Chapter 1

Introduction

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Why Is This Book Needed and for Whom Is It Intended?

This book is about a variety of types of brain. It comes at an opportune moment in the evolution of higher education (HE), as a growing number of neurodiverse students enter our universities. We can see this if we take dyslexia as an example. Between 1995 and 2005, numbers of known dyslexic students in UK HE increased by a factor of 10 (HESA, 2008a). Anecdotally, similar increases have been noted in the United States, Canada and Australia, although such detailed centralized statistics are not recorded in those countries. In the United Kingdom, the chain of events leading to this increase began with the expansion of awareness since the 1981 Education Act, which led to improved support for school students. From 1993 to 1995, the Higher Education Funding Council financed large numbers of special initiatives aimed at improving provision for students defined as disabled. Dyslexic people ceased to believe that HE was not for them. The flexible university arrangements, which seemed so far-fetched when proposed by a UK working party report in the 1970s (Kershaw, 1974), began to become a reality.

Subsequent legislation has continued this process. The United Kingdom followed the model of the Americans with Disabilities Act 1990 when it passed the Disability Discrimination Act (DDA) 1995 (HMSO, 1995). Dyslexia (or 'learning disability' in the United States) was included under the heading of disability. When this legislation was extended in the United Kingdom explicitly to apply to educational institutions (in the DDA Part 4, HMSO, 2001), it became illegal for these to discriminate against disabled students; higher education institutions (HEIs) began to come to terms with the need for 'reasonable adjustments'.

The experience of dyslexic students, and of universities in responding to their increased presence, is now true of a much wider range of students identified with specific learning differences. Writing of the treatment of autistic school students, Powell (2003, p. 4) states: 'Individuals who less than 20 years ago would have been described by those in authority as mystifyingly odd, and who would have had little formal schooling of an appropriate kind, and therefore little opportunity of progressing into further or higher education, are now … proving themselves able to gain access to higher education, and potentially to be successful within it.' Universities in the United States, Canada and Australia, as well as in the United Kingdom, are enrolling ever-increasing numbers of people identified with Asperger's Syndrome. The same applies to students who need support with mental well-being. UK statistics (HESA, 2008a) show the increases (see Figure 1.1).

Numbers of UK-domiciled HE students known to be on the autistic spectrum increased by a factor of almost six over this period. There are various limitations to these statistics:

- They refer to UK-domiciled students only.
- They include only those who have disclosed a disability to their universities.
- Other types of learning difference, such as dyspraxia, are included under the broad category of 'other disability', which includes health issues such as diabetes and epilepsy.

Nevertheless, the trend is clear. Where is the HE sector to turn for information about these students? Publications about learning differences have tended to be focused on children. Recent years have seen some books on dyslexia in HE (Riddick, Farmer and Sterling, 1997; Hunter-

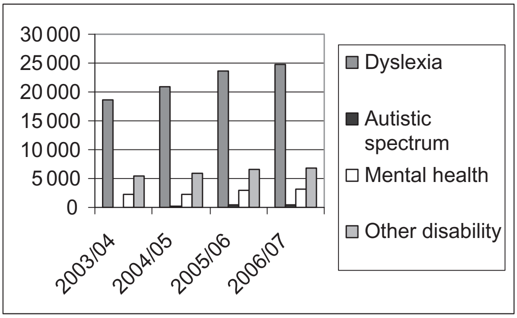

Figure 1.1 UK HESA statistics: selected types of disabled students, 2003–2007

Carsch and Herrington, 2001; Farmer, Riddick and Sterling, 2002; Pollak, 2005) and a practical handbook on Asperger's Syndrome (Jamieson and Jamieson, 2004). Internet information has been collated by a UK-based project (BRAIN.HE, 2008), which includes online conference papers on many of the types of students covered by this book; the number (and location) of visitors received by the project web site shows that there is worldwide interest in neurodiversity in HE. The project also carried out qualitative research with a wide variety of students (Griffin and Pollak, 2008). One theme running through the interview data was the extent to which the HE experiences of students identified with many types of learning difference were similar; another was the need for greater staff awareness of learning differences in general and inclusive practices in particular (see Chapters 11 and 12).

But there is not enough accessible information focused on neurodiversity in HE. This book is therefore for lecturers, support staff, HE managers and policy makers. It is unique in bringing together information about such a wide range of students.

The HE Context

In the academic year 1995–1996, there were approximately 1.5 million students in HE in the United Kingdom; by 2005–2006, numbers had risen to 2.5 million (HESA, 2008b). In Australia, total numbers increased from 634,000 in 1996 to almost one million in 2003 (Universitiesaustralia 2005). Anecdotal evidence suggests that similar increases are taking place in the United States. During the same period, the United States, Canada, Australia, New Zealand and the United Kingdom all enacted significant and wide-reaching legislation concerning disability, both in society in general and in education. This has had the effect of 'raising the profile' of inclusivity issues. The current trend is towards the unification of equality and diversity legislation and policy; the UK Equality Act (HMSO, 2006) was passed in 2006, and the Higher Education Academy has a Single Equality Scheme (HEA, 2008).

Such national initiatives also have the effect of provoking a re-examination of the very nature of HE, but this comes at a time when staff morale is being undermined, not only by increased student numbers but also by managerialism and marketization, with its concomitant bureaucracy. Equality and disability legislation also has the potential to conflict with academic and professional competency standards, an issue which will be examined in Chapter 12.

Language

This area will be discussed at some length, because it reveals a great deal about attitudes and beliefs.

The term 'neurodiversity' is relatively new. It was coined by autistic people in the United States in the 1990s (Harmon, 2004), with the aim of suggesting that far from being disabled or abnormal, people with atypical brain 'wiring' are as entitled to respect as anyone else, and that everyone can be placed on a range of spectrums. This book uses the term for that reason, and also because it believes in the adage 'nothing about us without us'. If the people concerned prefer the term neurodiversity, then those writing about them should adopt it; more importantly, those writing about the subject should be people who experience it themselves (and several of the authors in this book do). There is another reason for using the word 'neurodiversity': it is possible to include more types of student within its definition than are covered by the expression 'specific learning difference'. For example, the current view proposed by influential publications such as the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994) is that Asperger's Syndrome and Attention Deficit (Hyperactivity) Disorder (AD(H)D) are not learning differences but developmental disorders. In the mid-twentieth century, dyslexia was viewed in that way (Miles and Miles, 1999) – that is, as a medical matter rather than an educational one. This book proposes that in terms of HE, all types of neurodiversity constitute learning differences.

The value of the term 'neurodiversity' has been a cause of some disagreement among autistic people, centred on a polarization between those who seek some kind of 'cure' for autism and those who reject such thinking (www.neurodiversity.com). Anecdotally, there are some in HE in the United Kingdom who doubt the validity of the term, either on the basis that it does not avoid sounding medical, or because it is too 'liberal' and potentially distracts attention from the needs of a group of disabled people.

Language in the field of disability and learning difference is rightly seen as a highly sensitive matter. As with a medical model of disability, people identified with learning differences can be described as having 'disorders', 'deficits' and 'dysfunctions' – their differences can be seen as within-person problems, which they have to overcome (e.g. Snowling, 2000 in respect of dyslexia). On the other hand, a social model of learning difference proposes that if there is a problem, it is one for educational institutions; the disability of neurodiversity is socially constructed by the practices of HEIs and indeed by society in general (BRAIN.HE, 2008; DANDA, 2008). That is broadly speaking the stance adopted by this book, and is also the reason why the expression 'specific learning *difference*' is used, rather than 'specific learning *difficulty*'. The use of the word 'difficulty' places the problem within the person.

The definition of neurodiversity offered by Grant (Chapter 3) is comprehensive. Definitions of that kind will, however, always tend to be 'work in progress'. It may be that in the future, terminology preferred by those outside the world of education speaks of 'specific processing differences' or 'specific cognitive differences'.

However, just as the social model of disability does not deny the existence of impairments (Oliver, 1990), this book does not seek to suggest that all aspects of the experience of neurodiversity are easy for people to live with. It remains essential to give careful consideration to the way these things are described. Etymologically, the word 'impairment' is derived from the Latin for 'worsen', and is generally taken to refer to a diminution of strength, value or quality. In the context of disability, Barnes (1996) explains that while the earlier construction of the term focused on physical mechanisms, the definition has broadened to include learning and mental well-being issues. (For a different interpretation of the ideological aspects of the use of the word 'impairment', see Chapter 7.) Nevertheless, there are those who believe that use of the term 'neurodiversity' implies equal respect for all to the extent that the word 'impairment' is not required. In this field, there is virtually no vocabulary which has universal support, but there is agreement that under a social model, disability results from social organization, whether a person is a wheelchair user, partially sighted or dyspraxic.

Another term which is sometimes controversial is the word 'diagnosis'. For most people, this is a word associated with a medical context, but educational psychologists and other professionals have been using it for decades in connection with the identification of learning difference. The *Shorter Oxford English Dictionary* (Trumble, 2002) ('shorter' in that it consists of only two weighty tomes rather than 12) gives the chief definition of 'diagnosis' as 'the process of determining the nature of a disease'. But it also offers a figurative definition: '(a conclusion from) analysis', which is tolerable by those who favour a social model. Nevertheless, in the context of neurodiversity, it is easy to substitute the word 'identification'.

The same professionals often use the term ‘comorbidity’ to refer to a person identified with more than one learning difference. Etymologically, that means ‘having more than one illness’, and hence will not be used in this book. Another word which will not be used is ‘suffering’, as in ‘suffering from dyspraxia’. A more dignified alternative is ‘experiencing’. Similarly, the word ‘indicators’ will be used rather than ‘symptoms’.

Many types of neurodiversity are referred to as ‘conditions’. This is a term which also sounds medical, and the *Oxford Dictionary* indeed gives a specific definition of ‘condition’ as ‘a state resulting from a physical or mental illness’. However, the lead definition for that strand of the entry is ‘state, mode of being’, and as such it is acceptable.

Sometimes, the effort to avoid language which pathologizes people can result in the clumsy use of extra words (and of course the decision as to what makes for clumsiness is subjective). Does the expression ‘dyspraxic person’ put the dyspraxia first and the person second, semantically as well as syntactically? Is it therefore better to say ‘person with dyspraxia’? This raises the issue of the word ‘with’, as this is again quasi-medical, resembling as it does expressions such as ‘man with tuberculosis’. An important factor is the nature of the speaker (or writer). Ross Cooper (see Chapter 4) uses the term ‘dyslexics’, but he is dyslexic himself; it can appear offensive for someone who is not dyslexic to generalize about people in that way.

In some cases, the people involved have again coined their own terms. Some Americans identified with Asperger’s Syndrome refer to themselves as ‘Aspies’ (Willey, 1999), just as other Americans prefer ‘ADDers’ to ‘people with Attention Deficit Disorder’. These terms do not meet with universal approval; those who regard themselves as disabled (and hence entitled to any adjustments prescribed by law) tend to dismiss language which sounds ‘liberal’ or what is known in the United Kingdom as ‘politically correct’. At a UK conference on mental health in HE (UUK/HEA, 2006), it was suggested by some of the students present that they preferred to speak of ‘mental well-being’ rather than ‘mental illness’. This raises a problem as regards ways of referring to people. It is currently fashionable in the United Kingdom to use the word ‘issues’, as in ‘he has mental health issues’ rather than ‘he is mentally ill’. The case for referring to ‘service users’ in this context, rather than ‘patients’, is clear-cut; it is simply more powerful, just as ‘wheelchair user’ is more powerful than the dreadful expressions ‘wheelchair-bound’ or even worse, ‘confined to a wheelchair’. But what about ‘person with mental well-being issues’? Is this akin to ‘waste disposal operative’? The answer is no, because it is not a simple euphemism; it is a genuine attempt to avoid pathologizing people. But at the time of writing, the way forward remains unclear. Chapter 8 in this book uses the term 'ADDer' as both a handy abbreviation and a student-friendly locution.

In his discussion of the place of religion in society, Dawkins (2006) uses a card-playing analogy: do the sensitivities of religious people 'trump' (i.e. have superior power to) the views of nonbelievers? In the same vein, which attitude to neurodiversity language should predominate? In the case of dyspraxia and dyscalculia, there are no equivalent terms to 'ADDer' or 'Aspie' (although, as Chapter 5 shows, there is some debate about the expression 'developmental coordination disorder'). However, this book broadly favours user-friendly (or rather, neurodiversity-friendly) terminology.

It is necessary to reflect upon one further term: the adjective 'neurodiverse'. If the noun 'neurodiversity' is valuable, why not refer to individuals by such an adjective? An Internet search (in March 2008) showed that the term was being used by autistic people. Its use by others may nevertheless be problematic; in terms of 'othering' a person, is stating 'she is neurodiverse' the same as stating 'she has a specific learning difference'? Are we not all 'neurodiverse'? Readers may well recognize aspects of themselves in some chapters of this book, because individual indicators of each type of neurodiversity may be experienced by anyone. Each label applies mainly to people who experience most of its key indicators, all the time.

There are types of neurodiversity which have been omitted from this book for reasons of space: Tourette's Syndrome and stroke survival are prime examples. Students who experience these are present in HE, and there is a need for staff awareness regarding them. Psychologists seem to enjoy coining new labels for people, and some students are being labelled with 'dysgraphia' and 'dysorthographia', which are also not included in this book.

Labelling in itself has advantages and disadvantages. In respect of the label 'dyslexic', various studies have pointed out that it can serve as both an explanation and a source of hope (Miles, 1993; Riddick, Farmer and Sterling, 1997; Pollak, 2005). Several informants of the BRAIN.HE project (Griffin and Pollak, 2008) said the same about a variety of types of neurodiversity. However, a book such as this could be said to be perpetuating the use of such labels. Powell (2003, pp. 5–6) comments that a book with chapters on different types of 'special need' may serve to confirm the view that certain individuals are different, rather than promoting the concept of inclusive practice for all. On the contrary, the authors of this book agree with Powell's subsequent comment (2003, p. 6): 'If the goal of inclusion is to be attained, it will only be by considering the specifics of need as well as a pedagogy for all.' Greater awareness and understanding of such specifics, and particularly the themes which run through them, has enormous potential for increasing the ability of all educational institutions to provide truly inclusive learning and teaching. (See Chapters 11 and 12 for a discussion of the overlaps between types of neurodiversity, and of accessible and inclusive practice in HE.)

University staff have to deal with large numbers of students, who are heterogeneous in many different ways. Lecturers are of course aware of the need to retain students and to maximize their attainment. They therefore want to develop and deliver courses which meet the students' needs; they are also aware of the pressures of a number of agendas, such as the particular requirements of international students, mature students and those who have enrolled through widening participation initiatives. This book proposes not only that members of all of those groups may be 'neurodiverse'. Its principal point is that learning, teaching and assessment approaches which are inclusive of neurodiversity are beneficial to all.

Contents of the Book

The authors of this book bring a lifetime's experience to the task, in all cases in a professional context and in many cases from a personal point of view as well. The book can be read as a complete volume, but it is envisaged that many readers will prefer to select chapters which particularly interest them. There is occasional overlap between some chapters, for example, with regard to accessible learning and teaching practices and models of learning difference.

Conferences about particular types of students generally benefit from the inclusion of presentations, or panel discussions, by representatives of the kind of student under discussion. The approach taken in this book is to include the student voice in most of the chapters.

Chapters 2 and 3 set the scene by providing an overview of current policy and practice. In Chapter 2, Alan Hurst explores models of disability, policy drivers and the legal position which affects neurodiversity in HE at this time. Although the focus of this chapter is on UK disability legislation, the chapter will be of value to readers in any country where the legal position is similar. The core of Chapter 3 is the role of the chartered psychologist in providing formal identification of neurodiversity in an individual. David Grant shows how this work can be supportive for students; he uses case studies and quotations from students to explain the variety of neurocognitive profiles exhibited by the subjects of this book. Grant also proposes a definition of neurodiversity.

Chapters 4–9 are each focused on a particular type of neurodiversity. Ross Cooper (Chapter 4) presents a highly distinctive and challenging view of dyslexia. He offers what he calls a social-interactive model, calling upon universities to remove barriers to learning. Cooper's use of his own experience makes this a powerful argument. In Chapter 5, Sharon Drew gives practical examples regarding dyspraxia, which add usefully to the coverage of it in Chapter 3. She provides a concise checklist of indicators and a longer one for screening purposes. The chapter also includes many 'tips' for lecturers and advice for students on useful equipment.

Chapter 6 is a valuable addition to the paucity of information about dyscalculia in adults and in HE. The field of screening for dyscalculia in students of any age is very new; Clare Trott describes 'cutting-edge' work on a computer-based, HE-specific screening tool. She also presents plentiful examples of student voices and practical examples of supportive approaches. In Chapter 7, Nicola Martin challenges the 'triad of impairments' model of Asperger's Syndrome by suggesting that university staff might themselves exhibit such a triad in attempting to deliver good communication, flexibility and socially appropriate experiences to students. Her distinctive style of writing draws the reader into the world of an Aspie.

In Chapter 8, this book again presents an author with a distinctive style. Like Chapter 7, it offers a vivid portrayal of the experience of a type of neurodiversity, in this case AD(H)D. Mary Colley draws on her own experience in a variety of roles to explain not only the nature of AD(H)D, but also the kind of supportive practice which can be specific to it (such as medication, coaching and cognitive behavioural therapy).

Kitty McCrea (Chapter 9) covers mental well-being. Experiences such as depression have clear effects on people's ability to study, and are covered in the United Kingdom by disability legislation. The inclusion of this topic in a book on neurodiversity may be surprising, but the key point is that in the present climate, the kinds of students covered by this book often struggle to maintain their mental well-being. Chapter 9 points out that poor educational experiences before university, as well as during a course, can often lead to reduced mental well-being in a variety of ways. It makes clear that university marketing material should make positive statements about the institution's commitment to mental health, and provides many practical examples of ways in which this can be supported.

The next two chapters return to the overview stance adopted by Chapters 2 and 3. In Chapter 10, E.A. Draffan displays an encyclopaedic knowledge of the variety of assistive technology available to students, both mobile and desk-based. She includes many illustrations, informative quotations from students and a practical list of sources for the items covered. In Chapter 11, Heather Symonds addresses the potential mismatch between the way many students think and conventional approaches to learning, teaching and assessment. She picks up the theme of the UK Disability Equality Duty alluded to in Chapter 2 and relates this to curriculum design and strategies for academic assessment. Chapter 11 also covers virtual learning environments.

In the Conclusion (Chapter 12), the editor draws upon the combined insights of the authors to sum up the issues raised in the book. The chapter examines the themes of diversity and inclusion, overlaps between types of neurodiversity, admission and transition, identification, learning and teaching practices, and staff development. It also looks towards the future.

References

American Psychiatric Association (1994) *DSM IV. Diagnostic and Statistical Manual of Mental Disorders* 4th revised edition, A.P.A., Washington.

Barnes, C. (1996) Theories of disability and the origins of oppression of disabled people in western society, in *Disability and Society: Emerging Issues and Insights* (ed. L. Barton), Longman, London.

BRAIN.HE (2008) *Best Resources for Achievement and Intervention re Neurodiversity in Higher Education*, www.brainhe.com (accessed 20 May 2008).

DANDA (2008) *Developmental Adult Neurodiversity Association*, www.danda.org.uk (accessed 27 March 2008).

Dawkins, R. (2006) *The God Delusion*, Houghton Mifflin, Abingdon.

Farmer, M., Riddick, B. and Sterling, C. (2002) *Dyslexia and Inclusion: Assessment and Support in Higher Education*, Wiley, Chichester.

Griffin, E. and Pollak, D. (2008) Student experiences of neurodiversity in higher education: insights from the BRAIN.HE project. *Dyslexia*, **14** (4), in press.

Harmon, A. (2004) Neurodiversity forever: the Disability Movement turns to brains. *New York Times*, 9 May, http://query.nytimes.com/gst/fullpage.html?res=9C07E0D9143CF93AA35756C0A9629C8B63 (accessed 23 May 2008).

HEA (2008) *Single Equality Scheme*, Higher Education Academy, York, www.heacademy.ac.uk (accessed 20 May 2008).

Higher Education Statistics Agency (HESA) (2008a) *Disability 1994–2007*, www.hesa.ac.uk (accessed 23 May 2008).

Higher Education Statistics Agency (HESA) (2008b) *All Students at UK HE Institutions*, www.hesa.ac.uk (accessed 23 May 2008).

HMSO (1995) *Disability Discrimination Act.* Her Majesty's Stationery Office, London.

HMSO (2001) *Special Educational Needs and Disability Act*, Her Majesty's Stationery Office, London.

HMSO (2006) *The Equality Act 2006*, Her Majesty's Stationery Office, London.

Hunter-Carsch, M. and Herrington, M. (eds) (2001) *Dyslexia and Effective Learning in Secondary and Tertiary Education*, Whurr, London.

Jamieson, J. and Jamieson, C. (2004) *Managing Asperger Syndrome at College and University*, David Fulton, London.

Kershaw, J.D. (ed.) (1974) *People With Dyslexia: a report of the British Working Party on the Needs of the Dyslexic Adult*, British Council for the Rehabilitation of the Disabled, London.

Miles, T.R. (1993) *Dyslexia – the Pattern of Difficulties*, Whurr, London.

Miles, T.R. and Miles, E. (1999) *Dyslexia a Hundred Years On*, Open University Press, Buckingham.

Oliver, M. (1990) *The Politics of Disablement*, Macmillan, Basingstoke.

Pollak, D. (2005) *Dyslexia, the Self and Higher Education*, Trentham Books, Stoke-on-Trent.

Powell, S. (ed.) (2003) *Special Teaching in Higher Education, Successful Strategies for Access and Inclusion*, Kogan Page, London.

Riddick, B., Farmer, M. and Sterling, C. (1997) *Students and Dyslexia: Growing up with a Specific Learning Difficulty*, Whurr, London.

Snowling, M. (2000) *Dyslexia*, Blackwell, Oxford.

Trumble, W. (ed.) (2002) *Shorter Oxford English Dictionary*, Oxford University Press, Oxford.

Universitiesaustralia (2005) *Student Characteristics 1996–2003*, www.universitiesaustralia.edu.au (accessed 24 May 2008).

UUK/HEA (2006) *Mental Well-Being and Learning: Exploring the Connections*, Joint Conference on HE, London.

Willey, L.H. (1999) *Pretending to be Normal: Living with Asperger's Syndrome*, Jessica Kingsley, Bristol PA.