Disability and Discourse
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Analysing Inclusive Conversation with People with Intellectual Disabilities

Val Williams, Norah Fry Research Centre, University of Bristol
Dedication

To my family, Rob, Ben and Naomi, and for everyone at Norah Fry Research Centre, at the University of Bristol
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About the Author

Val Williams is a researcher at the Norah Fry Research Centre at the University of Bristol, where she has worked since 1997, following previous careers in education. She has always tried to work alongside disabled people and people with intellectual disabilities, in order to make sure they have a voice in matters that concern them. Val has wide-ranging interests in disability studies, as well as conversation analysis, and is an executive editor of the international journal *Disability & Society.*
Preface

by Members of ‘The Voice’*

This book has the title ‘intellectual disability’. We know that this is a word used in other countries in the world, and that is why it is in this book. This is just to say that in the UK, we don’t understand the word ‘intellectual disability’. You need to be quite free-minded to understand all these different words. It’s a different way of saying ‘learning difficulty’. That’s the word we normally use in the UK.

To write this preface (and the prefaces to Parts 1 and 2), we both read a summary of all the chapters in the book. Kerrie read out the summary onto an audio recorder, and Lisa listened and talked about what she thought. We both worked together on this preface. It’s really good to have self-advocates involved in a book like this. We are self-advocates ourselves, and we like to do things to help other people.

Most of us don’t live in institutions any more. But there are still problems. The social model tells us that there are barriers around. In Chapter 1, Val talks a bit about the social model. If a person uses a wheelchair, and goes to a cinema, and there are steps, how is she going to get up there? That’s a barrier. People with learning disabilities face barriers every day. But they can overcome their barriers and fight back. If we want to be independent, we can be. People can help each other, and advise each other.

This book is about talk. Sometimes people can talk, but sometimes they have problems in talking. One of us had a friend who couldn’t talk clearly. It’s important how people communicate, and you need to find out how they talk. Some people may use sign language. How can people talk to people with intellectual disabilities? They need to talk without being patronising. One of us said that if people are patronising, ‘I tell them to push off.’

This old lady came up to me, and patted me on the head. It made me feel really embarrassed, although I am normally strong about things.

* ‘The Voice’ is the name chosen by a small group of people with learning disabilities who work with staff at Norah Fry Research Centre, where the author is based.
People often talk to our support workers instead of talking to us, and that makes us cross. People also say ‘you’re doing well’, when we’re not. That can sound a bit patronising too. We have a voice, and we can speak up when we want to. But there are good times to get feedback, and we often like that. It gives us some sort of praise.

Why should you read this book? If you read the book, it would show you how we feel. Then perhaps you would understand how other ‘users’ would feel, and how they could have their own voice. And that’s the only way you can get through. And you should read this book, because it tells you about us, and it tells you what we want from you. And we want you to read the book carefully. And make sure we’ve been heard. Don’t get this book and just leave it on the shelf!
This book has come about because of inclusive research projects, in which people with intellectual disabilities played a central, guiding role. Therefore, their contribution to this book is absolutely vital, and I would first like to acknowledge all the people with intellectual disabilities I have worked with in the past 15 years. Their names appear in credits throughout the book and in their own publications: Julian Goodwin, Neil Palmer, Florence Turner, Brian Vasey, Chris Peacock, Stacey Gramlich, Natasha Snelham, Gordon McBride, Tiffany (Mouse) England, Kerrie Ford and Lisa Ponting. They’ve all been a fantastic source of inspiration to me. Second, I would like to acknowledge all my colleagues at Norah Fry Research Centre at the University of Bristol, who have supported me while I’ve been writing this. In particular, a big thank you to Kelley Johnson, who encouraged me to keep at it and to believe it is possible to write a book; also to Jan Walmsley for comments on earlier versions of some of the chapters. Wiley-Blackwell have been very supportive as publishers, and in particular I am indebted to the comments of the anonymous reviewer who had the enthusiasm and interest to read and give incredibly useful feedback on an earlier draft.

The painting on the front cover is by Claude Rimmer, who was an artist with intellectual disabilities, and is in memory of his talents. I am grateful to his family for allowing this to be published. Last, but most importantly, I am very grateful to all the people in self-advocacy groups and the support workers and people with intellectual disabilities who feature throughout the chapters of the book. They are the people who bring it all to life.
Chapter 1
Starting Points

The central interest: communication

This book is about communication. The research reported in these pages is based on recordings of people engaged in social activity. It is a type of research that is fascinating, because it offers a way to understand and change certain patterns in communication, patterns that regularly exclude some groups of people. Every time two or more people interact there is a fresh slate, an opportunity for each person to communicate with the other simply ‘as a person’ and to be open to new meanings, relationships and ways of interacting. Human communication can sound like something quite emancipatory – a tool for change! As the reader will suspect, it is not quite as easy in practice. In order to move towards more ‘empowering’ and equal situations in talk, it is vital to explore first the regular, routine power imbalances that affect many people. The chapters in this book therefore trace both problematic as well as positive aspects of communication as they are interwoven in the everyday here-and-now of people’s lives.

My central aim in this book is to deliver practical understanding of interactions with people with intellectual disabilities, so that those interactions can be carried out on a basis of equality. People with intellectual disabilities have a right to be included in interactions and have a right to speak out. All those who have an interest in communication, and in working alongside people with intellectual disabilities, will find much in these pages that will support new ways of communicating and working with individuals and groups.

Some readers turning to a book about intellectual disability will expect it to be about communication deficits: most surely, this book is not. Rather, it is about the way ordinary resources of social interaction are used in particular contexts by and with people with intellectual disabilities. Rather than offer ‘tips for support workers’, I aim to capture the complexity and intricate, moment-by-moment contingencies of two-way interaction. The extracts given through the text are detailed transcriptions of audio and video recordings of real-life activities, communication in which more than one participant was involved and where people were engaged in social activities, ranging from checking into a hotel or making a cup of coffee, to planning a research project and chairing a meeting.

Another, equally important starting point was my interest in finding ways to study human communication. Like other analysts, I started doing analysis of interactions because I was drawn to the study of how people understand and communicate with each other. Therefore, a parallel
aim of this book is to interest students, researchers and others who also want to study communication and are searching for inclusive and practical ways of approaching analysis. I use a methodology, described further in Chapter 2, which could be called eclectic, but draws largely on what is called applied ‘conversation analysis’, referred to as CA throughout (ten Have, 1999). I have taken a position that the tools of CA can be used as a practical methodological resource to explore issues of social concern. Moreover, I have carried out analysis in ‘inclusive’ contexts of research, involving people with intellectual disabilities themselves in the projects and in the analysis (Williams et al., 2009b). Because there are many conflicting positions and arguments about methodology within discourse analysis, the current book will not presume to side with one set of analysts or another. Instead, it will provide an account of how CA was practised within the current projects. All this is explained further in Chapter 2.

For those unfamiliar with CA methodology, I hope that this book will serve as a taster and a route into a fascinating area of study. Many would-be enthusiasts get put off by the technical and obscure façade of discourse analysis, and also by the seeming irrelevance of some of the findings about how communication is done. I have made a determined attempt to set analysis within a meaningful framework and to explain what I am doing, so that things are more accessible. I have also tried throughout the book to suggest and discuss why analysis matters. By following the analysis and reading some of the texts referred to in each chapter (e.g. Wooffitt, 2005), readers will be able to find out how the tools of CA could suit their own goals.

This book focuses on different social activities that contribute to having a voice in some diverse, lived contexts. It presents actual examples from research studies of what people have said to each other, but not as isolated comments given during interviews or presentations. For instance, the following lines are from a conversation between two people in a living room:

**Extract 1.1**

45. Sim right (.) would you like to help me with the coffee mate  
46. Al ((smiling)) if I ha::ve to  
47. Sim tt th tt ((LF))  
48. Al go on then↓ (0.2) did you take your cup in – you took your cup  
49. in didn’t you =  
50. Sim = yes I put in the sink yeah yes (0.2) ((gets up and walks to door))  
51. 52. sorry I’ve got nothing on my feet and I really should but –  
53. Al yeah ( ) you know you should but –  
54. Sim oh that’s another story isn’t it ((laughs))

Transcription conventions used throughout this book are explained further in Chapter 2; significantly the transcription above includes non-verbal noises such as laughter at line 47, indicated by LF. The numbers in brackets relate to the length of pauses in the talk, which are also of interest here.

The two people talking here are Simon and Alan. These are assumed names, like all the names in this book, except where it is acknowledged that people are active contributors and wish their name to be included. In extract 1.1, Simon is a man who has been labelled as having an ‘intellectual disability’ (or in the UK, where he lives, a ‘learning disability’). As they are talking, both men are also doing things – getting up from their seats, walking into the kitchen, and so on. However, there is also a sense in which their talk itself does things. In line 45, for instance, Simon uses talk to instruct his support worker, and at line 52 he accounts for the fact that he has nothing
on his feet. All these bits of talk perform actions in that they make it possible for the pair to get to the kitchen and to establish the task of making a cup of coffee. They also perform actions in reinforcing aspects of the relationship between Simon and Alan, whom Simon refers to as ‘mate’. A central task for Simon is about ‘doing control’ and being able to instruct his support worker in a pleasant and friendly way.

The topic of control is an important one in this book. It could be approached (as it often is) via a conventional research interview, by asking people how they feel about the choice and control in their lives. Research participants then reflect on their experiences and talk about how they perceive those experiences. When people like Simon talk about their lives, a researcher can literally give them ‘voice’ by listening, by giving them a forum and perhaps by publishing their words. I have been committed to all of those things for several years and have supported people with intellectual disabilities to be authors in their own right (Palmer et al., 1999a; Gramlich et al., 2000).

In this book I am more interested in analysing choice and control in action, through the medium of talk. In other words, I am interested to see how these things (such as giving instructions amicably) are done in the ebb and flow of real-life interaction. For instance, an analysis of the above extract could focus on the way in which Simon approaches the instruction which he gives to his support worker in line 45, and also the way that instruction is taken and built into a joke in line 46. It would notice perhaps also how Simon’s instruction puts him into a powerful position of control vis-à-vis his support worker, a position which then shifts on a line-by-line basis, when for instance Simon apologises for having nothing on his feet at line 52. Taking control of one’s life can be seen as a sensitive and subtle task when viewed as real-life interaction.

This book covers two quite contrasting areas of life for people with intellectual disabilities and for those who work with them. Part 1 focuses on communication that happens in everyday life. In particular, the reader will find many conversations with support workers who are working on a one-to-one basis for a person with intellectual disabilities. Part 2 turns to talk in more formal, public situations where people with intellectual disabilities are representing others, speaking up for themselves as a group and campaigning or researching for change. As Goodley (2003) has pointed out, personal and political lives have to be linked: voice and power are central concepts in both these arenas, and one of the central questions throughout this book concerns the links between communication in private life and in collective settings. If I had to pick out one thing I have gained from writing this book, it is a more informed understanding of the massive gulf between what happens in the private lives and the public lives of people with intellectual disabilities, and some of the missed connections between these two arenas.

All the central chapters are based on analysis of communication and feature transcripts from recordings of events that actually happened. That is what discourse analysis, and in particular CA, does, and the methodological tools for this approach will be briefly introduced in Chapter 2. One of the central and most important matters is to do with the stance of the analyst. When faced with a transcript of communication that actually occurred, the trick is to try and see it afresh without making any assumptions about who is who, or about wider issues such as power and equality (see Schegloff, 1998, 1999a & b; and the discussion in Chapter 2). These matters arise from the analysis rather than from any preconceived theories or positions. Therefore, I will try to avoid, in this chapter, any attempt to tell readers everything I know about people with intellectual disabilities. There are many other books which give comprehensive accounts of the field (e.g. Grant et al., 2005). Instead, this chapter merely aims to set some markers relating to identity and the social model of disability. The rest will emerge from the analysis, and the final chapter will serve as a repository for some discussion of the social issues that have arisen from that analysis.
Why does identity matter?

Through studying communication I soon became interested in identity, and would recommend particularly the stance taken by Antaki and Widdicombe (1998b). Their position is that identity is not a given, but is something that can be called on as a resource and reconstructed within talk (see also de Fina et al., 2006). Therefore, there are very close links between communication and identity, and nowhere is this more true than for people with an ‘intellectual disability’. The identity of ‘intellectual disability’ is frequently foregrounded in talk and can affect the way in which conversation is conducted, often with negative implications for people with that label. By the same token, however, it is possible to construct more empowering and meaningful ways of interacting, where people with intellectual disabilities literally ‘have a voice’, and where they can speak up for themselves. Communication, identity and disability are thus intimately linked.

My initial interest in identity came about because the people I worked with in a research group in 1997–2000 had an interest in labelling. In fact, they rejected strongly the label ‘learning difficulty’, which was the term used for ‘intellectual disability’ in the UK in some circles. One of the group members is on record as saying:

The words ‘learning difficulty’ were given to us by other people – by those people who diagnosed us. We know we’ve got this problem, seeing, speaking, understanding – but it doesn’t mean we have to have this label on our forehead. I feel like screaming, because people laugh. (Minutes of Self-Advocacy Research Group meeting, 15 January 1997)

The labelling debate itself can easily go off at a tangent, because of the multiplicity of terms. People referred to as having a ‘learning disability’ or ‘learning difficulty’ in the UK are labelled in different ways across the globe. ‘Intellectual disability’ or ‘intellectual impairment’ are the terms most commonly used now in Australia, New Zealand and at an international level, and there are other terms current in the USA, Canada and some European countries. Most of these terms have been disputed by people to whom the labels are applied, but since the current book aims for clarity internationally, I have chosen to use the term ‘intellectual disability’. However, as will be seen from the preface to Part 1, some of the people I have worked with do not relate to that term. Formerly, people in the UK preferred the term ‘learning difficulty’, as was established in 1994 by researchers who consulted with people in the People First movement (Sutcliffe & Simons, 1994). However, the term ‘learning difficulty’ has always been a source of some confusion in an international context, where it is often taken as synonymous with ‘dyslexia’. This is not what is meant here. The people featured in this book all have some kind of enduring and generic impairment, which affects their ability to learn and to manage their lives.

It is relatively easy to follow these debates about which label to use. But the labelling debate is not resolved simply by selecting the appropriate label for the moment. It is also about what is actually meant by the category ‘Intellectual Disability’. Many books about intellectual disability start from the presumption that an intellectual disability is something that a person either ‘has’ or ‘does not have’, like an illness. However, as Rioux and Bach (1994) pointed out in the title of their book, disability is ‘not measles’. Others (see Rapley, 2004) take a social constructionist view, and would argue that ‘intellectual disability’ is an entirely culturally constructed phenomenon. There are some complex issues to face in working out what ‘social constructionism’ can mean in the context of the kind of analysis done in this book and these will be picked up again in Chapter 2. For the moment, it is enough to note that a study of communication in action is bound to be interested in the ideas of social constructionism, which would claim that categories such as ‘intellectual disability’ can literally be talked into being (Rapley, 2004: 1–7) and do not necessarily have any solid existence outside that talk.
Such arguments invariably provoke a reaction, especially in those who live with someone with an intellectual disability. Social constructionism seems to brush aside the problems of an intellectual disability, and indeed the very definition (see the latest edition of the classification manual from the American Association on Intellectual and Developmental Disabilities, 2010). Definitions of ‘intellectual disability’ are nearly always premised on ideas about an inability to manage one’s own life. The current English ‘Learning Disability’ strategy (Department of Health (DH), 2009) adopts the definition introduced in 2001:

- a significantly reduced ability to understand new or complex information, to learn new skills;
- a reduced ability to cope independently;
- which started before adulthood, and with a lasting effect on development.

(DH, 2001: 14)

These facts about people are not idle abuse, brought about by an arbitrary label. Enduring cognitive differences do of course affect how people live their lives. People with intellectual disabilities across the globe have an assessed need to receive support precisely because they cannot cope independently with their lives; if they did not receive support, they would be in danger or at risk (see Fyson, 2009, for an airing of some of these dilemmas). The discourse of ‘incompetence’ (Simpson, 1995) underpins and justifies why people need support in the first place. Any description of the lives of people with intellectual disabilities at the start of the twenty-first century has to take into account their needs for social support, as well as their current devalued position in society. What the people included in this book have in common is that someone has decided at some point that they have an ‘intellectual disability’ – that is their diagnosis, their category or their label, bringing with it many distinct social experiences. For convenience, this book will refer to people with intellectual disabilities, where necessary, by that label.

Nevertheless, it would also be true to say that individuals with the label of intellectual disability do not constitute a homogeneous group, and the fact that they are grouped together under one banner is in many respects a cultural accident, an artificial phenomenon (Beart et al., 2005). There are considerable cognitive and functional differences between the people featured in the following chapters. For instance, at one end of the scale, people with intellectual disabilities may have little or no speech, have multiple or complex physical or sensory problems and perhaps also engage in behaviour which challenges those around them. The term also covers those who are quite independent and would be able to travel to another town or country with little support; they may be able to read, write and speak for themselves. Moreover, it can be appreciated that what counts as an intellectual disability in one society will not necessarily be considered an intellectual disability in another. Functional limitations are relative to the culture, the situation and the goals that people have. For instance, Rao (2006) discusses how Bengali mothers define ‘normality’ in a family-related way, depending on the achievement of yardsticks in social competence in Bengali culture. This is a quite different perspective from that which prevails in Western cultures, particularly in educational settings (Frederikson & Cline, 2002). Aspis (1999), for instance, describes herself as a ‘disabled person who has been labelled by the system as having learning difficulties’:

This makes it very clear that the name and the identity ‘learning difficulty’, have been imposed on me by the system, in particular the education system which pre-defines ‘learning ability’. (Aspis, 1999: 174)

There are now global policy goals to afford all citizens greater autonomy and control. The first guiding principle of the UN Convention on the Rights of Disabled People enshrines the notion of individual choice and states that all disabled people should be accorded:
Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons. (UN, 2007: 5)

Some of these issues do not sit happily together. How, for instance, are we to accept that someone can have autonomy in making important life decisions if, at the same time, we know that person needs support to be in control of everyday matters such as budgeting, going to a leisure centre or understanding time? At present, these tensions are seldom transparent in policy, although they are wrestled with in law. In the UK, some of the issues surrounding capacity have been clarified through the 2005 Mental Capacity Act. This legislation attempts to give clear guidance about how an individual can be assessed as capable, or incapable, of making a particular decision on a particular occasion (Jepson, 2008; Myron et al., 2008; Swift, 2008). Although the guidance associated with the Act emphasises the importance of support for individuals to make their own decisions, nevertheless for the first time in the UK, a precise definition of ‘incapacity’ is formally acknowledged through this legislation. The assessment of incapacity should explicitly be made separately for each context, each person and each decision, and the Act expressly states that blanket assumptions of incapacity should not be made because of a person falling into a particular category.

What does all this mean for people with intellectual disabilities themselves? At one level, the reality is often a life lived as a ‘learner’, struggling to gain the competence needed for a free and more independent lifestyle:

People with learning difficulties must demonstrate their competence prior to being granted autonomy … Competence is not liberation, although it may form part of it for some individuals. (Simpson, 1999: 154–5)

It could well be that this tension is becoming yet more marked in the global market of the twenty-first century. For instance, Dowse (2009) explores the increasing impact of neo-liberalisation and market forces on people with intellectual disabilities, and reaches the conclusion that the challenge of ‘being competent’ is becoming evermore extreme. People in society generally are increasingly valued and rewarded according to their intellectual abilities, and this is bound to have a knock-on effect on the position of people who lack those abilities.

Many of the people with intellectual disabilities I have worked with have been caught up in issues relating to their identity (see also Nunkoosing, 2000). They do not want to accept that their ‘intellectual disability’ defines them, and they would prefer to learn new skills and have recognition for their achievements. For instance, when the people in the research group in the ‘Finding Out’ project wrote up their work in a chapter for a published book (Palmer et al., 1999a), they described themselves as ‘people with intellectual abilities’. Yet they took part in organisations and activities that were defined by the fact that they had ‘intellectual disabilities’.

This book will explore in Chapters 3 and 4 in particular, with real examples, how ideas about incompetence inform and underpin the way in which other people talk with people with intellectual disabilities, how their decisions are vetted and how they themselves may seek approval for achievements in their everyday lives. Ideas about incompetence are very pervasive in Intellectual Disability thinking, without necessarily being consciously articulated. That is what is meant by a ‘naturalised’ discourse; it forms a backdrop to the ways in which people talk with each other, and it is an important job for discourse analysis to unpick and reveal what lies behind the way people communicate.

From this brief exposition I hope that I have given an idea of some of the debates about intellectual disability identity and the tensions underpinning them. Readers who wish to read further about these debates are referred to Beart et al. (2005) for a review and also to Finlay and Lyons (1998) and Craig et al. (2002). The changing of labels is one part of the battle about identity
waged by people with ‘intellectual disabilities’; as Eayrs, Ellis and Jones (1993) argued, the word used to refer to people does matter, and people have a right to choose the concept for themselves. However, whatever the latest term adopted for ‘intellectual disability’ it is also important to acknowledge that it has never been value-neutral in contemporary society. It implies a life set apart, with lesser rights than most citizens in the community (Tideman, 2005), and that separation is visible both in the private and the public encounters which are traced through this book. Through analysing everyday interactions it is possible to unpick some of these matters, and to start to understand how people both draw on a range of identities in order to communicate with each other, and how they reinforce and repackage those identities afresh on each occasion they talk. Approaches to identity using CA are explored further in Chapter 2, pp. 27–30.

The social model of disability

In order to gain a different, and hopefully more productive, perspective on the lives of people with intellectual disabilities, it is essential to take into account ideas that emerged in the 1980s and 1990s from the disabled people’s movement. The social model of disability (Oliver, 1990; Barton, 2004; Finkelstein, 2004) was formulated by disabled people because of their concerns about how they were being treated as misfits within a society that is primarily constructed around the needs of non-disabled people. They argued that they were disabled by society rather than by their individual impairments. The enduring contribution of the social model has been to turn attention away from the ‘problems’ of the individual and towards the barriers created by society. These can range from physical barriers (e.g. steps or lack of physical access to public buildings) to social or attitudinal barriers (lack of understanding or prejudice), and are always about institutional problems that may result in disabled people’s rights not being respected.

As Oliver (2004) argues, the social model in itself is a tool – it was originally formulated in order to fight back against the predominant, medicalised view of disability – and it has been profoundly influential precisely because it helps people to see disability in a new light. There have been many concerns, discussions and additions to the ideas at the heart of the social model (see for an example Thomas, 2004). However, the essential strength of the model has not changed, particularly in its application to practice.

It is easy enough to find examples of social barriers in what is known about the lives of people with intellectual disabilities (French, 1999; Abbott & McConkey, 2006). For instance, just as surely as people who use wheelchairs may be physically excluded (by lack of accessible toilets, ramps and lifts) so also people with intellectual disabilities are excluded by a society that is premised on the intellectual ability of all of its citizens (Dowse, 2009). It is still extremely rare for people with an intellectual disability in Western cultures to have paid employment (Beyer et al., 2004) because economies depend on increasing technical skills at work. Social exclusion indices paint a bleak picture for people with intellectual disabilities across the globe (Redley, 2009).

The social barriers faced by people with intellectual disabilities could be viewed as a very high wall, separating them effectively from the ordinary social achievements that make life worth living for most people. Todd and Shearn (1997), for instance, listed marriage, employment and personal relationships as being absent in the lives of most people with intellectual disabilities, and commented that:

People with intellectual disabilities seem to occupy a marginal social space typically occupied by the sociological form of strangers. (Todd & Shearn, 1997: 343)

The situation has not changed dramatically in the UK in the intervening years, as Welshman and Walmsley (2006) testify and as was borne out by a national survey in 2005 (Emerson et al., 2005).
What do these exclusions have to do with communication? If one thinks of the barriers faced by learning disabled people as macro-level barriers to certain material and physical goods (e.g. a house or a job), then it is hard to see how interaction can matter. Just by talking, people cannot solve every problem. However, as Watson (2003) observes, the exclusion faced by disabled people is enacted on a daily basis in the social practices of everyday life. The larger sociological forms of exclusion are visible in the conduct of individuals:

Disabling social relations are everywhere, they are part of disabled people’s everyday life … (Watson, 2003: 51)

The social business of the world takes place via communication between individuals. Therefore, when the discourse analyst looks at small chunks of that communication, it is possible to analyse how they both reflect and constitute the barriers faced by disabled people. There are frequent references to disabling communication in the literature and personal biographies of disabled people, for instance critiques of those who implicitly measure ‘disability’ against measures of what it means to be ‘normal’ (Swain & Cameron, 1999). To continue the metaphor, the high wall shutting out people with intellectual disabilities is made up of countless smaller bricks and mortar in the communication surrounding them.

An example of the link between discourse and social barriers is found in ideas about independent living. A recent review has found that people with intellectual disabilities throughout Europe are often excluded from policies supporting independent living (Townsley et al., 2009), because of the assumption that they would not be able to choose their own lifestyle responsibly and manage ‘independently’. These assumptions are reinforced every time someone talks down to a person with intellectual disabilities, treating them like a child or disbelieving what they say. Assumptions can also be built into higher-level discourses, such as the discourse about independence itself. In the field of intellectual disability, and among professionals in that field, independence is often talked about as ‘doing everything on your own’. It follows, therefore, that people with intellectual disabilities are forever learning ‘independence skills’ so that they can move further on towards that goal. Disabled academics, however, have argued that independence actually means being in control of your own support. Independence can be supported and does not imply that the individual literally has to do everything for himself (Morris, 1993; Office for Disability Issues, 2008). The Disability Rights Commission defined independent living as:

All disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people ‘doing everything for themselves’, but it does mean that any practical assistance people need should be based on their own choices and aspirations. (Disability Rights Commission, 2002)

As this new type of discourse surrounding independent living becomes more widespread, it can provide a challenge to assumptions about people with intellectual disabilities and thereby help to change the way people are treated.

Although social model theorists and discourse analysts have not always seen eye to eye (Oliver, 1996; Rapley, 2004), the social model is nevertheless a very useful starting point for a book that is about interaction with others in society. The analytic lens will be focused on those points of contact with other people, and my aim is not to offer insights about presumed brain processes or cognition of people with intellectual disabilities, but rather to unpick the way in which ordinary resources of communication are used by and with people with intellectual disabilities. Social models of disability, as Barton (2004) explains, were created by disabled people and are rooted in self-definition of disablement, by disabled people themselves. This is well expressed by Swain and Cameron in Disability Discourse (Corker & French, 1999):
The emergence of a discourse on disability around the social model … has provided disabled people with alternative forms of reference within which to build their own identities. (Swain & Cameron, 1999: 76)

That is why it is appropriate to think about the social model when exploring autonomy and voice. However, as in all discourse analysis, this book takes the position that theories emerge from data, and that the best way to look at real examples of communication is with a ‘fresh’ eye, unencumbered by theory (Silverman, 1999). That is why any further contribution to ideas and theories will be left until after the analysis, and it is only in the final pages of this book that I return to issues about identity and the social model of disability.

The research context

The two main studies on which this book is based were deliberately set up in ways that challenged and overturned assumptions about power, and in which notions of voice, control and autonomy were paramount. Equally, they provide contexts which become the focus for analysis, particularly in Part 2. The inclusive nature of the projects cannot be taken for granted, and this will be discussed further below. However, the topic and background of each study are also important to note, since this helps to clarify some of the extracts analysed in this book. Therefore, the following sections offer some very brief introductions to the rationale of each research study.

Background to ‘Skills for Support’

Part 1 (Chapters 3–8) is entitled ‘Individual Voices’ and concentrates on examples of conversations from everyday life encounters between people with intellectual disabilities and their support workers. Most of these are taken from a research study called ‘Skills for Support’ (see also Williams et al., 2009a, 2009b; Ponting et al., 2010). It was funded by the UK Big Lottery and was a partnership project between an academic research centre (the Norah Fry Research Centre, University of Bristol) and a disabled people’s organisation (the West of England Centre for Inclusive Living – WECIL). The aim of the research was to analyse, from the point of view of people with intellectual disabilities themselves, what ‘good support’ constituted. Two people with intellectual disabilities had paid jobs in this project, working with the author in a team based at WECIL, and during the final phase of this study over 20 hours of video data were collected from 14 pairs of support workers and people with intellectual disabilities (Ponting et al., 2010; Williams et al., 2009a, 2009b).

Since 1996, disabled people in the UK have had the opportunity to take a direct payment instead of a direct social service to meet their support needs (DH, 1996), and the philosophy behind direct payments is one of choice, control and empowerment for individual service users. Having previously worked with people with intellectual disabilities to explore the ways in which direct payments could be supported (Gramlich et al., 2002), I was now keen to see how the relationship with support staff played out in practice. Previous research about community engagement for people with intellectual disabilities in residential homes (Felce et al., 2002; Mansell et al., 2002) has emphasised that the single factor that makes a difference to outcomes is staff practices. Further, as will be explored in Chapter 2, discursive work in this area (Antaki et al., 2007a, 2007b) has emphasised the problematic nature of routine communications between staff and residents in care homes. By contrast, the focus in the ‘Skills for Support’ project was on
people who used direct payments and employed their own staff. It seemed to me and to my collaborator, John Kelly, that people would get more personal power because of the type of relationship they had with their support staff. We both hoped as well that this relationship could be turned around through the mechanism of a direct payment. Instead of the staff being in control, now the disabled person could be the ‘boss’ of their own staff (Gramlich et al., 2002).

More recently, the benefits of choice and control have been embedded in the personalisation agenda of the UK government. The government has set out its universal vision for personalised services for all disabled and older people who need a social service (PMSU, 2005; DH, 2006b). A key mechanism for achieving this control over one’s own life is to be the personal budget, defined as:

A clear, upfront allocation of funding to enable them to make informed choices about how best to meet their needs. (DH, 2008b: 5)

A personal budget is a wider concept than a direct payment; it includes the idea that people will know about the money allocated to them and will be able to get support to plan for themselves how they want that money to be offered. One of their choices may be a direct payment; another may be to hand over the budget to an organisation which provides the services they require. However, even if the service user chooses to pay an organisation or to opt for more traditional services, the goal is that they will still have control over the outcomes for their own life (Daly & Roebuck, 2008).

Will the brave new world of personalised services turn around the lives of people with intellectual disabilities? There are undoubtedly still tensions here, which will be explored throughout this book. I will show in Part 1 that supporting people to be in control of the everyday fabric of their own lives and decisions is not always as straightforward as it sounds. However, I am chiefly interested (as were my colleagues in ‘Skills for Support’) to gain insight into new, more personalised ways of working, and so Chapters 5–8 in particular will seek to elucidate the shape of more ‘equal’ interactions between people with intellectual disabilities and those who are employed to support them.

**Background to the ‘Finding Out’ project**

The other main research project, which features particularly in Part 2, took place before ‘Skills for Support’ and was a short study in which a group of people with intellectual disabilities ran their own project, with voluntary support from the author (Palmer et al., 1999a; Williams, 1999). At that point, there had been few examples of similar research involving people with intellectual disabilities, and we wanted to explore, to the limits, what it could mean for these people to actually have research roles. There were four people with intellectual disabilities in the research group, which existed for some two years. During the first few months group members decided to carry out some focus group interviews at other self-advocacy organisations in the area. Their aim, in the words of one of the members, was ‘to find out whether other people with learning difficulties are hitting their heads against a brick wall like we are’ (Palmer & Turner, 1998). The four research group members compiled a list of questions to talk about in the focus groups, and I helped them to arrange six visits, all of which were recorded on audio and video tape, as were most of the sessions we held on a weekly basis to run the group and learn about research.

In inclusive research nothing can be taken for granted; doing this type of work throws into question both the strategies for inclusion and also the activity called ‘research’. The process of carrying out the ‘Finding Out’ project was also written up in Williams (1999) and provided the
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basis for a discourse analysis in Williams (2002). It is the latter analysis that informs the current book. Like all social activities (e.g. a criminal trial, a university seminar, a reunion of friends), research is built up from a wealth of communication events. By studying these events, it is possible to gain a better idea of what characterises a particular social activity, and indeed, social research events have been analysed in this vein before (Silverman, 1973). The aim of my own discourse study was essentially to provide an analytical description of the 'Finding Out' project. Instead of assuming that people with intellectual disabilities could automatically step into academic 'research' roles, I set out to analyse the communication events that formed and shaped the research activity. My basic question was 'What actually happens between the people involved in an inclusive research study?' I was interested in what inclusive research actually meant in terms of actual communication practices. It is mainly data from this project which feature in Part 2 (Chapters 9–13), which is entitled 'Collective Voice'. These chapters focus on more public situations, where people with intellectual disabilities are representing others, speaking up through their own organisations or conducting their own research project.

Participation and voice

By claiming to do research, it could be said that people are taking part in collecting and creating their own knowledge. Therefore, a few words are in order here about the background relating to participation generally.

If people with intellectual disabilities are considered to be 'oppressed', then this institutionalised oppression can be challenged. With some support, people with intellectual disabilities, like Black people or women, have set up their own organised movement, which has been called 'self-advocacy' (Sutcliffe & Simons, 1994; Dybwad & Bersani, 1996). Like the idea of 'having a voice', the term self-advocacy is a loaded concept. It is only used at all because the people to whom it refers have not previously been able to advocate for themselves, as Goodley points out:

The term self-advocacy has been applied to account for the self-determination of minority groups who have historically been denied a 'voice' ... the self-determination of people with learning difficulties is emphasized and members of this labelled group are referred to as self-advocates. (Goodley, 2000: 7)

Goodley's formulation of 'self-advocacy' might sound straightforward, but of course these things are always more complex when they are played out in practice, as I explore particularly in the later chapters of this book. For a start, there are worries about the authenticity of people's 'voice', if this has to be channelled and supported through non-disabled people; this will be explored particularly in Chapters 10 and 12. Another tension exists in relation to the very self-identification of people with intellectual disabilities. One of the major campaigns of self-advocacy groups concerns the battle against categorisation and labelling; but if someone does not even identify as a 'person with intellectual disabilities', how can he or she be part of a movement purportedly owned by people with that label?

Participation in public affairs is associated not only with power, but also with the collective power that people have when they come together and campaign for their own rights (Beresford, 2001; Barnes & Mercer, 2007), challenging the status quo. That element of challenge is the positive point of this book. If it is possible to analyse how social forces of exclusion are re-enacted and constructed in everyday talk, it is also possible to consider ways in which the 'voice' of service users can contribute to changing policy and practice. Instead of being passive recipients of inadequate services, disabled people are now expected to take a full role as active citizens and to
determine what types of support they need. These notions of choice and control are at the heart of current Intellectual Disability policy in the UK and across the Western world (Johnson et al., 2010). Consider the following UK policy statement:

People with intellectual disabilities are amongst the most socially excluded and vulnerable groups in Britain today. Very few have jobs, live in their own homes or have real choice over who cares for them. Many have few friends outside their families and those paid to care for them. Their voices are rarely heard in public. This needs to change. (DH, 2001: 14)

There is an assumption here that the ‘voices’ of people with intellectual disabilities need to be heard and that this in itself will help to reverse the social exclusion they face. Using the methodology in this book, it is possible to get behind the rhetoric and to analyse how that participation may happen. The extracts in Part 2 focus particularly on ‘collective voice’, in situations such as meetings, research visits or public events.

This notion of voice is enshrined in the 2007 Convention on the Rights of Disabled Persons, of which one of the guiding principles is: Full and effective participation and inclusion in society. The question could be asked, of course, why some people may need a human rights statement in order to participate and ‘be included’; the implication is quite clearly that they belong to a category of people who are excluded and that ideas about participation and voice are being marked out as something significant and unusual for them. For instance, the English government’s disability policy (DH, 2001; PMSU, 2005; DH, 2006b) uses the following aspirational statement to urge policy-makers, service managers and commissioners to listen to what service users want:

At the same time as giving people greater choice and control over the services they use, we also need to ensure that everyone in society has a voice that is heard. (DH, 2006b: 7.4)

Does everyone have a voice ‘that is heard’? The situation for people with intellectual disabilities in public policy is arguably more problematic than for many other minority groups. In theory, the same injunctions to participate apply to people with intellectual disabilities, just as to other service users. Government disability policy (DH, 2001, 2006b) urges policy-makers, service managers and commissioners to listen to what service users want, and the ‘learning disability’ strategy, Valuing People (DH, 2001), claims that people with intellectual disabilities ‘should be fully involved in the decision-making processes that affect their lives’ (para. 4.27).

Despite the rhetoric, those of us who have been involved in supporting people with intellectual disabilities in self-advocacy forums, in consultations or in research are generally aware of the tensions and criticisms revolving again around worries about their intellectual capability (see Concannon, 2005, for some useful examples and discussion). Either people are criticised for not participating in a meaningful way or they are criticised for not being representative of the majority of people with intellectual disabilities (Fyson & Fox, 2008). Many people claim that people with intellectual disabilities can only participate in public policy if they are competent and autonomous (Barnes, 2002), and there have therefore been many discussions about the participation of people with intellectual disabilities in the UK and Australia (Frawley, 2008).

Another key concern is the role played by non-disabled supporters. For instance, Redley and Weinberg (2007) found that people with intellectual disabilities were frequently not speaking for themselves in participation forums, but were prompted, guided and moulded by supporters who did not have intellectual disabilities. Like Redley and Weinberg’s study, the present book seeks to find direct evidence of interaction in order to gain a deeper understanding of what is going on in the social activities which constitute ‘having a voice’. However, unlike Redley and Weinberg (2007), a wider range of social activities, participants and contexts will be sampled – both ‘front