

## 1. INTRODUCTION

This is a book about people with profound and multiple learning difficulties and disabilities (PMLD) – people who, in the main, cannot write or speak much for themselves - and those who are best able to speak up on their behalf – their parents, carers and teachers. Books on disability would fill many libraries; books on profound and multiple disabilities a few shelves; and books devoted to exploring the lives of profoundly disabled people, and the experience of those who care for and work with them, rather less than that. It is the last of these that this book is given over to.

It is not so long ago that any such exercise would have been regarded as eccentric. Times are changing: in recent years we have witnessed the growth of disability rights movements, the emergence of disability studies as a multi-disciplinary activity in its own right, and such legislative landmarks as the 1995 UK Disability Discrimination Act (DDA), as amended by the Special Educational Needs and Disability Act 2001, and the Americans with Disabilities Act Amendments Act 2008. Notable recent policy initiatives in England include Healthcare for All (2008), an inquiry into access to healthcare for people with learning disabilities and the Children and Families Act (2014), which includes legislation to support children and families with special educational needs. A significant review, more closely focussed on the people discussed here, is the Salt Review (2010) into the supply of teachers for pupils with severe, profound and multiple learning difficulties. We will be returning to this review in due course.

In writing this book I had two principal aims: to provide some insight into the lives of people with profound learning difficulties and disabilities, and of those who are closest to them, and to offer introductory thoughts on some of the broad philosophical issues that arise from reflection on profound disability. I say 'philosophical' issues, and they are that, but they also number amongst the basic questions and conundrums that any person who lives and works with profound disability will come up against at one time or another; questions about love and care, dignity and respect, dependence and independence, human capabilities and the value of human beings.

I am not aware of other work having aims that precisely match these; but I have learned much from writers who have sought to include the experiences of people with profound and other cognitive disabilities in their own theoretical research on disability (Disability and Society 1999; Knox et al 2000; Chappell 2000; Brett 2002).

### **Giving voice to profound disability**

It is easy to state these aims, more difficult to do justice to them. Though I have sought to 'give voice to profound disability' it has not been possible to include the voices of profoundly disabled people themselves. It is certainly possible to communicate with people with profound disabilities, and to elicit their thoughts on many matters that affect them, including their needs, wants and preferences. It is a challenge of a different order, however, when what is wanted is reflection on one's status, value and capabilities. There is a pressing question, one which developments in technology and pedagogy should assist with, as to what more can be done to utilise and develop forms of augmentative and alternative communication,<sup>1</sup> so as to enable profoundly disabled people to communicate, and, amongst other things, to contribute to a research exercise of this kind. The absence of testimony from profoundly disabled people is, it must be said, a conspicuous omission; nevertheless, I have sought to give ample space to those who are closest to people with PMLD, and, as far as possible, I have allowed the people I interviewed to speak for themselves, both when describing their own experience and when offering thoughts on the questions this book is designed to look into.

This is not a work of social science. It would even be misleading to say that the experiences presented here are drawn from a 'sample' of carers and professionals, since the group of people I interviewed was not identified in accordance with sampling methodology. The process of finding respondents was largely opportunistic; most interviewees live and work in the South East of England, which is also where the 5 schools I have spent time in are located. The testimony is collected from interviews undertaken over 5 years with 102 people who parent, live with, care

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<sup>1</sup> That is, communication methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language.

for, teach or otherwise work closely with people with profound disabilities: parents, grandparents, (extended) family members, support workers, head teachers, teachers, learning support assistants and interpreters, along with miscellaneous others, including neurologists, musicologists, theatre directors and religious leaders. Particularly with respect to carers and teachers I sought out voices from numerous ethnicities, and people of varying ages and socio-economic backgrounds. Most interviewees are women, in keeping with the profile of primary carers and teachers of people with profound disabilities. And most of the profoundly disabled people discussed here are either children or young people, aged between 3 and 25 years.<sup>2</sup> The interviews tended to last between 1 and 2 hours: they had a common structure but they also allowed respondents to explore any of those aspects of living with profound disability that were of greatest interest or were otherwise pre-occupying.

I encouraged respondents to speak at length, and candidly, about their experience. But, owing to personality, or culture, or both, not everyone is able or willing to disclose their innermost thoughts, some of which may be painful or embarrassing, or relate to something which it would be easier not to face head on. In any case, it is a big 'ask' to invite someone to talk openly about their love for or their life with a person with profound disabilities. Profound disabilities present daunting challenges: some people were understandably reluctant to disclose what they might consider as intimate details of their private lives, or to discuss some of the feelings that go along with a demanding relationship - anger, for example, or envy of others' good fortune. One respondent, Cheryl Arvidson-Keating, an eloquent and outspoken mother of a profoundly disabled girl, is well aware of the sensitivities and complications. Shortly after our interview she posted the following thoughts on a blog:

My experience . . . is that there is an Inner and an Outer world. The 'Inner World' [includes] people who understand how you are living . . . people with similar lives that you meet at the hospice or the disabled parent support group; in the Consultant's waiting room or at the Wheelchair Skills Training Course . . . You may also have a few close friends that are also in your 'inner world', who you can vent to, who *get it*. Your child's professionals may or may not get it, it depends on their experience, their empathy and how closely you work with them.

And then, there is everyone else. They are in the 'Outer World'. They are the people who you keep a

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<sup>2</sup> It would be a valuable exercise to conduct a study of this kind focussed on older people.

smile in your pocket for. When they ask how you are doing, you don't tell them that you were awake four times turning N in the night and then spent twenty minutes scrubbing feed off the carpet and had to bath and change her before you went out because she tried to help you hold the bolus and her co-ordination was so poor this morning that it went everywhere, so you were late taking L to school again and she was unsettled and didn't want to go and you were late getting back to pick N up to take her to her short-notice Orthotics appointment you got because her splints are so painful that she can't walk in them - and therefore at all - and so you didn't have time to park at the hospital and you fumbled getting N from the car seat to the wheelchair and ricked your back and she was grumpy and wouldn't let the Orthotocist look at her feet without you holding her whilst she screamed and ... so on.

You just get the smile out, paste it on and say '*Oh, we're fine! How about you?*' Because you know that if you do start talking, you'll start crying with exhaustion; and they aren't close enough to you to have to deal with that.

I have to trust you a very great deal to let you in to my inner world in real life. So I say, to you 'Outer World' people . . . parent-carers of disabled children do talk about . . . grief . . . anger and desperation. We just don't talk about it with you. And it's not because we are deliberately excluding you - at least, that's not my reason. It's just that it's such a huge thing to explain that it's simpler to paste on the smile and talk about other stuff (Arvidson-Keating 2014)

Some parent-carers will experience less grief and anger than others; but anyone should be able to understand the principal point that Cheryl is expressing. I, being neither close friend nor confidant, represent the 'Outer World', with all that that implies for the ability and preparedness of respondents to open up to me.

Regardless of candour or inhibition, it should be no surprise if parental reflections turn out to be partial, or sanguine, or based more on hope than expectation. The perspective of a neuro-disability specialist is helpful here. Michelle is a consultant paediatric neurologist who has worked with profoundly disabled children and their families for many years. She is the first to admit that in the process of arriving at judgements about treatment, including life-saving treatment, the knowledge and experience of patients and their families is indispensable; as it is for making judgements about someone's existing and anticipated quality of life, a judgement that will feature in any decision about whether to resuscitate a child, or to keep her alive. Michelle remarks that 'intensivists' - specialists providing care and treatment to patients in intensive care - may only gain first-hand knowledge of patients and their families in that one context. They cannot see for themselves how patients and

families adjust to their lives and constraints over time. The intensivist may see grief and despair when the diagnosis is first disclosed, but not how strong and resilient people can be; how, one year later, two years later, the child who was struggling to live, and the parents who were struggling to keep themselves from falling apart, may all have adapted to the point that they are now well, and coping well, with their new lives.

On the other hand Michelle can see that parents are not always the best judge of their children's prospects, or what their children are likely to be capable of. It is always her intention to learn as much from the parents and children as time allows, and she is the first to acknowledge that parents are often a good judge of their child's capabilities; but there are also examples of parents with inflated expectations of their child, or whose beliefs and expectations are at odds with testimony from other sources - reports from schools and physio-therapists for example. If a parent is saying one thing, whilst all the evidence is suggesting another, there is inevitably a question about the extent to which the parent has hold of the whole truth.

Of course it is the most natural thing in the world for a parent to hope against hope, or to believe that her child will walk unaided or communicate with words when all the evidence suggests that this will not be possible. And sometimes, against (almost) all expectation, a parent turns out to have been closer to the truth about her children than anyone else. At the very least, hopes and aspirations should be treated with care, even if they are destined to be disappointed. Whilst, therefore, it is necessary to consider whether a feeling or a hope has a basis in fact, it is also important to show sensitivity to what carers believe and yearn for, even if the facts remain obstinately set against them. In any case, it is sometimes hard to ascertain what the 'facts' are, or where the line between 'fact' and 'aspiration' lies exactly; moreover, believing that something is so, and willing it to be so – 'my daughter *will* learn to walk, no matter what it takes!' – can make it more likely that it *is* so one day. The pursuit of dreams and sheer determination can make a difference to how things turn out – to what is, after all, possible. This is taking us into the realm of philosophy.

## Philosophical reflections

The second of the book's aims is to provide some philosophical reflection on the experiences described here. It is closely related to the first, since I intend to illustrate the importance of human testimony for philosophical thinking about disability, as provided by those closest to people with profound disabilities. Their experience has weight, both because it is their experience, and for the illumination it casts on some of the more abstract questions that philosophy deals with.

The discussions to follow are intended as an introduction to a few of the many philosophical questions raised by reflection on profound disability - about dignity, respect, care, dependency, human capabilities and the value of human beings. My intention is to introduce these subjects (no more than that), to show how they are related to each other, and how each is pertinent not only to the lives of profoundly disabled people but to all of us at some stages in our lives. There are numerous other questions barely mentioned here – about personhood, identity, power, oppression, freedom and justice – which I could equally well have chosen to concentrate on, and about which philosophers of disability have written extensively (Kittay 1999; Francis and Silvers 2000; Carlson 2010).

The philosophical questions that *are* discussed go to the heart of what many of us value and care about. But it is not always easy to articulate and explain basic values, nor what they imply for how we should behave. Consider how we think about respecting people and their dignity: that we should show respect for people and not violate their human dignity are among our most basic precepts, and they are included in regulations specifying standards of conduct in educational and other institutional settings. However, whilst there is a consensus that these precepts should inform the ethos and pedagogy found in special schools, it is much less clear what their practical and theoretical implications are or should be. Ought we always to judge, to take a practical example, that we are failing to show respect for a pupil if we choose to talk over her head, if she cannot understand what we are saying, or even appreciate *that* we are indeed talking over her head? Or, to take a theoretical example, does respect for persons imply that a principal pedagogic goal is the promotion of pupil's autonomy, even as this applies to a child with a life limiting

condition who is in a lot of pain, and for whom any new routine will induce considerable distress?

I will seek to show how the experiences described here illuminate such philosophical questions such as these. To do that it is necessary to have an eye to the philosopher's perennial concerns with truth and argument; to claim no more on behalf of someone's testimony than their testimony warrants; to notice any inconsistencies; and to be aware of any evidence that might either support or detract from the truth or plausibility of what has been said.

A great deal has been written about 'truth' and 'interpretation' in the context of disability, but I shall not offer much discussion here.<sup>3</sup> I aim to show respect for truth and consistency, but seek also to allow ample room for people's interpretations of experience; and not only their interpretations, but also their hopes and aspirations, for these too play a sustaining role in the lives of those who care for and teach profoundly disabled people.

The question, 'Is it true that this child is and always will be profoundly disabled?' is misleadingly simple. It might be true that she is profoundly disabled, owing to a genetic endowment, or it might be true not only in virtue of that, but also in virtue of how she is perceived by significant others and in the eyes of society generally. The 'social model' of disability draws attention to the extent to which disability is related to perceptions, attitudes and assumptions embedded in the culture of a society. On this model the term 'disability' is reserved for incapacity whose source lies in societal practices, whilst 'impairment' is the term preferred for incapacities rooted in biology and genetics. This terminological development is just one of many advances made by writers working on theoretical models of disability. Since this is not in the main a theoretical book there is not space to discuss the social model of disability here, although it is hoped that the writing shows sensitivity to its many insights.

Throughout, the philosophical discussion is designed to supplement and grow out of reflections provided by the people I spoke with. Indeed, the relationship between

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<sup>3</sup> These are difficult subjects, requiring a subtle treatment, and any discussion that is either perfunctory or inexperienced is likely not to be worth embarking upon.

their testimony and any philosophical discussion is reciprocal: the experiences described here inform philosophical reflections, just as these reflections are intended to illuminate, or sanction, or raise a question about some of the more prevalent beliefs, claims and ideas expressed by interviewees.

### **‘Profound and multiple learning difficulties and disabilities’**

Although mindful of recommendations under the social model, I have made extensive use of the term ‘disability’ in this book, including in the phrase ‘profound and multiple learning difficulties and disabilities’. This phrase has kept its place since it is used and preferred by almost all the people I have spoken to, and it remains in common parlance in special schools in England, and in policy literature on disability. This may prove temporary, since the terms ‘impairment’ and ‘disability’ mark a real and important distinction. Nevertheless, I would ask readers who prefer alternative phrases to allow this concession to domestic nomenclature. At the very least, I aim, throughout, not to make any unwarranted assumptions about the scope, nature or source of any disability referred to.

This explains why the phrase ‘profound and multiple learning difficulties and disabilities’ is retained; but I should say more about how it tends to be used and understood, and how as a category it is distinguished from other categories of disability. Conceptions of PMLD remain a source of controversy: there is some dispute about the terms, categories and methods of measurement used to identify the forms and degrees of profound impairment, and the various dimensions to be taken account of – behavioural, physiological, emotional, and so on (Ouvry 1987: 12-16; Cleland 1979: 1-4). There is, moreover, an ongoing debate about the implied distinction between ‘severe’ and ‘profound’ disability and what any definition of PMLD implies for levels of support and autonomy (Tassé 2013). In the past the World Health Organisation (WHO) had suggested several categories of what it then referred to as ‘retardation’, relating each category to an I.Q. range. The categories included mild mental retardation (I.Q. 50–69), moderate mental retardation (I.Q. 35–49), severe mental retardation (I.Q. 20–34) and profound mental retardation. This last was characterised thus:



The IQ is under 20. Comprehension and use of language is limited to, at best, understanding basic commands and making simple requests. The most basic and simple visuo-spatial skills of sorting and matching may be acquired, and the affected person may be able with appropriate supervision and guidance to take a small part in domestic and practical tasks. An organic etiology can be identified in most cases. Severe neurological or other physical disabilities affecting mobility are common, as are epilepsy and visual and hearing impairments. Pervasive developmental disorders in their most severe form, especially atypical autism, are particularly frequent, especially in those who are mobile (WHO 1992: 230).

Questions remain about the validity and reliability of the standard instruments used to measure intelligent quotients at any I.Q. levels, and especially at the lowest levels. In recent advice to the WHO the American Association on Intellectual and Developmental Disabilities (AAIDD) recommended that 'profound' and 'severe' learning disabilities are treated as a single category on the grounds that 'collapsing all individuals with I.Q. scores below 40 into one category is more scientifically and psychometrically supported' than attempting to impose a classificatory cut-off point five standard deviations below the population mean (ie., I.Q. 5-25). In short: 'existing standardized tests of intelligence cannot reliably or validly distinguish individuals with I.Q. scores below 40.' (Tassé 2013: 127, 129).

The Diagnostic and Statistical Manual of Mental Disorder (DSM-IV-TR) describes profound disability as including 'considerable impairment in sensorimotor functioning', 'retardation with some neurological condition' and as requiring the 'constant need for 'pervasive support' (DSM-IV-TR: 43-44.). In the fifth edition of the DSM profound disability in the social domain is such that 'the individual has very limited understanding of symbolic communication . . . express[ing]. . . desires and emotions largely through nonverbal, non-symbolic communication'. And in the practical domain the 'individual is dependent on others for all aspects of daily physical care, health and safety' (DSM-V 2013: 58; 61).

Each of these past and present stipulations has been variously interpreted, and it will emerge that the category of PMLD does not always lend itself to simple generalisations about its boundaries and what should be included within them. Moreover, many of the permissible generalisations are provisional since much remains to be discovered about the capacities of people with profound disabilities.

The tendency in the past was to under-estimate potential, partly because educational and other developmental interventions were either not thought of or badly conceived, and partly because social expectations were set as low as they were. There is no reason to think that this tendency has been eliminated.

In the most general terms it is widely agreed that, in addition to extensive learning and cognitive disabilities, people with PMLD will have a combination of physical disabilities, sensory impairments and developmental disorders. In their review of literature Dee et al suggest that profoundly disabled people share two characteristics: a profound cognitive impairment or learning difficulty and a complex aggregation of difficulties in more than one area of their lives (Dee 2002: 4). Likewise, Lacey asserts that people with profound and multiple learning disabilities face difficulties of two kinds: 'they have more than one disability and . . . one of these is profound intellectual impairment' (Lacey 1998: ix).

The Salt Review was commissioned by the United Kingdom government to examine the supply of teachers trained to meet the needs of pupils with severe or profound and multiple learning difficulties and disabilities. This is the definition of PMLD proposed in the review, and subsequently adopted by the Department for Education:

Pupils with profound and multiple learning difficulties have complex learning needs. In addition to very severe learning difficulties, pupils have other significant difficulties, such as physical disabilities, sensory impairment or a severe medical condition. Pupils require a high level of adult support, both for their learning needs and also for their personal care. They are likely to need sensory stimulation and a curriculum broken down into very small steps. Some pupils communicate by gesture, eye pointing or symbols, others by very simple language. Their attainments are likely to remain in the early P scale range (P1-P4) throughout their school careers (that is below level 1 of the National Curriculum) (Salt 2010: 14).<sup>4</sup>

A footnote adds: 'It is important to be clear that PMLD does *not* include pupils who have complex medical needs without any associated cognitive difficulties' (ibid).

I adopt an understanding of 'profound and multiple learning difficulties and disabilities' that is consistent with the definition offered by the Salt Review. But there

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<sup>4</sup> The P scales were created by the Qualifications and Curriculum Authority (QCA) in order to assess children who did not attain at least Level 1 on the National Curriculum.

are many distinctions and complexities that this phrase might encourage us to overlook, and which will often be the subject of discussions to follow.

### **Profoundly disabled people in England**

Whilst this book is not only about profoundly disabled people in England, but about profound disability generally, it is worth providing a brief snapshot of the PMLD population in England, so as to give some idea of how many people are thought to have profound disabilities in a country of approximately 56 million people, and of how many schools cater for profoundly disabled children.

The Centre for Disability Research has provided estimates of existing and predicted numbers of adults and children with PMLD in England. The estimates are based on assumptions of varying degrees of reliability; in particular, there is uncertainty about predictions of estimated mortality rates, although the overall pattern of predictions remains consistent even if mortality rates vary substantially (Emerson 2009: ii).

The number of children aged under 18 with PMLD living in England in 2008 was estimated at 14,744; the number of adults aged 18 or over was estimated at 16,036 in 2008, and 16,234 in 2009. The figure for adults was projected to rise to 22,035 by 2026, with an average annual percentage increase of 1.8% (Emerson: 5, 7). These figures suggest that, 'in an 'average' area in England with a population of 250,000, the number of adults with people with PMLD receiving health and social care services will rise from 78 in 2009 to 105 in 2026, and that the number of young people with PMLD becoming adults in any given year will rise from 3 in 2009 to 5 in 2026' (Emerson 2009: ii). These rates 'will be higher in communities that: (1) have a younger demographic profile; or (2) contain a greater proportion of citizens from Pakistani and Bangladeshi communities' (Emerson: 7). The estimates give evidence of a sustained and accelerating growth in the number of adults with PMLD in England, the acceleration owing to an increase in birth rates in the general population (Emerson: 7).

Consistent with Emerson's data, there is evidence of a rising number of *pupils* in England as having PMLD (Male and Rayner 2007; Male 2009), and increased

survival rates and more effective clinical interventions are likely to contribute to a further increase in the PMLD school population (Emerson & Hatton, 2008). The Salt Review suggested that in 2009 there were approximately 9,000 pupils with PMLD in the education system in the United Kingdom; 82% of these were educated in special schools, 15% in maintained primary schools and 3% in maintained secondary schools. In their national survey of pupils with PMLD in England Male and Rayner 2007 found that there were more boys with PMLD than girls (approximately 2:1) and that PMLD was more common among Pakistani and Bangladeshi children than among other ethnic groups. More than half of head teachers considered that their PMLD pupil population had increased 'significantly' or 'somewhat' in recent years, and that these pupils had increasingly complex needs (Male and Rayner 2007; Male 2009).

The profiles of national and school based populations will vary from one country to the next, but it would be a surprise if the tendency observed here was not shared in many parts of the world - that of a population of people with PMLD that is not only growing, but growing at an increasing rate from one year to the next.

### **The scope of this book**

This book is, first and foremost, about people with profound and multiple learning difficulties and disabilities; hence the need to have some idea of who exactly we are talking about and the numbers of people to whom this description applies. If, indeed, profoundly disabled people were the exclusive object of attention, this would be more than justified, for reasons that should already be apparent, and also because they number amongst the most 'vulnerable members of our society today' (Healthcare for All 2008). But in fact, although profoundly disabled people constitute the primary focus, they are not the only people on whom the discussion has some bearing; for it is a significant objective to explore features of their lives that are common to all of us at one point or another – dependency, vulnerability, the need for care, and the need to be, and the need to be treated as being, a somebody and not a nobody. These are characteristics that apply not only to the 9,000 or so pupils with profound disabilities in England in 2008, nor to the then English population of about 30,000

profoundly disabled people; they apply to everybody - the 7 billion or more human beings on the planet.

### **Advice for readers**

Any author would wish that their book is read from beginning to end, and I share that wish myself. But reading a book from cover to cover is a sizeable undertaking, particularly if it contains sections that are heavy going, as people who are not philosophers may find anything that is remotely philosophical. I suggest, therefore, for those for whom philosophy is anathema, or a little scary, that you skip the philosophical bits at first – particularly chapters 3, 6 and 9 - and read only the stories and words of the interviewees, which, in any case, make up a good portion of the whole. There should be enough there for anyone to get their teeth into. But I suggest only that you skip the philosophy ‘at first’: the philosophical questions are not levered in from the outside, as it were; they emerge quite naturally from the thoughts and experiences of people whose voices make up the bulk of this book. And if some of the philosophy is hard, then - I feel bound to say - that is not my fault; the questions are intrinsically difficult, and there is no way of getting around that.

I have made every effort to use plain English, not quite always, but almost always. I make minimal use of footnotes and other technical devices that would be out of place here. And whilst I make occasional use of acronyms I seek to keep these to a minimum.<sup>5</sup> As far as possible I avoid becoming embroiled in theoretical discussion of difficult concepts that crop up from time to time – concepts such as ‘truth’, as applied to what parents say and believe about their children, or ‘human dignity’, as applied to the status of profoundly disabled people - although I do need to say something about each of these. This, doubtless, will frustrate the more philosophically inclined, so I should say at the outset that this book is intended as offering only the most introductory discussion of the philosophical questions that feature here. The principal objective is simply to raise these questions and to illustrate their importance and complexity; nothing more. In any case, that is likely to suffice for most readers, and

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<sup>5</sup> This includes use of the acronym ‘PMLD’, which has its place, but which should not monopolise the means of identifying the group of people it refers to.

for anyone looking for more advanced philosophy that can be found in the texts included in the 'recommended reading' at the end of the book.

## **Synopsis**

I will explore several dimensions of the lives of profoundly disabled people: their capabilities, dependency, value, dignity and care. I allow ample space for people both to talk about their experience and to reflect on it, and many sections of the book are taken up with their words, not mine. On three subjects - capabilities, valuing profoundly disabled people and caring for them - I judged it beneficial to include chapters on some of the theoretical questions that tend to be discussed, but readers are not obliged to agree, and those who do not may prefer to move swiftly on.

### *The capabilities of profoundly disabled people*

Chapter 2 explores the great variety of capabilities amongst people with profound disabilities and the numerous inventive ways in which their capabilities are uncovered and developed. I look at the progress that people make in their lives, whether by small steps or large, and consider the lives of children for whom progress is inevitably limited and sometimes no longer possible. I examine how progress is assessed in the context of school curricula, and ask whether the contributions of profoundly disabled people - to their relationships, schools and communities – are always entirely captured by the language of 'capabilities'.

In an introduction to the theory on human capabilities, offered in chapter 3, I explore how capability theory is expounded by Amartya Sen and Martha Nussbaum, two of its best known advocates. The chapter is designed both to acknowledge the contribution of capability theory to our understanding of the condition of profoundly disabled people, and to express some scepticism about the extent of that contribution. I suggest that capability theory exaggerates the importance of human agency and freedom in the context of what is of fundamental importance for any human being, and in particular, for people with profound disabilities.

### *Dependence and reciprocity*

No matter what our range of capabilities, large or small, we are all dependent on others, particularly at the beginning and end of life, and not only then. Eva Kittay writes that dependency 'is not only an *exceptional* circumstance' and that to see it as such 'reflects an outlook that dismisses the importance of human interconnectedness' (Kittay 1999: 29). It is one purpose of this book to illustrate the interconnectedness Kittay speaks of, including in the discussion of caring for and valuing other people. In chapter 4 the emphasis is less on the carer and caring relations, and more on dependent people themselves. I offer a series of pen portraits, and discuss dependencies and reciprocal relationships, along with the conflicting priorities that arise when the level of dependency leaves a doubt about the possibility of reciprocity and the value of pursuing independence.

### *Valuing profoundly disabled people*

Chapters 5 and 6 look at the value and moral status of human beings with PMLD. In chapter 5 we hear from parents who speak unreservedly about their love for their children, and explore how love reveals what is most precious in a human being. We learn of the difficulties that arise when love and care is not always returned or recognised, but also how much profoundly disabled children bring to people's lives, whether or not love is reciprocated in kind, and irrespective of any capacity for verbal communication. Faith and non-religious conviction lie at the centre of the lives of many parents and teachers, as is briefly discussed, whilst in the final section we see how easy it is to run out of words when discussing love and the value of a human life, not least because these can be such difficult subjects to find adequate words for.

No one who contributed to this book had any doubt that children and adults with PMLD are as important and precious as anyone else. And yet there are questions about our value that are not easy to answer. How should we explain the value of human beings, and how is this related to our moral status? Are human beings *equally* valuable, and, if so, what accounts for our equal value? The value of a human being can be thought about from several points of view: as it is revealed in our personal relationships, and in our dealings with those we love and care for; as

expressed in the context of moral rights and duties that apply to all persons, whether or not we are personally related to them; and in the context of politics, including the rights and entitlements that attach to persons in virtue of their status as citizens. This last is discussed in chapter 3, whilst in chapter 6 I discuss how we value people from the personal and moral points of view.

### *Dignity and respect*

Most of us believe that all human beings have dignity – human dignity – and that each of us should be treated with a basic respect. But what exactly is ‘human dignity’ and what do we mean when we say that everyone ought to be treated with respect? These are not easy questions; nor is it always easy to know whether how we are speaking to, or holding or otherwise treating a profoundly disabled person is consistent with showing respect for their dignity. She may not be able to tell us; she may not even recognise our behaviour as being either consistent with her dignity or as amounting to a clear violation of it. In chapter 7 I begin by looking at examples of how teachers and carers talk about treating someone with respect. I then explore what the basis of dignity and respect might be, including the idea that respect for a person essentially involves making an effort to see the world from their point of view, I look at the various ways in which we can see someone, either as a person, or as someone less than a person, and I explore why it matters that someone with PMLD should be seen as a person, including the importance of their being acknowledged by and connected to other people.

### *Caring for profoundly disabled people*

The quality of the lives of people with profound and multiple learning difficulties depends in large measure on how well they are cared for. Chapter 8 includes accounts of what it is like to live with and care for a child who is profoundly dependent. The demands on carers differ one to another, and each day in the life of each carer is different. Even so, it is worth recording the experiences of a handful of carers, for although each of their stories is unique, each also includes many features that characterise the lives of most people who care for highly dependent children: the routines and arrangements, demands and impositions, anxieties and frustrations, the



tiredness and 'never-endingness' of care – along with the surprises, satisfactions, rewards and joys.

Chapter 9 serves as an introduction to the theory of caring – what it is, why it matters and its role in an ethic of care. I explore the idea of caring, and how it has been variously conceived, and examine how caring is related to feelings, practices, knowledge and trust. I also take a look at the idea of caring relations, and, in particular, at how to give an account of reciprocity between carer and cared-for that does justice to the contribution of people with profound disabilities.

### *Looking ahead*

The book ends by reflecting on a number of emerging themes and on the wealth of experience shared by the many contributors. I explore the potential for further enquiry, both in the way of collecting testimony, especially from profoundly disabled people themselves, and in the way of collaborative research between practitioners and the academic community.

### *Recommended reading*

For each of the principal subjects explored here I recommend a handful of philosophical books that I have found to be especially valuable, and which offer discussions that are more advanced than anything presented in these pages.