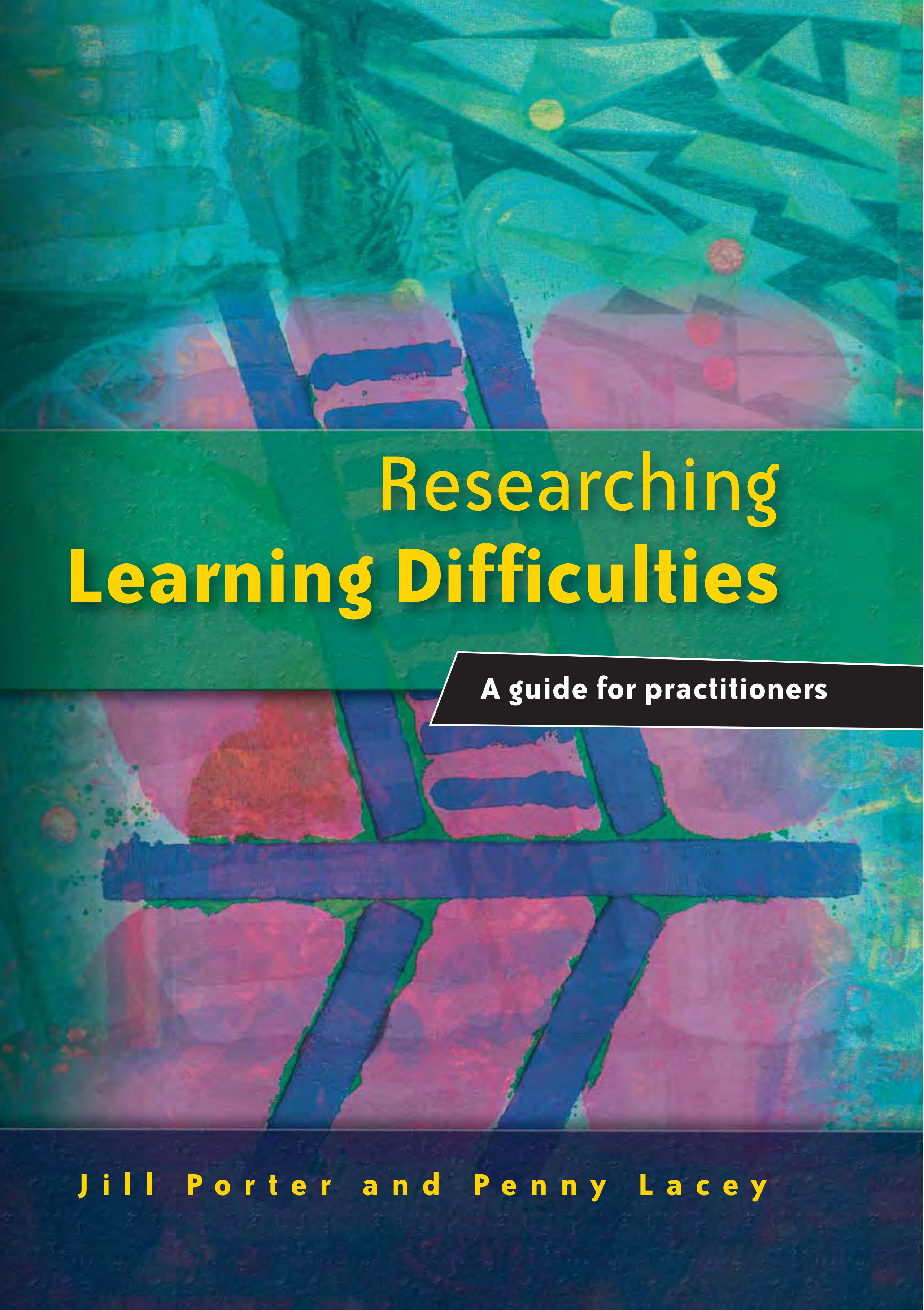

Researching
Learning Difficulties

A guide for practitioners

Jill Porter and Penny Lacey

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FOREWORD

Engaging with children and young people with learning difficulties tends to push one into the role of researcher. We find ourselves continually adducing, testing and revising hypotheses about why the child or young person is behaving in a particular way. To be a researcher is to seek systematic evidence, to reflect upon that evidence and as a result to move inductively or deductively to a deeper understanding of the world. The process can be summarised in the mathematician George Polya's problem-solving approach: understand the problem, try to use experience from related problems to plan an attack, carry out the attack and finally ask yourself whether you really believe the answer you've got (Polya, 1957).

Jill Porter and Penny Lacey bring to that process a rich depth of knowledge and experience of (in total) over 50 years of working with, and researching the lives of, children, young people and adults with learning difficulties. Both now, as well as conducting research in the field, train professionals in research methods and supervise research students investigating research questions relating to learning difficulties. They are thus uniquely well placed to open the issues to a wider audience and there is a striking synergy in this book between knowledge of learning difficulties and understanding of the research process.

In writing about the research process Jill Porter and Penny Lacey highlight issues emerging with increasing prominence over the last few years. This includes a strong emphasis on the ethical aspects of research about, and with, children and young people with learning difficulties. A decade ago it would have been rare to find a doctoral thesis or research report in which substantial material addressed ethical issues, but it would now be unusual not to find a section devoted to this, at the very least within an account of methods and methodologies. The salience of these issues is illustrated by the increasing reference to ethical codes developed by professional bodies such as (in the UK) the British Educational Research Association, the British Psychological Society and the British Sociological Association. Similar bodies internationally also provide ethical guidelines. The possible tensions surrounding ethical decisions in research are highlighted when this involves bringing together professional groups who have traditionally worked in separate spheres. One person's gatekeeper is another's co-researcher; one researcher's commitment to sustaining confidentiality is another's abdication of social responsibility.

There is a pressing need for good research evidence as a basis for decisions about policy and provision. The political culture of initiative after initiative (Sure Start, Children's Fund, Children's Trusts, Valuing People, SEN Action Programme, P scales, etc.) can leave users bewildered and focusing on surviving the latest initiative; lacking time, energy and motivation for systematically evaluating those policies. The role of universities is surely to keep addressing the hard (and perhaps unpopular) questions and one mechanism for bringing clarity to the kaleidoscope of new policies is sound research. Research will lack credibility and impact if it is conducted in a token way. Sadly, public money is being wasted on poor quality and bland 'evaluations' which act only as a sop to funders and a brief 'stroking' to those whose work has been 'evaluated'. This timely book, written in a highly accessible way, with a transparent and evident understanding of the context implicitly reflects Polya's guidance and so provides a coherent basis for users as well as practitioners, of research involving children and young people with learning difficulties.

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Polya, G. (1957) *How to Solve It* (2nd edn). Harmondsworth: Penguin.

INTRODUCTION

In many ways this book has an ambitious agenda. It is not targeted at a single discrete audience; instead it celebrates the diversity of work that is currently undertaken in the field of learning difficulties with a concern to enable people working within different spheres of activity to share something of their work to contribute to the bigger picture. This is especially important when working within a minority field that is easily overlooked by more generic service providers. It is also consistent with services which are commonly multi-disciplinary as the focus of activity is less sharply delineated with respect to education, health and social care and where collaboration between agencies has been government policy for almost 50 years (Lacey, 2001). It would appear from our analysis of the literature that when it comes to research practices only a minority of researchers look beyond their own discipline. Indeed, they often fail to look for relevant literature outside their own field, thereby not capitalising on that which is already known.

One of our overriding drives is the desire to ensure that provision for people with learning difficulties continues to develop, and at a faster pace than in the past where the rhetoric has often not matched the reality of the daily lives of many people with learning difficulties. It is a time when the aims of provision are less easily defined in a generic way. When quality of life is recognisably less about concrete and tangible services and more about the quality of relationships. When choice and diversity of provision are argued for but we have still to develop those decision-making skills in *all* people with learning difficulties. When community placement can lead to a diminution of social networks rather than expansion. When the agenda for inclusion has not only created tensions of deciding where schooling takes place but has created a potential strait-jacket in our perceptions of the nature of the curriculum. Arguably research has never been so important in enabling us to determine the way forward.

Evidence suggests however that research in the field of learning difficulties is diminishing – at least as measured through publications. Nowhere is this so apparent as in the fields of education and health. There are many potential reasons for this including tensions that make research hard to carry out in this field, not least the difficulty of delineating the client group and validating research on small, heterogeneous populations experiencing diverse forms of provision. These issues are explored within this book from the perspective of both the user and the producer of research with the intention of aiding the reader in accessing research which is directly relevant to the field in which they work and in critically evaluating the implications for their own practice and research.

The aim is to provide a source book for teachers and other professionals working with children and adults with learning difficulties and disabilities that will enable them to:

- access selected recent and relevant research in the field of learning difficulties, drawn from a range of disciplines and groups of people
- reflect on different types of research methodologies, their relative strengths, weaknesses, constraints and possibilities in relation to learning difficulties
- undertake their own research in the field of learning difficulties.

Values and assumptions underpinning research

Typically discussion of the values underpinning research tend to polarise viewpoints, seeking to make firm distinctions and emphasise differences. The result can be a stereotyping, a caricature of people working within different paradigms. Traditionally a distinction is made between quantitative and qualitative approaches to research but as we shall argue, there is a need to go beyond simply categorising research with respect to the type of data produced and to look at the underlying philosophy. Descriptions of positivist research often conflate their approach with those adopted for the study of natural science and fail to recognise the developments and changes in thinking that have occurred in scientific methodology. What we don't often hear is an acknowledgement that post-positivists see knowledge not as absolute proof but as conjectural, seeking ways 'to establish procedures and criteria that can support commonly adjudicated truth claims that do not depend solely on those subjectively experienced or believed' (Phillips and Burbules, 2000, p37).

The value of subjective beliefs underpins the use of interpretevist and social constructionist approaches to research where the emphasis is on exploring meanings. To pursue this transforms the relationship between the researcher and the researched as dialogue and interpretation are fundamental to the process of inquiry. Thus while one approach does not deny the possibility of multiple *truths*, the other actively explores multiple *beliefs*.

The strongest contesters of both these research paradigms are those who argue for research to be emancipatory, that there needs to be a sea change in the power relationship between researcher and researched and to privilege the voice of the disabled. This concern draws our attention firmly to the political nature of research and the question of who sets the research agenda. Dyson (1998) argues for researchers 'to become reflexive in their awareness of how they are enmeshed in these processes, for them to struggle against the undue exercise of power, and for them to align their researching with the interests of the less powerful rather than he more powerful' (p3). He also draws our attention to the way in which foregrounding one voice silences others: 'for every group recognized as oppressed, another's oppression is denied or ignored' (p10). This is a potent reminder in a field where the voices of some are more easily accessed than those of others. As he continues: 'research which proceeds on the assumptions about coherent voice and clear political agenda may foreground and advantage those groups who conform most clearly to that image at the expense of those groups who do not …' (p11).

In representing research which spans the range of approaches we aim to promote a dialogue between researchers that recognises the relative contributions to be made and the place and importance of different kinds of knowledge. More globally there is a demand for evidence-based practice, a phrase now firmly linked with positivist and post-positivist approaches to research. As we will argue, these approaches often pose particular difficulties for studying small and heterogeneous populations. However, interpretative approaches can also be problematic as the dialogue which plays a central role in their methodology places limitations on the richness of data collected from those at the heart of the service – the consumers. This in turn can shift the emphasis from research which has an explicit emancipatory function to that which is better described as participatory. In this book we examine these methodological difficulties and bring together the literature on offsetting them, drawing on expertise both within and outside the field of learning difficulties to make suggestions for the way forward.

An outline of the book

Chapter 1 takes a historical perspective on learning disabilities and on learning disability research. We felt it was important to give an overview of what had occurred over the previous century before examining in detail current research. We look back through the twentieth century at the slowly evolving change in attitudes towards people with learning disabilities, the development of provision and, of course, research, noting the twin discourse of care and control that permeates accounts at the time.

Chapter 2 is set firmly in the present and examines what shapes the agenda for research in learning disabilities and difficulties. We look for example at who carries out research, and at different types of research and their contribution to forward planning. We consider the different ways in which research is funded and at the types of research and research practice required by different funders. We highlight concern for the utility of research that shapes the view of what is worthwhile and fundable research, the emphasis on impact and on dissemination. Collaborative research is seen as central to achieving these qualities, ensuring a stakeholder influence on the research agenda. There is increasing recognition of the importance of participatory research among some funders of research, most notably voluntary bodies. Other funders may recognise the rhetoric but be slower in heeding the additional time requirements and the cost implications of this. Where time and money are limited it is likely that those who are most difficult to reach will be those whose views are sacrificed in order to meet deadlines.

In Chapter 3 we examine the trends in research, comparing publications that fall a decade apart. We do this not so much to make future predictions but to examine the continuities between the rhetoric of research and its practice. To this end we look at changes in both topics and methodologies. The outcomes of this analysis have in large part shaped the contents of this book. Our analysis of research strategies was notably hampered by the need to make interpretations of the design and methodology adopted. Others have also pointed to the lack of specific reference to design (Hogg *et al.*, 2001), as if description of research methods or tools is sufficient to justify the approach to research. This no doubt has contributed to some of the limitations in the robustness of the data noted in many reviews of the literature. Little research can be described as adhering to interpretative or constructivist designs. Although it is not uncommon for qualitative data to be collected, it is often either reduced to categories that are subsequently treated numerically or used as illustrative of views through the use of quotes with little verification or further analysis, thereby compromising the integrity of the research.

Our review highlights the high proportion of research that can be considered evaluative. This includes both large- and small-scale studies, complex studies of services and simpler investigations of interventions. We chose to make a distinction between studies that are explicitly referred to by the authors as using an evaluation design from those which might also be described as having the purpose of evaluation. We carry this through to dividing into two separate chapters the evaluation of services and those of instruction strategies or interventions. Although this reflects current practice we have done this with a number of reservations. One of the difficulties for research that looks only at instruction without reference to the wider service in which it is being used is that it makes an assumption that these factors have no impact on practice. We would argue that the culture of the service, its organisation and systems are highly likely to have an impact on the use of a particular strategy however tightly described or structured it might be. It is unlikely for example, that there are no differences between the way, say, a particular ICT programme might be used in a day-care setting, a further education college or a work setting. In order to evaluate this programme it might well be important to examine the culture, organisation, staffing and other aspects in operation as well as the expressed aims of the establishment.

In Chapter 4 we look at broad issues of evaluation, utilising the general literature to inform a more specific look at the challenges of evaluation in the context of learning disability services. Strategies for evaluating services have largely moved away from simple measures, based for example on 'on-task' behaviour, to the collection of multiple measures but notably using 'quality of life' as the prime indicator together with an economic assessment of costs. At one level the use of these tools enables comparisons across studies but they presuppose the efficacy of using globally defined standards. Their use can be criticised as reductionist unless they can successfully reflect the individual values of all service users. We also highlight the danger of cost utility measures whose primary function is to consider whether the money could be used more effectively elsewhere, a short stepping stone to placing a value on the life of a person with learning difficulties. We therefore consider the limitations of using such indices and argue for the importance of looking not simply at outcomes but also at the processes including the systems and structures that support change, thus emphasising the formative potential of evaluation research. One of the fundamental issues in evaluating services must be the inclusion of stakeholder views and arguably the service user should be central in developing the research.

In Chapter 5 we look more specifically at evaluation in the context of instruction and intervention. Our analysis suggests that researchers intent on adopting experimental and quasi-experimental designs to investigate interventions need to ensure that there is compatibility with the theoretical model which underpins the theory of change or intervention. Structured systematic interventions such as those based on aspects of applied behaviour analysis are particularly well suited to these methodologies while those underpinned by other theories of learning may be better served by ethnographic methodologies. We look at recommendations for good practice in the use of these different methodologies.

Our exploration of methodologies highlights the difficulties for researchers but also reveals the potential of adopting new developmental approaches to analysis such as those described under the banner 'design experiments.' These methodologies, which aim to investigate how, when and why learning occurs, include iterative cycles of reflection but with a more overt role for theory than action research has historically done. Thus theory is used to generate the design but not as a straight-jacket to impede other explanations of change. Collaboration forms an important element of the work and again the link with practitioners working in the field is fundamental to ensuring an ongoing programme of evaluation. This methodology has exciting new potential in creating and exploring novel learning environments that are underpinned by a body of research data.

A recurring theme of the book is the importance of including the views of participants and in Chapter 6 we examine the continuum of involvement from collaborative research design and dissemination, through to eliciting the views of those with limited communication skills. We adopt a broad stance to promoting participatory approaches embracing those who recognise the importance of including the voice of all those with learning difficulties and those who more fundamentally seek to close the gap between the researcher and the researched. Although we would debate whether it is appropriate to specifically refer to this research as emancipatory, we would suggest that research will be most meaningful where service users have an input into establishing the research agenda. Indeed, for those who have the most difficulty expressing their views it is vital that the research questions are relevant. If we are actively to seek to gain data that has a demonstrable validity we must recognise that it is difficult to express an opinion if the question has no interest or place in your life.

Our chapter on participatory research explores a number of challenges that researchers face. We caution against setting too firmly the parameters of what is possible, drawing on innovatory studies to illustrate developments in the field. At the same time we recognise that despite these creative approaches researchers can inadvertently constrain the range of views expressed through the selection of different modes of response. The selection of symbols, methods that produce visual imagery such as the camera, ICT or simple drawing may all impact on the type of message that is conveyed. One of the recurring issues is the need to validate the views expressed through the collection of additional data using other methodologies. For us these other means are to be seen as a supporting resource rather than the main evidence. One might make the same case for the use of proxies where the starting point for discussion might be an account of the expressed views of the person whether this is based on linguistic or behavioural data, prior to systematically checking with others who know the person well.

We also raise a number of key ethical issues, taking as guidance the twin principles of the pursuit of truth and preserving the psychological well-being of the individual. These principles raise a number of tensions for the researcher and we illustrate how others attempt to address them. It becomes apparent in our analysis that the process of assent, the cornerstone of ethical practice, should not be seen as a one-off event to be gained at the start of the project, nor to be replaced by the consent of a gatekeeper.

Chapter 7 is devoted to small-scale research and the aim here is to draw together small-scale examples throughout the rest of the book and with a variety of other studies to examine the value of such research. Four aspects of small-scale studies are considered in detail: qualitative case studies, action research, ethnography and practitioner research, and part of the aim is to encourage practitioners to carry out their own research.

The final chapter is entitled ‘Looking beyond the discipline’ and its aim is to encourage readers and researchers to move beyond their comfort level and consider research that has been carried out in disciplines other than their own. We show how, on the whole, researchers are discipline-bound and rarely venture outside, even when citing other research that has influenced their thinking. We use the example of challenging behaviour to explore the perspectives of different disciplines and conclude with an examination of a small number of papers that are multidisciplinary in origin.

As the reader will conclude we have not taken a purist stance to research, espousing the adoption of one paradigm in favour of another, nor one particular research design. However a number of specific messages are central to our research position:

- There is a distinctive contribution to be made by different approaches to research in the field of learning difficulties.

- The veracity of research depends in part on achieving consistency between the research question, the design and methods adopted and the criteria by which we judge the authenticity of the findings.
- The use of a mixed paradigm approach therefore requires the application of different criteria to different parts of the study. Research that aims to discover the ‘truth’ is likely to be judged in relation to its validity and reliability. Research that aims to explore ‘meanings’ is likely to be judged in relation to such criteria as its credibility, transparency and confirmability. Mixed paradigm research therefore has to adopt different steps to establish its worth in different parts of the process. Moreover, there will be a shifting relationship between the researcher and the researched, as the emphasis changes from valuing objectivity to subjectivities.
- Although ‘best fit’ provides a useful guide in selecting the approach to research, it is not unproblematic.
- Given the heterogeneity of the population and provision, there is an important role for small-scale formative studies that are informed by theory and collaborative in nature.
- Greater attention needs to be given to stakeholder views in the development of a research agenda, and the involvement of participants in the research process.

While we would not claim to be the first in framing these views, it is timely to review their place in the field of learning difficulties. In focusing very specifically on issues of research design in this field we aim to raise the quality of research that is carried out by making the issues underlying the process of decision-making more transparent. Inevitably the result is that there is more to consider; the process becomes more complex as there is a realisation of the need to go beyond developing appropriate research tools to tackling the thorny issues of design, which appear from the literature to often get overlooked. We aim to raise the level of expertise of new professionals entering the field of research and to nudge experienced researchers into considering alternatives to their well-trodden ways. If research *is* to have a contribution to make to the development of future provision then we must ensure that it is of an appropriate quality to do so.

CHAPTER 1

Historical perspective

This first chapter focuses on

- historical perspectives on learning difficulties
- research associated with learning difficulties.

We begin with a general historical overview of learning difficulties across the past century, primarily to give a backcloth against which to view changes in research during that time. Our aim is to bring together different contexts. It is more usual to find, for example, a history of education for children (Pritchard, 1963; Cole, 1989) or of adult care (Kanner, 1964; Race, 1995) or recently, of the lives of individuals with learning difficulties (Atkinson *et al.*, 1997).

We have tried to maintain authenticity by referring to people with learning difficulties in the terminology of the day. Those writing in the first half of the twentieth century largely use the terms 'idiots', 'imbeciles' and 'feebleminded' and those in the second half use 'severely and moderately subnormal', 'mentally handicapped' or, in the case of the USA, 'mentally retarded'. It was not until the last few years of the century that people started to use 'learning difficulties' or 'learning disabilities'. Across the centuries, people with learning disabilities have been variously feared, revered, despised, pitied, tolerated, respected or largely ignored. The past century, for example has seen huge changes from the workhouse and eugenics movement, through institutionalisation and de-institutionalisation to community care and disability rights. Children with severe disabilities have moved from being viewed 'ineducable' through to being educable (but requiring segregated provision) to being eligible for education alongside their non-disabled peers in mainstream schools. People's thinking has shifted considerably, but not evenly, across the last 100 years. The inter-war years, for example, did not produce substantial change in the lives of people with learning disabilities, partly because of the Depression and the lack of funding for services but also because intelligence was thought to be fixed and any attempts to change it were futile.

In writing this chapter we are mindful that the history of learning difficulties has been a marginal activity that has led to 'errors and unsupported assumptions' (Stainton, 2001). The increasing use of life history accounts provides important insights into the lives of people with learning difficulties. In contrast professional accounts both objectify and sanitise events. There is also a noticeable gap in accounts of how national policy translated to local action. Armstrong (2003, p1), writing in the context of special education, highlights the 'competing and often contradictory discourses, policies, social interests and practices' that are also notable in our wider history of provision. It is also important to recognise that consensus on solutions can be reached despite competing viewpoints (Myers and Brown, 2003). It is difficult to investigate the past without employing the perspective of the present and that lens will inevitably reflect the values and assumptions of the writer. Having established our recognition of these limitations, we proceed with an account in which we have divided the twentieth century roughly into four sections: early part of the century; inter-war years; post-war years; latter part of the century.

Early part of the century

In this era people with learning difficulties were referred to as 'feebleminded' (or sometimes 'moron' in the USA), 'imbeciles' and 'idiots'. Definitions of these terms are quoted by Tredgold in the 1908 edition of his textbook *Mental Deficiency* (pp75–6) in the following way:

> *Feeblemindedness* (high-grade amentia). This is the mildest degree of mental defect and the feebleminded person is 'one who is capable of earning a living under favourable circumstances, but is incapable, from mental defect existing from birth, or from an early age, (a) of competing on equal terms with his normal fellows; or (b) of managing himself and his affairs with ordinary prudence'.
>
> *Imbecility* (medium-grade amentia). The imbecile is defined as 'one who, by reasons of mental defect existing from birth, or from an early age, is incapable of earning his own living but is capable of guarding himself against common physical dangers'.
>
> *Idiocy* (low-grade amentia). The idiot is defined as 'a person so deeply defective in mind from birth, or from an early age, that he is unable to guard himself against common physical dangers'.

There was a fourth category at this time:

> *Moral imbecility.* The moral imbecile is 'a person who displays from an early age, and in spite of careful upbringing, strong vicious or criminal propensities, on which punishment has little or no deterrent effect'.

This last category included people who had no intellectual impairment but who were considered to be morally defective. They were considered to be at risk to themselves or other people through a weakness that made them vulnerable to exploitation by criminals and immoral people. Unmarried mothers could become categorised as morally defective. For much of the century there was considerable confusion between mental and moral defectiveness, which led to the incarceration of many people who, in reality, were capable of independent living.

The early years of the century have been characterised by a continuation of the charitable acts carried out by Victorian philanthropists. The Industrial Revolution had brought attention to people who could not cope with new technological and commercial processes. There appeared to be a genuine concern, by some people, in the fate of the mentally deficient and a feeling that they should not be left to fend for themselves or placed in lunatic asylums. The work of Itard and later Seguin (Race, 1995) suggested that idiots and imbeciles could be trained in basic skills, and Mary Dendy, a pioneer in special education, opened her school for the feebleminded in 1902 in an era when other special schools were being founded for the blind, deaf and physically defective. The first open-air school (Borstall Wood) began in 1907 (Pritchard, 1963).

This optimism that was discernible at the beginning of the century appeared not to last long. Tizard (1958) suggests that there were two major events that precipitated the turn to pessimism. The first was the development of the science of genetics, building on Galton's work of the previous century, and the second was the development of ways of measuring intelligence. The first led to the Eugenics Movement which influenced public feelings and social policy for many years. In 1909 Tredgold published a paper on the feebleminded, illustrating beliefs at this time. He said:

> In the first place the chief evil we have to prevent is undoubtedly that of propagation. Next society must be protected against such of these person that have either definite criminal tendencies, or are of so facile a disposition that they readily commit crimes at the instigation of others. Lastly, even when these poor creatures are relatively harmless, we have to protect society from the burden due to their unproductiveness'. (pp102–3)

He recommended the development of 'suitable farm and industrial colonies' which could be self-sufficient, and contain the feebleminded and prevent their propagation. Studies of the families of the feebleminded had shown cases where several of the members were mentally deficient and there was a fear that society would be overrun with socially inadequate people. For example, in the US, Goddard, in 1912, wrote about a family called Kallikak with 480 descendants of one man who had a child with a feebleminded girl: 143 were feebleminded and 46 normal. The rest were unknown or doubtful. 36 of the 480 were reported to be illegitimate, 33 'sexually immoral', 24 confirmed alcoholics, 3 epileptics, 3 criminals and 8 kept houses of 'ill-fame'. Kanner (1964, p130) comments that: 'the story of the Kallikaks kindled a spark which soon burst into flames and drove a number of volunteer firefighters to frantic activity'.