

Breaking the Silence:
Institutional responses to people
who use atypical communication
strategies



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Declaration

The research in this thesis has not been submitted for a degree at this or any other university.

The thesis contains no material that has been published or written by another person except where due reference is made.


Rosemary Crossley ✓

13 November, 1997

Contents

DECLARATION	I
CONTENTS.....	II
FIGURES AND TABLES	V
ABSTRACT	VI
ACKNOWLEDGMENTS.....	VII
PROLOGUE.....	1
SECTION 1. PLACING COMMUNICATION IMPAIRMENT IN CONTEXT	3
CHAPTER 1. SETTING THE SCENE	5
1.1. <i>The construction of disability</i>	9
1.1.1. Pathology, impairment, disability, and handicap.....	10
1.1.2. Disability and technology.....	10
1.1.3. Disability and variation	11
1.2. <i>Incidence of communication handicap</i>	13
1.2.1. Hearing loss—prevalence.....	13
1.2.2. Expressive communication impairment—prevalence.....	13
1.3. <i>Precision and position</i>	16
1.4. <i>The model of treatment</i>	18
SECTION 2. FROM SIGN TO SPEECH—THE EXPANSION OF COMMUNICATION	
INTERVENTION FROM THE DEAF TO THE MUTE.....	20
<i>Difficulties of nomenclature</i>	20
CHAPTER 2. SPEAKING HANDS—RECOGNITION AND TREATMENT OF DEAFNESS.....	29
2.1. <i>Unsystematic intervention—individual expedients</i>	29
2.2. <i>The Enlightenment and after—establishment of a diagnosis of deafness separate from idiocy</i>	31
2.3. <i>The development of manual communication techniques for the deaf</i>	36
2.4. <i>The social progress of deafness</i>	39
CHAPTER 3. FINDING A VOICE—RECOGNITION AND TREATMENT OF MUTENESS.....	48
3.1. <i>The care of muteness</i>	48
3.2. <i>Establishment of a diagnosis of severe physical handicap separate from idiocy</i>	53
3.3. <i>The stigma of degeneracy</i>	56
3.4. <i>Unsystematic intervention and individual expedients—introducing non-speech communication techniques</i>	59

3.5. <i>The social progress of cerebral palsy</i>	63
CHAPTER 4. THE DEVELOPMENT OF NON-SPEECH COMMUNICATION TECHNIQUES.....	66
4.1. <i>The development of augmentative and alternative communication</i>	66
4.1.1. Unaided communication—Makaton signs.....	69
4.1.2. Aided communication—communication boards to computers.....	70
4.2. <i>The professionalisation of non-speech communication</i>	72
4.3. <i>Establishment of a diagnosis of severe communication impairment separate from idiocy</i>	80
CHAPTER 5. MUTE = DUMB—SPEECH AND INTELLIGENCE—THE SPECIAL RELATIONSHIP	85
5.1. <i>“This is Dopey. He don’t talk none”—the perception of intelligence in people with severe communication impairments</i>	85
5.2. <i>Assessment of atypical communicators</i>	94
5.3. <i>Intelligence and etiology</i>	102
5.3.1. Down syndrome.....	103
5.3.2. Persistent Vegetative State	116
CHAPTER 6. TREATING EXPRESSIVE IMPAIRMENT: CHALLENGING INTELLECTUAL IMPAIRMENT	124
6.1. <i>A very few words—limited communication for people labelled intellectually impaired</i>	125
6.2. <i>Mute does not equal dumb—the development of facilitated communication training</i> ...	132
6.3. <i>Unsystematic intervention and individual expedients—facilitating communication prior to 1986</i>	134
6.4. <i>Facilitated communication post-1986—a new DEAL</i>	145
SECTION 3. INSTITUTIONAL RESPONSES TO ATYPICAL COMMUNICATION	
STRATEGIES AND THEIR USERS	158
CHAPTER 7. COUNTING PEOPLE, COUNTING COST—STATE RESPONSES TO PEOPLE WITH SEVERE COMMUNICATION IMPAIRMENTS	160
7.1. <i>Conceptualisation, definition, enumeration</i>	161
7.2. <i>Accommodating SCI: Sensory disability</i>	164
7.3. <i>Accommodating SCI: Physical disability</i>	165
7.4. <i>Accommodating SCI: Intellectual disability</i>	169
7.5. <i>Accommodating SCI: Conclusion</i>	170
CHAPTER 8. SILENT WITNESSES—NON-SPEECH COMMUNICATION AND THE LAW	172
8.1. <i>Early history</i>	173
8.2. <i>English law: deaf-muteness in court</i>	173
8.3. <i>Severe communication impairment in court</i>	176
8.4. <i>Testimony with augmentative communication</i>	179
8.5. <i>Testimony with facilitated communication</i>	180
CHAPTER 9. MEDICAL, ACADEMIC, AND PROFESSIONAL ATTITUDES TO PEOPLE WITH SEVERE COMMUNICATION IMPAIRMENTS	193
9.1. <i>Professional relationships</i>	194
9.2. <i>Professional perceptions of disability</i>	197

9.3. <i>Professional reactions to disability</i>	202
9.3.1. Segregation	202
9.3.2. Neglect	204
9.3.3. Death-wishing	206
9.3.4. Use as research material	209
9.3.5. Characterisation as animals (or vegetables)	213
9.3.6. Viewed as irremediable	215
9.3.7. Viewed as ineducable	217
9.4. <i>Professional assessment of disability</i>	219
CHAPTER 10 PROTECTING THE BOUNDARIES—PROFESSIONALISM UNDER CHALLENGE	224
10.1. <i>Professional belief systems</i>	224
10.2. <i>Professionalism under challenge</i>	226
10.3. <i>Professional rivalries</i>	235
10.4. <i>Disability creation</i>	241
10.5. <i>The professions and disability: power relations</i>	244
SECTION 4. ACCOUNTS BY THOSE WHO USE ATYPICAL COMMUNICATION	
STRATEGIES	246
CHAPTER 11. IN THEIR OWN WORDS—EXPERIENCES AND PERCEPTIONS OF PEOPLE WHO USE ATYPICAL	
COMMUNICATION STRATEGIES	247
11.1. <i>Disempowerment</i>	249
11.2. <i>Segregation and isolation</i>	250
11.3. <i>Individual misconceptions</i>	262
11.4. <i>Individual ignorance</i>	264
11.5. <i>Talking politics</i>	269
11.5. <i>Achieving inclusion</i>	274
CONCLUSION	278
GLOSSARY OF TERMS	283
COMMUNICATION	283
NEURO-MOTOR IMPAIRMENTS	285
SPEECH IMPAIRMENTS	287
HEARING IMPAIRMENTS	289
BIBLIOGRAPHY	290
APPENDICES	313
APPENDIX #1—DECLARATION ON THE RIGHTS OF DISABLED PERSONS	314
APPENDIX #2—DECLARATION ON THE RIGHTS OF MENTALLY RETARDED PERSONS	318

FIGURES AND TABLES

FIG. 1	PATHOLOGY/IMPAIRMENT/DISABILITY/HANDICAP	FACING 10
FIG. 2	HEARING LOSS BY AGE	FACING 13
FIG. 3	COMMUNICATION HANDICAP BY DISABILITY AND SEVERITY	FACING 14
FIG. 4	SEVERE DISABILITY	FACING 162
TABLE 1	CAUSE OF COMMUNICATION HANDICAP	FACING 15

Abstract

This study compares the introduction and expansion of non-speech communication for people with receptive impairments with the introduction and expansion of non-speech communication for people with expressive impairments. It documents the introduction of specific non-speech communication strategies—sign, augmentative communication and facilitated communication—and discusses the controversies which have ensued. It examines institutional responses to the use of atypical communication strategies: in particular, it examines the treatment of people with communication impairments by the state and the reaction of the legal and professional establishments to the introduction of new communication techniques.

The primary hypothesis guiding the study was that repeating patterns would appear, both in attempts to change the status of different groups and in professional intervention and reaction. The secondary hypothesis was that the group recognised longest—the deaf—would have come closest to achieving acceptance.

Both hypotheses were supported to some extent. It is possible to discern repeating patterns both in the introduction of new communication techniques and in attempts by professional groups to control their use; and while people who cannot hear have not yet achieved full acceptance and understanding, they are considerably closer to both than are people with diagnoses of physical or intellectual impairment who cannot speak.

Acknowledgments

This thesis is the culmination of 25 years work with people who cannot talk, each of whom has contributed something to the attitudes and experience which underlie this text—as have my fellow workers, good and bad, and the families I met along the way. As part of my research I conducted a large number of interviews with people with communication impairments and those associated with them. While in the event changes in the plan of the thesis have meant that few of these interviews are quoted from directly, all contributed to my knowledge of the area, as did discussions with my colleagues at ISAAC, DEAL and the FC Institute. I thank everyone who gave me their time. Many people out there are dedicated to empowering people without functional speech, and I am grateful for their inspiration and encouragement.

Throughout my research I was very fortunate to have the support of an Australian Postgraduate Award. Nonetheless, this document would not exist without the input of my supervisors—Helen Borland, Ron Adams and Michael Hamel-Green. I have been blessed with supervisors who have been both interested and interesting, keeping me to a timetable while allowing me freedom to pursue promising lines of inquiry. Their support, and that of Jane Trewin and other administrative staff in the Faculty of Arts, and the offices of Postgraduate Studies and Information Technology, has been invaluable.

Anne McDonald and Chris Borthwick, my housemates, have over the past four years sacrificed much of their lives to this project. Their contributions have been crucial.

Thank you, everyone.

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Prologue

A journey of a thousand miles starts with one step. The step which led me to research society's responses to people who use atypical communication strategies occurred in 1965. I was an undergraduate and had a holiday job as a teaching assistant at a day centre for people with cerebral palsy. Each Friday morning it was my job to take one of the students to the nearby shops to purchase ingredients for the lunch we would cook together. On this particular day I was wheeling Brett, a teenager with spastic quadriplegia and no speech. Brett had all the paraphernalia of severe disability—callipers, straps, a tacky sheepskin and a bib. As I was wheeling him down the street a middle-aged woman with blue hair and white gloves stopped me. “You must have done something dreadful to have a child like that,” she said. The cruelty and stupidity of the remark are obvious, as are some of the other assumptions on which the woman was operating. She assumed that I must be Brett's mother because no-one other than a mother would be seen with such a child. She also assumed that Brett was unaware and uncomprehending.

Brett understood everything she said. No-one who knew Brett could doubt his lively intelligence or overlook his wicked sense of humour. Sadly, Brett died before the advent of the communication techniques and technologies which have liberated the language locked inside many others like him since the sixties.

That walk with Brett brought home to me for the first time the burden of prejudice under which people with severe disabilities and their families labour. It also made Brett's disempowerment patent. Without a voice he could not respond. Without a voice he was at risk of being

viewed as object, not person. That walk started an engagement with people without speech which has led me to write this thesis some three decades later.

It would be false to pretend that this thesis is solely the product of disinterested research. It is the product of research viewed in the light of my own experiences since that walk with Brett. During this thirty years my life has become increasingly intertwined with the lives of non-speakers. While I have not experienced life without speech, I have taught and lived with people without speech. The experiences which I have shared with people who cannot talk give me a different perspective from that of a less engaged researcher. I believe that it adds to, rather than subtracts from, the validity of my results. As Harlan Lane contends:

Even if we could write history as documentation, we should not. If the historian's subject turns on sustained outrages against fundamental human values, as mine does, is he to deny his humanity and pretend indifference? (Lane, 1984: xv)

My journey parallels that of the development of non-speech communication. At this time only someone who has made such a journey can hope to investigate this topic fully because the texts are not yet there. They are being created now, by people without speech and their fellow travellers, in whose minds and diaries the recollections of the growing years of non-speech communication are stored.

Section 1. Placing communication impairment in context

According to German philosopher Jurgen Habermas there is a universe of meaning that is

hermetically sealed to the view of observers incapable of communicating....The life world is open only to subjects who make use of their competence to speak and act. They gain access to it by participating, at least virtually, in the communications of members and thus becoming at least potential members themselves. (Habermas 1984:112)

More simply, Anne McDonald wrote that to have a severe communication impairment is to risk being placed “totally outside the boundaries which delineate the human race.” (Crossley & McDonald, 1980: vii)

This study explores those boundaries. It covers the period since the formalisation of sign language communication for the deaf in the late eighteenth century and compares the introduction and expansion of non-speech communication for people with receptive impairments with the introduction and expansion of non-speech communication for people with expressive impairments. It examines societal responses to the use of non-speech communication strategies by people with varying communication impairments, in particular the reactions of administrative systems and professional establishments to the introduction of new communication techniques. While it focuses on Australia it also contains material from other western countries.

Currently people with severe communication impairments are seen as belonging in one of three broad categories: sensorily impaired, physically impaired or intellectually impaired. This study documents the changes in status which have occurred for members of each category as the

nature of their communication problems has been recognised, alternative communication strategies have become available, and members of the group have become their own advocates. It also assesses how well each group has succeeded in attaining full participating membership of the wider society.

Hypothetically, establishment of effective communication and provision of appropriate educational options should result in recognition of learning capacity, with citizenship rights, inclusion and acceptance following. This thesis examines both the past and current societal status of different groups of individuals with communication impairments, primarily from English-speaking countries, in terms of their progress through this sequence. It attempts to document the changes in status which have occurred for each group, and to explore the dimensions of power in the communication between people with severe communication impairments and social institutions and professional structures.

The primary hypothesis guiding this thesis is that repeating patterns will appear, both in attempts to change the status of different groups and in professional intervention and reaction. The secondary hypothesis is that the group recognised longest—the deaf—will have come closest to achieving acceptance, and that today children who are deaf are more likely to progress through a sequence of diagnosis and intervention leading to acceptance than children whose communication impairments are not due to deafness.

Chapter 1. Setting the scene

Few of us will ever do anything more complex than learn to speak the language which surrounds us in infancy. Virtually every baby has grasped the basics of its surrounding language by the age of one. The child speaks very little, if at all—developing fine motor control takes time and practice—but it has established the foundation of understanding which will lead to mastery of spoken language within the next few years. Nobody teaches a baby to speak. Nobody teaches a baby to understand. The baby learns to associate the peculiar sounds that the humans around it make with the people, the objects and the happenings in its environment (Pinker, 1994: 266).

By the age of two or so children without communication impairments know that the world “is open only to subjects who make use of their competence to speak and act.” (Habermas, 1984: 111) They proceed to do a lot of work refining their pronunciation and extending their vocabularies and their command of syntax. They learn many social conventions about greetings and farewells and please and thank you and what words get you into trouble and when to whisper; and by the time they start elementary school they are really amazingly good communicators (Pinker, 1994: 269-273). Five-year-olds may have speaking vocabularies of 5,000 words and understand many more than they say; estimates of adult vocabularies vary widely from speaker to speaker and researcher to researcher, ranging from 10,000 words to 50,000 plus (Pinker, 1994: 150).

This thesis is about the one person in two hundred who cannot say those words (Borthwick, 1994: 34). This chapter briefly describes the impairments which prevent people speaking and introduces the main

groupings of people with communication impairments and the communication strategies their members use¹.

There are two main classes of communication impairments: receptive and expressive. Hearing or speech impairments can either be present from birth or acquired later in life. A developmental communication impairment affects a child's learning and socialisation. An acquired communication impairment alters the interaction of an individual with his/her social group or groups.

The acquisition of language is a complex process, and there are many points at which it can break down. Babies who cannot hear do not develop language without special intervention unless they are born into a signing household (in which case they acquire visual, signed language naturally, in the same way as a hearing child in a speaking household acquires auditory, spoken language). Called pre-lingually deaf, they are at great risk of linguistic, social and educational deprivation if their impairment is not diagnosed and addressed early in life.

Occasionally babies who can hear have something wrong with the neurological system involved in decoding speech, and are unable to attach meaning to the sounds they hear—they, too, may be left without language. Those who have difficulty storing information will be slow in acquiring vocabulary and syntax, and their comprehension and expression will be impaired relative to their age peers.

Severe expressive impairments exist in isolation relatively rarely, and when they do are called Specific Language Disorders. More frequently they are associated with other diagnoses, commonly Cerebral

¹ Some of the material in this chapter has been published in *Speechless* (Crossley, 1997).

Palsy, Autism, Down syndrome or intellectual impairment of unknown etiology. Whatever the cause, basically children who have difficulty accessing motor or verbal memory will have problems using spoken language and children who have neuro-motor problems affecting control of the muscles of the mouth and throat will find production of intelligible speech difficult or impossible.

People who started life with normal hearing and whose speech developed normally may lose either or both in later life. Hearing loss may occur as the result of illness or drug reactions, injury, environmental exposure to noise or old age. While loss of hearing after speech and language have developed certainly creates significant problems these are of a different order of magnitude from the problems posed by pre-lingual deafness. Most individuals who develop hearing impairments as adults retain fluent speech. They also retain whatever language, literacy and academic skills they acquired before becoming deaf: while they may not be able to hear the voices around them, they have language and understand the social system in which they exist. Because of their pre-existing skills they are better able to utilise technical developments such as hearing aids, 'bionic ears', captioned television and telephone typewriters than people who have always been deaf (although, of course, most people with acquired hearing impairment still use no technology other than a hearing aid). Even lip-reading is easier for people who already know the language and the way it is put together.

One cause of speech loss is mechanical damage to any of the organs involved in speech production, such as excision of the larynx or laryngectomy. People who lose speech as the result of localised damage are usually able to use their hands normally and retain writing skills. If so,

they have more communication options than people whose speech loss is due to neurological impairments which may affect all physical abilities. The major causes of acquired neurological impairments affecting speech are acute illnesses such as encephalitis, progressive neurological disorders such as motor neurone disease, accidental brain damage, stroke, neurosurgery and the dementias.

While most people have at least some knowledge of deafness, relatively few know anything about people who can hear but not talk. Individuals are described as having severe communication impairments when their speech and handwriting are insufficient to meet their communication needs. The term is usually used in relation to people with no speech or very little intelligible speech, but it may also be applied appropriately to people whose speech, while clear and fluent, is still not meaningful or representative of their real thoughts.

Impaired speech may be replaced or augmented by gesture and body language, manual sign, handwriting or typing, and communication aids.

Gesture and body language are used to some extent by almost all people. While some formalised gestures, such as nodding the head for 'yes' and shaking for 'no', are powerful, there are intrinsic limits on the sophistication of communication obtainable by gesture and body language alone. In particular, while a person can respond to questions or circumstances through gesture and body language, initiating and carrying on a conversation is virtually impossible.

Manual sign is as powerful as speech for face-to-face communication, providing that no physical or neurological impairment affects signing capacity and that all parties to the interaction share extensive sign vocabularies—can use and understand thousands of signs,

that is, in the same way as adult speakers use and understand thousands of words. Few people who are not deaf have been exposed to sufficient manual sign to acquire large vocabularies. Manual signing consequently attains its full power only when used in the deaf community.

Handwriting is as powerful as the literacy skills of writer and reader. It loses the inflection given by speech, sign and gesture, but it is probably the most common way of compensating for speech incapacity caused by acute illness in older children or adults. Keyboards or alphabet cards may be used by people who cannot produce intelligible handwriting.

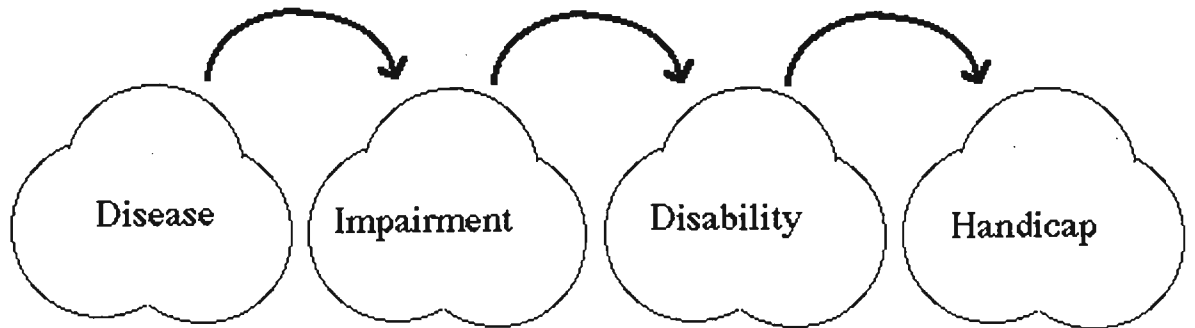
Communication aids are devices specifically developed or adapted for use by people with severe communication impairments. Because they have very varied skills, needs and problems, there is a large range of communication aids. Some people with severe communication impairments can use their hands: others cannot, and have to use alternatives such as mouth sticks, headsticks, switches or eye-pointing. Some can read and spell: others cannot, and need communication aids on which language elements are represented by pictures or symbols. Some individuals use wheelchairs which can accommodate large communication devices: others walk and need small, light aids. Some have the funds to purchase high tech equipment: others do not. A communication aid may be as simple as a piece of cardboard with NO and YES written on it or as complex as a laptop computer controlled with one switch which allows the user to speak on the phone (using an artificial voice) or type an essay.

1.1. The construction of disability

The World Health Organisation's International Classification of Impairments, Disabilities and Handicaps (ICIDH) breaks disablement into organic change, impairment, disability, and handicap. Impairment,

Figure 1—Pathology/Impairment/Disability/ Handicap

(from Borthwick, 1994: 6)



disability and handicap are not fixed quantities. What they mean depends on the surrounding society and the technologies available to it.

1.1.1. Pathology, impairment, disability, and handicap

The central point is that the construction of disablement moves from characteristics of the body (such as disease or deformity), to operations that the person is unable to perform because of those characteristics (impairments), to everyday activities that they are unable to carry out as a result (disabilities), and to the disadvantages they suffer as a consequence (handicap).

See Figure 1

For example, Jo has auditory nerve damage (pathology). He cannot hear (impairment) and cannot use an ordinary telephone (disability). Whether this disability constitutes a handicap depends on where Jo is living—in a nomadic community with no phones, it is not; in a community which provides telephone typewriters (TTYs) and has a relay service it is an inconvenience but not a handicap; in any phone-dependent society without accommodations for deafness it is a handicap.

1.1.2. Disability and technology

Technology can cause impairments, it can cure or compensate for them, and it can change the requirements for living in society in ways that turn some disabilities into handicaps and some handicaps back into mere disabilities. The same impairments affect people's lives differently in the 1890s and the 1990s. This is not primarily because special technology has been developed over the century to help people with disabilities: rather it is because the interplay between technology and society has over that time changed the world they have to operate in.

One hundred and fifty years ago there were no telephones to put deaf people at a disadvantage. Nor were there any hearing aids. The most sophisticated aids available to deaf people were the speaking tubes and ear trumpets used by elderly people. When the hearing aid replaced the ear trumpet it was part of the whole wave of change that followed the discovery that speech could be turned into electromagnetism and back into sound, a change that arose in part because Alexander Graham Bell, the inventor of the telephone, had a deaf mother and was a teacher of the deaf. His first invention had been ‘an instrument for transmitting vibrations’ to help lipreaders distinguish between the letters P and B. From that endeavour it was only a small jump to the ‘harmonic telegraph’, as Bell at first called the telephone. Whatever Bell’s intentions, however, it is not clear if the hearing aid helped people with hearing loss as much as the replacement of written correspondence by phone calls disadvantaged the profoundly deaf:

In his desire to restore speech to the deaf, Bell had invented the one device that more than any other would prove their undoing, closing hosts of jobs to them, and depriving them of all the services and comforts that would be carried thereafter by an undulating current and no longer by a person. (Lane, 1984: 353)

There was not a direct trade-off between the two devices, with the new hearing aids making the new telephones universally accessible, because hearing aids only benefit those who have residual hearing.

1.1.3. Disability and variation

Hearing loss represents an instance of identical impairments being formed into a number of very different disabilities. Those who are deaf from birth (prelingually deaf) have different problems, needs and attitudes from those who become deaf in childhood or adult life after having had an unaffected opportunity to learn spoken language, and this group is different

again from those who lose acuity with age. Prelingually deaf people have many of the characteristics of a linguistic and cultural minority, being largely dependent on the use of sign language, and resent it being assumed that they are disabled by their impairment rather than by the reluctance of society to learn their language. The Australian Association of the Deaf describes this group as those who

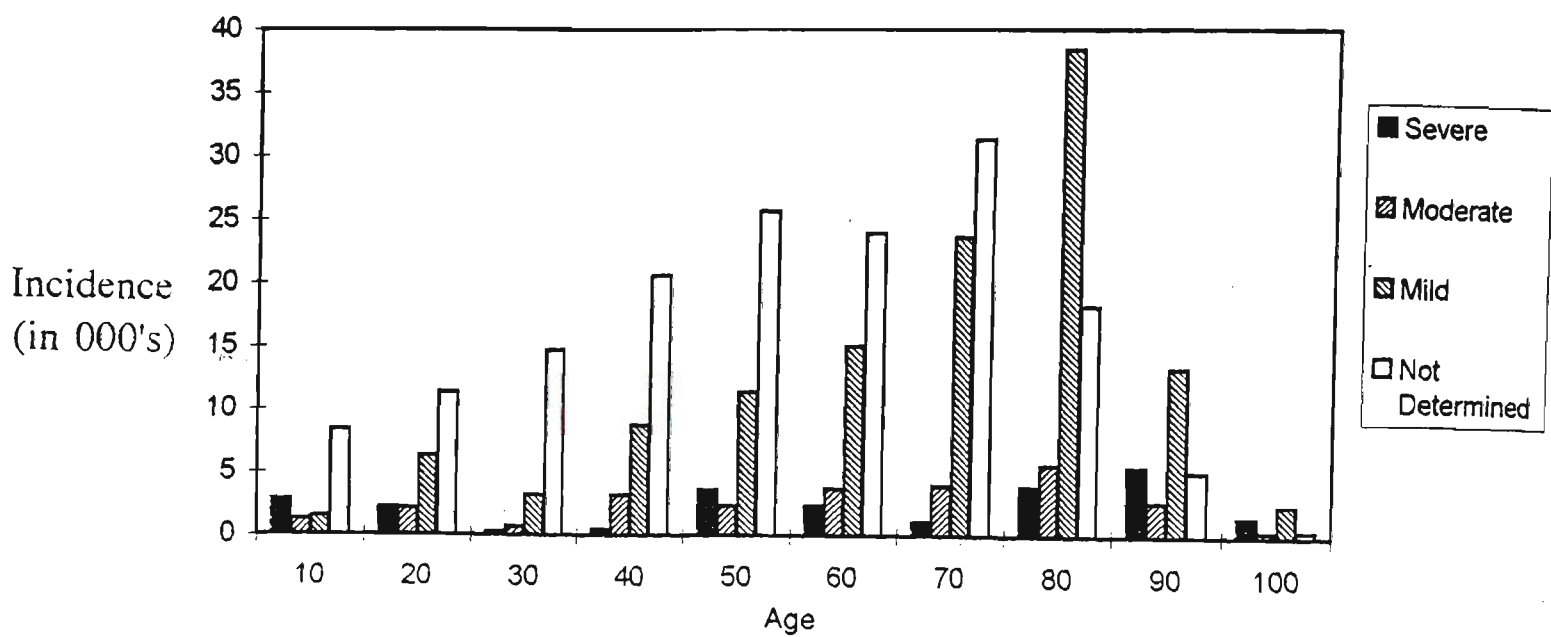
were born deaf or became deaf early in life. They usually were educated in special settings for deaf students. They may speak or lipread when communicating with hearing people (or write notes) but their preferred method of communication is Australian Sign Language ... both among themselves and with the increasing number of hearing people who understand some Auslan ... this last group of people [is] now frequently referred to as 'The Deaf Community'.

The Association notes that

Many members of the Deaf Community do not regard themselves as 'impaired' or 'disabled' and resent being so labelled, even though the hearing community's attitudes and practices may make life in an essentially speaking-hearing community very difficult for them at times, often preventing them from achieving their full potential or obtaining their rights as Australian citizens. They usually prefer to be called 'Deaf' rather than hearing impaired: they do not believe themselves to be 'impaired'. (Power, 1992: 43)

A reference, therefore, to the Deaf community does not pretend to be a statement about all people with a particular level of hearing acuity but, rather, one about a particular component of that population. As can be seen from Figure 2, prelingually deaf people are in fact a minority, forming between five and ten percent of the total. That proportion will continue to fall as the rubella epidemics recede into the past and the number of older people continues to rise (Borthwick, 1994:45).

Figure 2—Hearing Loss by Age ('000) 1988 ABS figures



1.2. Incidence of communication handicap

1.2.1. Hearing loss—prevalence

Australian Bureau of Statistics (ABS, 1990: 113) figures suggest that 23,800 Australians (0.21% prevalence) have a severe, 27,200 a moderate, and 134,700 a mild hearing loss (with 31,700 not determined), a total prevalence of 1.90%. The prevalence of hearing loss has increased since 1981 in older age groups but has decreased for younger age groups. Congenital hearing loss is generally not detectable at birth, and the average age of identification of hearing problems in children is approximately 2.5 years.

See Figure 2

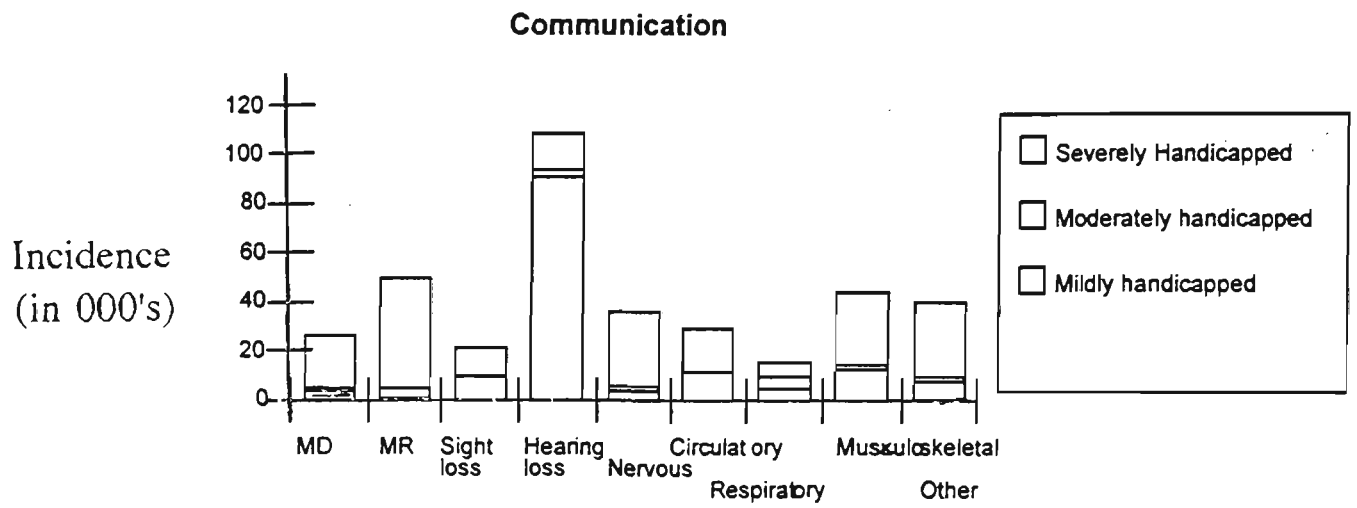
Epidemiological studies of deafness or hearing impairment put the rate of severe deafness or hearing impairment at between 0.1% and 0.2%, agreeing with the ABS (Borthwick, 1994:45). Definitions of severity vary notably, influencing reported prevalence.

As noted above, control of rubella has reduced the incidence of developmental deafness or hearing impairment considerably, but this fall will be to some extent compensated for by an increase in hearing impairment among older people as the Australian population profile changes.

1.2.2. Expressive communication impairment—prevalence

ABS figures suggest that 77,100 Australians with mental disorders and 333,300 people with physical conditions, a total of 400,500 and a prevalence of 2.45%, have communication handicap. Of those, 198,900 have a severe handicap, 58,000 a moderate handicap, and 143,600 a mild handicap.

Figure 3—Communication Handicap, by Disability and Severity
 ('000) 1988 ABS figures



MD=mental deficiency

MR=mental retardation

See Figure 3

The ABS category of communication handicap is grouped in 'Areas of handicap' rather than 'Primary disabling condition'. It includes both receptive and expressive disorders and thus covers hearing impairment and visual impairment (affecting written language use) as well as speech impairment. The breakdown of disability groups within this category is as shown above. There are many problems with ABS figures in this area: it is, for example, unclear how musculoskeletal and circulatory disorders can be associated with communication impairment unless they include people with stroke or arteriosclerosis who should properly be classified in 'mental disorder'. Together musculoskeletal and circulatory disorders contribute a significant 23% of the total, with intellectual impairment adding 12%, mental illness 7.5%, hearing impairment 30% and visual impairment 7%. Hearing impairment is obviously the largest single category of communication handicap. It should be noted that the ABS figures give no indication of the numbers who cannot speak or whose speech is so impaired as to require supplementation.

A 1986 survey of the Victorian prevalence of severe expressive communication impairments (SCI) (Bloomberg & Johnson, 1990a) sought data on 'nonspeaking' people. It identified 5,034 people with SCI, a prevalence rate of 0.12%. As reporting in a number of areas was less than optimum the authors regarded this as a minimum estimate. The letter of request stated that the survey sought information on

the number of people in Victoria with a severe communication impairment. These are people who are unable to get their message across using speech....Results of this survey will supply us with information to provide a better service for nonspeakers in the future....A person with a severe communication impairment is someone for whom speech is temporarily or permanently inadequate to meet all of his or her communication needs. This does not include people who do not speak

Table 1, Causes of Communication Problem (from Bloomberg & Johnson, 1990a)

Cause	2-21 years		22-40 years		>40 years	
	N	%	N	%	N	%
Unknown (N=1818)	884	49	728	40	206	11
Cerebrovascular accidents (N=773)	12	1	15	2	746	96
Cerebral Palsy (N=676)	442	65	172	25	62	8
Genetic/congenital (N=437)	236	54	168	38	33	8
Developmental delay (N=273)	273	100	N/A		N/A	
Autism (N=209)	183	88	26	12		
Progressive neurological disease (N=199)	38	17	29	15	132	66
Trauma (N=149)	65	43	49	33	35	23
Tumour or infectious disease (N=84)	31	38	33	39	20	24
Elective mute (N=74)	32	43	23	31	19	26
Psychosis (N=65)	13	20	26	40	26	40
Surgically related disorders (N=52)	5	10	4	8	43	80
Surgically related dysfluency (N=18)	9	49	4	22	5	28

(Bloomberg & Johnson, 1990a: 55)

because they are deaf nor does it include people who appear unaware of their surroundings. (Bloomberg & Johnson, 1990a: 55)

It is possible that the survey's use of the term 'nonspeakers' reduced the reported prevalence. A number of communication disorders such as aphasia and echolalia leave people with some speech but severely restricted communication, and these may not have been notified. The survey also excluded people (such as those, for example, regarded as being in a persistent vegetative state) who appeared unaware of their surroundings: a question arises here as to whether these people appear unaware of their surroundings because they have severe communication impairment and cannot communicate their awareness to those around them.

Nearly three quarters of the people presenting with SCI, 3,574 people or 71%, were regarded as having an intellectual handicap. Of these, 1742 or 48.7%, had intellectual disability of unknown etiology. Causes of the communication problem were tabulated by Bloomberg & Johnson (see Table 1). More than half (52%) of nonspeaking people were doubly disabled, having cerebral palsy, say, listed as a primary cause of the communication problem and also being regarded as having an additional intellectual disability.

Prevalence of the milder forms of communication handicap has not been precisely surveyed in Victoria. An English study on the need for speech therapy suggests: that over half of people diagnosed as intellectually disabled have 'a severe language deficiency or an articulation defect or both', a general prevalence of 0.28%; that post-stroke dysphasia and dysarthria affects 0.04% of the population: that communication disability following progressive disorders such as MS affects 0.14%; that head injuries contribute 0.028%; and that some 12% of children have

speech problems (Enderby & Davies, 1989: 305). Such estimates emphasise the scope for uncertainty in diagnosis and classification.

Prevalence of individual speech impairments such as apraxia, dysarthria and aphasia is unknown. All conditions are more prevalent among older age groups, but are generally subsumed under the statistics for dementia. There are no available data on the incidence of apraxia among the elderly—except that it has been suggested that half the people who have aphasia may also have apraxia, and some 400,000 aphasic survivors of stroke (eighteen cases per ten thousand) live in the United States. These conditions will increase with an ageing population: U.S. figures suggest a rise of 64% in speech handicaps in the over-65 age group between 1970 and 1980 (Borthwick, 1994: 34).

1.3. Precision and position

The apparent precision of the figures given in 1.2 is misleading. Different assumptions and different definitions inevitably render any measurement of disability to some extent arbitrary:

There is not a clear standard of healthy ability, from which deviations may be measured: there is only an average, which measures, depending on your point of view, an average measure of health or an average measure of disablement. We are all limited ... as to the activities in which we engage and the levels at which we pursue them. None of us is simultaneously both Olympic athletes and Nobel prizewinners. For the most part we are content if there are things we can do without regarding ourselves as 'disabled' because of the things we cannot do. People are regarded as 'disabled', and can regard themselves as 'disabled', when their range of feasible choices does not overlap with the statistical norm—with the stereotype of the model in the Coca-Cola commercial—but their range of choices can nonetheless be, or can be made, as wide as that of any other person: as wide, but in a different area. (Borthwick, 1994: 11)

It is tempting to make deductions from ABS figures about community attitudes to people with communication impairments and about

the relatively advanced position of the deaf (who are, after all, separately enumerated). However, ABS disability statistics are both confused and confusing. Deafness is more clearly visible because the diagnosis coincides with the impairment. Expressive communication impairment, on the other hand, is not clearly visible because it is associated with a large number of diagnoses and does not have clear boundaries. This uncertainty arises in part because the concepts of illness and disability are themselves ill-formed.

Official statistics do not merely hold a mirror to reality. They reflect presuppositions and theories about the nature of society. They are products of social, political and economic interests that are often in conflict with each other. By the questions asked (and not asked), categories employed, statistical methods used, and tabulations published, the statistical systems change images, perceptions, aspirations. (Alonso & Starr, 1992: 1-2)

Outside the statistics we have a different process of classification. Disability is not seen as a standard against which people can be objectively measured. It is seen in social terms. It is seen as incurable, though not necessarily untreatable: that is what distinguishes a regular twice-a-year disabling attack of asthma, which is a chronic illness, from a regular twice-a-year disabling attack of flu, which is just an illness. And it is seen as differencing, and thus to a greater or lesser extent socially defining: people with arthritis may see themselves as different from the central social image, feel a common identity with other people with the condition, and form themselves into self-help groups, while people with poor teeth see themselves as normal, see no common identity between each other, and just go to the dentist.

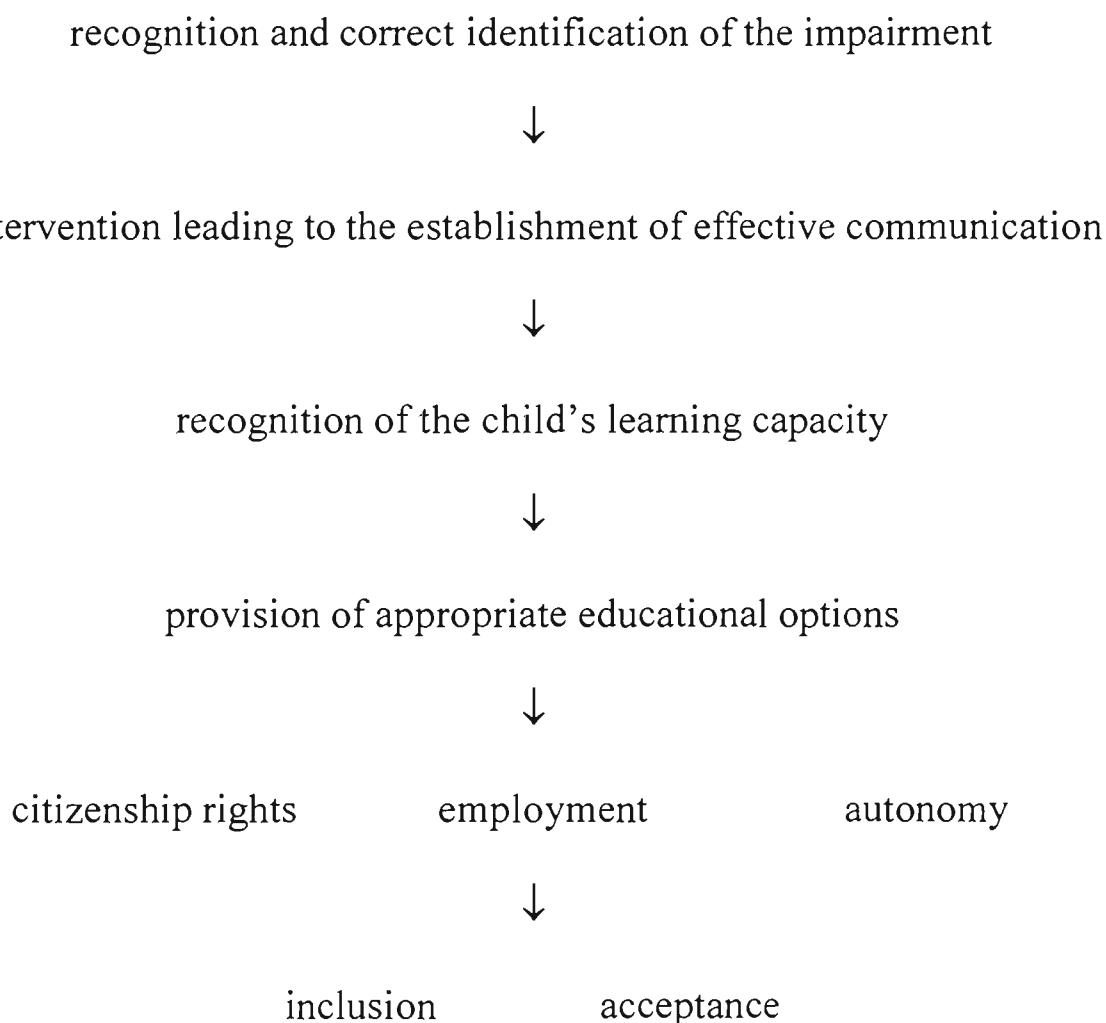
Our labels are based on the extent to which we can separate the person from their condition and imagine them without it—the extent to which we feel that the condition is an intrinsic and inherently distorting

part of the person rather than a random accident, something that they are, rather than have, and something that they are and we are not.

My hypothesis is that the group most affected by this identification of the person with the condition is the group with unremediated communication impairments.

1.4. The model of treatment

For any child born with any communication impairment an ideal course of events would be:



Achievement of these goals by any child with a communication impairment is dependent not only on the child's individual circumstances but also on whether these goals have previously been achieved by any

other members of the diagnostic group to which the child belongs, whether this sequence is generally accepted as achievable by group members, and whether the accommodations which make it achievable are in place.

This model of treatment bears a superficial resemblance to what would seem *a priori* the commonsense model of historical development: an impairment would be identified; an intervention would be established; the capacities of people with that impairment would be established; their rights would follow from their capacity; and their acceptance would crown the social movement. The actual historical development of disability groups has deviated from this model in many respects, and the nature of the difference is instructive. The chapters that follow examine the history of the three main sub-groups of people with communication impairments—those seen as primarily sensorily, physically, or intellectually impaired—in order to compare their development both with each other and with this model. The thesis concentrates on those people born with severe receptive or expressive impairments—the pre-lingually deaf who cannot understand speech even with hearing aids, and hearing individuals without functional speech.

Section 2. From sign to speech—the expansion of communication intervention from the deaf to the mute

The previous section described and enumerated communication impairments as they are understood today. This section looks back in history to the earliest references to communication impairment, and delineates the successive separation of different types of communication impairment from the general category of non-communicative idiocy. Before moving into history, however, it is necessary to examine and clarify terms.

Difficulties of nomenclature

In the nature of things it is difficult to find historical illustrations of attitudes to individual impairments from contemporary sources. Until people conceptualised a diagnosis such as severe communication impairment as a discrete problem, they did not—could not—speak about it. Equally, in describing differences they used a terminology—idiot, moron, imbecile—which we do not now find politically correct, and which today might not have the meaning it originally had. It is important to use the original terminology precisely because it is not clear exactly who may have been included in a category such as “idiocy”: translating it into today’s politer “intellectual impairment” or “learning disability” would give a false impression of specificity and exclude groups such as the deaf who would not now be included under the intellectual impairment umbrella, but who may have been in the past.

Earlier classification systems operated on different principles from those operating today, which are based on a combination of etiology and

impairment. After all, when the most commonly accepted etiology for disabilities was divine retribution it was scarcely possible to use etiology as a basis for classification. Ambrose Paré's list of reasons for the birth of two-headed girls, goat-boys, hairy girls and similar developmental disabilities illustrates the difficulties faced by doctors working in this tradition:

- 1) God's glory
- 2) God's wrath
- 3) Too much semen
- 4) Too little semen
- 5) Imagination
- 6) The narrowness of the womb
- 7) The unbecoming position of the mother
- 8) A fall or blows
- 9) The rotting of the semen
- 10) Accidental illnesses
- 11) The mixture of seed
- 12) Artifice of wandering beggars
- 13) The influence of demons (cited in Scheerenberger, 1983: 30)

Until the era of the Enlightenment the most important distinction in society was between workers and beggars, and within the latter group few meaningful distinctions were made between (in the language of the time) the deaf, the fools, and the mad. Unless major issues of property were involved, people saw little need to distinguish between identically demanding groups. Indeed, for most practical purposes all these groups were dealt with along with the unemployed as undifferentiated burdens on society. Wolfensberger records, for example, that in early New England

lunatics, “distracted” persons, people who were non compos mentis, and those who had “fits” were all classed together, perhaps with vagabonds and paupers thrown in...Connecticut’s first house of correction in 1722 was for rogues, vagabonds, the idle, beggars, fortune tellers, diviners, musicians, runaways, drunkards, prostitutes, pilferers, brawlers—and the mentally afflicted. (Wolfensberger, 1975: 12)

It is not easy in these circumstances to be sure what impairments are being referred to in any contemporary account. Some retrospective diagnoses can be made from iconographic sources, at least where conditions with visual elements (Down syndrome, the goitre of cretinism, microcephaly or macrocephaly) are present (Gilman, 1982), but this assistance is rare.

Furthermore, the emergence of a group—the deaf, say—as holders of a separate identity does not mean that that distinction then becomes automatic and unproblematic under all historical circumstances. In some times and places, in some contexts, the distinctions might again be regarded as irrelevant. Wolfensberger points out that one hundred years after the work of the Abbé de l’Épée (see below, 2.2) deafness was still for some purposes regarded as akin to retardation:

The National Conference on Charities and Correction, between about 1875 and 1920, often grouped the idiotic, imbecilic and feeble-minded with the deaf, dumb, blind, epileptic, insane, delinquent and offenders into one general class of “defectives” ... [and] many state institutions were for both the retarded and the epileptic ... an incredible range of deviances were associated with retardation: indeed, they were seen to be caused by it: illness: physical impediments: poverty: vagrancy: unemployment: alcoholism: sex offences of various types, including prostitution and illegitimacy: crime: mental illness: and epilepsy. All these were called the “degeneracies.” (Wolfensberger, 1975: 14)

It is not simply that several distinct handicaps and social problems were housed together, or treated alike, or seen as related: they were in a real sense seen as essentially the same thing. Governor Philip’s First Fleet, similarly, included not only criminals but also idiots, the feeble-minded, and lunatics, and for a number of years no special provision was made for

the latter groups. The first institution for people with mental conditions was Castle Hill, built in 1811, followed by New Norfolk in Tasmania in 1829, Easter Plains in South Australia in 1846 and Yarra Bend in Victoria, also in 1846. These lunatic asylums catered for the insane, idiots and imbeciles alike. The first Victorian establishment to make any distinction between these groups was Kew Cottages, opened in 1887, which was designed to house only people who would now be classified as intellectually impaired (Lloyd, 1987: 5).

Intellectual impairment, under the many terms that have been applied to this grouping through history, was not a fixed and unchanging classification. In the first years of the European settlement of Australia idiots were scarcely distinguished from criminals: at other times criminals have been scarcely distinguished from idiots. In Goddard's words, "Every feeble-minded person is a potential criminal." (Goddard, 1914, quoted in Safford & Safford, 1996: 168). Concepts of deviance can embrace all deviations from the societal norm.

'Mental Retardation', a more modern concept than idiocy, has been described as historically, socially, and geographically,

what is left over when 'rogues, vagabonds, the idle, beggars, fortune tellers, diviners, musicians, runaways, drunkards, prostitutes, pilferers, brawlers', have been taken out of asylums ... and sexual deviants, deaf people, people with mental illness, paupers, people with cerebral palsy, habitual drunkards, consumptives, unmarried mothers on welfare, epileptics, habitual criminals, drug addicts and people engaged in the white slave trade ... have been removed from the sanctions imposed on the feeble-minded. (Borthwick, 1995: 530)

As we have successively become conscious of each group its placement within 'Mental Retardation' has appeared anomalous and it has been removed.

Not only are definitions of disability culturally based (see 1.1 above), but definitions of disability are subject to change over time. Consequently, it is virtually impossible to find any statement about people with intellectual impairment dating from more than forty years ago that covers, and covers only, the group now given that label. There is little stability of meaning or interpretation of any of the terms used in this area, and every previous generalisation about intellectual defect covers a slightly different population. More particularly, earlier statements are not only less differentiated but also more concerned with social functioning and less concerned with individual functioning: that is to say, more concerned with ability to work (and not beg or be a charge on rates) than ability to carry out such individual operations as mobility, hearing, or communication. These abilities may emerge from context, but they did not interest many people: Scheerenberger is able to find only two attempts to describe idiocy diagnostically before the mid-seventeenth century (Scheerenberger, 1983: 1-43). Correspondingly, my reading of texts dating from or referring to the time before the eighteenth century has turned up very few statements about people nominated as having a communication impairment (see 2.1 below): it does not appear to have been a concept that presented itself to past eras as a descriptor other than in certain situations such as legal proceedings, in which language was the central element. It is thus the case that statements about that specific group of people who have severe communication handicap must be extracted on an instance-by-instance basis from statements about larger groups with different names.

The situation is further complicated by the frequent use of people with disabilities as metaphors for other areas of life. Observation was moulded by a belief that the world was a complicated system of divine

semiotics. The bestiaries of medieval Europe, it has been said, were composed by people who

lived not in a world of visible facts but rather one of symbols ... the pelican, which was believed to nourish its young with its own blood, was the analogue of Christ, who feeds mankind with His blood. In such a world there was no thought of hiding behind a clump of reeds actually to observe the habits of a pelican. There would have been no point to it. Once one had grasped the spiritual meaning of the pelican, one lost interest in individual pelicans. (Chambers, 1984: 3)

The same principle applied to some extent in the social sphere. People with disabilities were seen less as diagnoses than as embodied maxims. The Ship of Fools, for example, a very popular iconographic motif through the middle ages, represented not only the supposed Germanic custom of rounding up people with mental disabilities and pushing them off in a boat down the river to find sustenance elsewhere (Foucault, 1965: 8) but also the vanity of existence. The tradition of drawing moral lessons from the world survived the rise of secular society: the varieties of communication handicap described in 1696 by Swift (himself a governor of Bedlam) in *A Tale of a Tub* are obviously governed by the need to correspond with the requirements of political disparagement.

Is another [inmate] eternally talking, spluttering, gaping, bawling, in a Sound without Period or Article? What wonderful Talents are here mislaid! Let him be furnished immediately with a green Bag and Papers, and three Pence in his Pocket, and away with Him to Westminster-Hall [to be a lawyer]. (Swift, 1958: 177)

This lack of differentiation occurs not only in primary sources but also in many modern discussions of the area. Foucault's *Madness and Civilisation* (1965), for example, draws no distinctions between intellectual impairment and madness: he speaks of the medieval fascination with the topic of the Ship of Fools as if it concerned only madness, which is plainly not the case, and makes no mention of the presence of idiots in the asylums of the Enlightenment, when they made up a significant

proportion of inmates. His discussion of the recurring image of Pinel removing the chains from the madmen of the Bicêtre ignores the presence in the asylum of “vagrants, epileptics, imbeciles, the aged and the infirm ... [and] swindlers, defaulters, pickpockets, thieves, forgers, pederasts, etc” along with “lunatics” (Scheerenberger, 1983: 46). In 1801, Pinel in fact reported that 30% of his population were idiots (cited in Scheerenberger, 1984: 68). Again, even Gilman’s seminal 1982 work *Seeing the Insane* makes very little differentiation between ‘idiotcy’ and ‘madness’: the title makes no mention of the ‘idiots’ whose pictures make up a large a part of the book, and Gall’s plates of microcephalic skulls are described as being ‘of the mentally ill’ (Gilman, 1982: 109). The pervasive invisibility of people with intellectual impairment is a significant handicap to any historical analysis in this area.

It is also the case, of course, that the currently-used term ‘intellectual impairment’ shares with all its ancestors an extremely wide coverage. The inclusion of the large numbers with ‘mild’ impairment with the small minority with ‘profound’ impairment brings into the same category people who are societally disadvantaged and people with massive brain damage, people who talk normally and people with massive communication handicaps, people who can pass for normal and people who wear physical stigmata. Within each ‘level’ (with all the definitional problems that are associated with ranking diagnoses along a single linear scale) there is also an infinite range of individual differences. The same problems occur with ‘deaf’, which covers a range of impairments from minor hearing loss to total lack of hearing, acquired pre-lingually or post-lingually.

Adding to the confusion arising from changes in nomenclature over time are differences in nomenclature from place to place. In Australia the

professional term for those diagnosed as cognitively impaired has been for some years 'intellectually impaired', and in 1988 the association for professionals working in the field changed its name from the Australian Group for the Scientific Study of Mental Deficiency (AGSSMD) to the Australian Society for the Study of Intellectual Disability (ASSID). Politically active members of the society use the term 'intellectually disadvantaged'. The most common sobriquet in the United States is 'mentally retarded' with some use of 'intellectually disabled' or, confusingly, 'severely handicapped'. In the U.K. the current professional term is 'learning disabled', whose meaning bears little resemblance to the American 'learning disability', which is regarded as a distinct diagnosis specifically not involving 'mental retardation'.

Further questions of nomenclature arise in regard to what have been in various eras regarded as technical terms. Regardless of their technical application, in all eras these terms have also been more or less overt epithets: their stigmatising effect can be seen in, for example, the words of Jesus given in the Bible (King James Version) as "whosoever shall say, Thou fool, shall be in danger of hell fire." (Matthew 5.22) One era's 'political correctness', furthermore, easily slides into another era's insult, as new labels rapidly acquire the negative connotations of the old (Hastings et al., 1993: 464). Rather than place every use of these successively abandoned terms in inverted commas they should be understood as referring to the descriptive labels used by certain people at a particular time in a particular context. A reference to the "insane, idiots, and imbeciles" neither asserts the existence of conditions corresponding to those categories nor endorses the use of those words to describe individuals.

Having briefly outlined the field of non-speech communication and having introduced the key players and concepts, it is now necessary to examine the situation of each category of non-speakers more closely. The first non-speakers to be seen as a discrete category were those whose muteness was the result of a sensory impairment, deafness.

Chapter 2. Speaking hands—recognition and treatment of deafness

This chapter outlines the history of the deaf, the first group of people with communication difficulties to be clearly distinguished from the generality of communicatively-impaired social failures. It traces the communicative and academic progress of the group from the sporadic attempts to educate isolated deaf individuals to the provision of systematic education and the opening of educational institutions specifically for the deaf, and examines the controversies attendant on these developments.

2.1. Unsystematic intervention—individual expedients

The handicaps Judeo-Christian society placed on the profoundly deaf were always harsh. In Leviticus 19.14 the Israelites were commanded by their god to have compassion towards the deaf, or at least not curse them, but this indulgence did not extend to equality of civil rights or duties: they were not permitted to own property, and the Talmud grouped idiots and the deaf together. These entrenched prejudices continued through the empires of Greece and Byzantium, and in the early Christian era St. Augustine relied on the text in Romans 10.17 that “faith cometh by hearing, and hearing the word of God” to decree that those deaf from birth were excluded from salvation. Despite these incentives, no generally accepted methods of communication evolved for the profoundly deaf until the eighteenth century.

While visual communication, the language of mime and gesture, developed wherever there were communities of deaf people, it was limited and idiosyncratic, used for everyday needs, not as a medium of academic instruction (Groce, 1985; see also, for an example in the legal context,

Ruston's Case in 8.2 below). Some individual deaf children were educated, especially in wealthy families: in Spain, particularly, such instruction was encouraged because, as mutes were not at that times considered persons at law, an estate and title passed by primogeniture to a mute heir would be lost to the family (see 8.1 below). There had been no general appreciation, however, of the fact that a deaf child might be as able to learn as well as a hearing child, providing the instruction was provided in an accessible medium.

Because children typically spoke before they read, and because common methods of teaching reading involved reading aloud, it was generally thought (despite occasional evidence to the contrary) that speech was a necessary condition for literacy. And even if speech was not strictly a pre-requisite for literacy, it might be needed to verify written output, according to the first book on deafness written in English, *Philocophus: or, The Deafe and Dumbe Mans Friend*, published in 1648:

If a man be dumbe and deafe by nature, fo that he can neither write nor speake, he cannot make his Teftament: but if thefe defects be fevered, that hee can either write or speake, he may make his Will and it is of force. This therefore is to be obferved: A man both deafe and dumbe by nature, cannot make his Will ... But if he be not mute or deafe by nature, and hath learnt to Paint or Write, hee may make his Teftament. Yet fome fay that inn making a laft Will, there is neede of an articulate voyce, and that fignes will not suffice.² (Bulwer, 1648: 105)

Obviously the very existence of Bulwer is evidence that the deaf were recognised as a group of “otherwife ingenious men” by at least some people in England at that time (*ibid.*: 76). However, foreshadowing future controversies, Bulwer’s aim was to exhibit the

2 The text is somewhat ambiguous, in that it is unclear whether the ‘fignes’, presumably hand signs, are inadequate in isolation or inadequate to support a written Testament.

Philofophicall verity of that subtile Art, which may inable one with an obfervant Eie, to Heare what any man *fpeaks* by the moving of his lips.

UPON THE SAME Ground, with the advantage of an Hiftorical Exemplification, apparently proving, That a Man born Deafe and Dumbe, may be taught to Heare the *found* of words with his Eie, & thence learn to *fpeake* with his Tongue. (ibid.: cover)

Given the legal sanctions which deaf people labored under at this time, Bulwer's emphasis on speech is scarcely surprising. Nonetheless, elsewhere he writes of a boy who lived in the Court of the Landgrave of Hesse, a boy though "*deafe and dumbe fo witty*" that his use was "to declare with a marvellous readineffe by geftures of his body, and by motions of his fingers, any new thing he *feeth* done in the Court or City." (ibid.: 78)³

2.2. The Enlightenment and after—establishment of a diagnosis of deafness separate from idiocy

Until the eighteenth century heredity was the most important factor in almost everybody's life. Some people were born peasants, some were born princes, and the notion that everyone's talents should be developed to the maximum of their capacities simply would not have made sense. People were expected to do their duty in that sphere of life to which it had pleased God to call them, a view reiterated up to the modern day in the still-popular hymn "All Things Bright and Beautiful". Written by a Mrs. Alexander in the nineteenth century, the second verse goes

The rich man in his castle,
The poor man at his gate,
God made them high or lowly
And ordered their estate.

3 Harlan Lane, whose immensely detailed history of deafness (*When the Mind Hears*, 1984) is an invaluable source of information in this area, refers to a number of other seventeenth-century accounts of the teaching of the deaf, only to 'stand them down' on the basis that they are second-hand accounts (Lane, 1984: 68-69). He says of Bulwer that he "wrote three books about the deaf and never taught a deaf man." (Ibid.: 69) This does not, however, impeach his value as a source of information on contemporary attitudes to deafness.

It was clear that God had not ordered deaf people to do very much. Attitudes to the deaf, like attitudes to the structure of society, were so much taken for granted that it was only when there was at last a possibility that they might be altered that they were explicitly formulated. When deaf sign was formalised the hope was that it would enable the deaf to do what they had not done before—in the words of the French Academy of Sciences in 1749, to “acquire the abstract and general notions that they lack, to relate to others in society, and to reason and act like people who had lost their hearing after reaching the age of reason” (Lane, 1984: 78).

The first systematic attempts to educate deaf people occurred in France in the second half of the eighteenth century, largely through the efforts of one man, the Abbé de l’Epée. The Abbé learnt the local sign language, and adapted that to provide a vehicle of instruction which he used to teach deaf-mutes to read and write French—for them, a second language.

The crucial difference between earlier educators of the deaf and these contemporaries of Itard [the Abbé de l’Epée and his student Sicard] is that the former taught only one or two exceptional pupils at a time, often children of wealthy families that could afford a master tutor in residence. l’Epée and Sicard brought the deaf together in a community where numerous children of all classes received instruction. (Lane, 1977: 197)

The work of Epée also differed from that of his predecessors in that his teaching methods were public. Other educators, such as Pereire (a contemporary of Epée’s who taught a relatively small number of people with residual hearing to talk), had regarded their methods as proprietary secrets, to be handed down in one family as a reliable source of income (Lane, 1984:73).

The standardisation of linguistic forms involved in a standard sign language also has parallels in the prescriptive dictionary-making of bodies

such as the Academie Française and the preferment of the chosen national language over provincial dialects.

“Governments do not realize, nor feel keenly enough,” a deputy expostulated, “how much the annihilation of regional speech is necessary for education, the true knowledge of religion, the ready implementation of the law, national happiness and political tranquillity.” (Lane, 1984: 436)

By the same token, signed French was considered superior to a standardised sign language but inferior to spoken French:

The French had then, even more than they do now, a single idea of what it was to be a Frenchman. Frenchmen spoke French, the language that was the vehicle for the most advanced literature, government, philosophy, and science. The new order had no place for other languages. (Lane, 1984: 437)

The success of the Abbé’s work had important theoretical implications for cognitive theory. First, it demonstrated that deaf people were not intrinsically stupid, as had been thought: they lacked a means of acquiring information rather than the ability to process and use it. Second, and equally important, it confirmed that the acquisition of written language could be divorced from the acquisition of speech. Though this proposition was not clearly articulated at the time, nearly two centuries later it was to have important implications for the education of the mute.

The Abbé de l’Epée became famous, and philosophers and emperors visited his school to marvel. This fame did not normally attach to his students: Laurent Clerc records that when one died after some fifty years at the school they were unable to discover a surname for the mortuary register (Lane, 1984: 11). After some decades l’Epée gave way to his student the Abbé Sicard. Sicard learned sign language from the young Jean Massieu, who was almost the first deaf person who was famous for being deaf, and who took it upon himself to serve as an advocate for the deaf. Importantly,

Massieu was a teacher of the hearing as well as the deaf. He taught not only Sicard but Thomas Gallaudet, a leader in education for the deaf in America (Lane, 1984: 155-8). Other deaf people with special talents (Juan Navarette, a student of Titian and known as Il Muto, had been a famous painter) had occasionally had their lives recorded, or at least noted. Massieu had an autobiography (Lane, 1984: 19). The first step had been taken towards the claim by deaf people to have control over their own characterisation. Massieu had a surname, as Epée's earlier student had not, as Itard's Victor had not.

From France deaf education spread throughout the world. Epée's school opened in 1755. The first English school for the deaf opened in 1760, 1784 saw the first Italian school, and the first American school followed in 1817, when Laurent Clerc, one of Massieu's deaf students, crossed the Atlantic. Following the same Enlightenment principles the first school for the blind, too, was established in 1784 in Paris (Scheerenberger, 1984: 50).

Clerc, in Lane's retelling, enunciates one insider's view of deafness:

the deaf are the equal of any man ... Deafness is an infirmity for some, a source of strength for others, simply a condition of existence for most. It is my condition. I am what I am ... I have no wish to be anyone else or anything else, and I never have. (Lane, 1984: 134)

This view has been implicitly or explicitly contested by many of those involved in the treatment of the deaf in the 180 years since Clerc.

Clerc was famous partly because he was seen as a freak: deaf people who had free communication were at the time unusual. While deaf education made this more common, people who were both deaf and blind, such as Laura Bridgeman and later Helen Keller, stretched the communication techniques of the day because of their inability to see hand

signs, and their communicative success was to make them celebrities. Their representation may have been formed and distorted by the biases of the time, but they were certainly individuals—subjects and not simply objects.

Biographies of Keller do not generally concern themselves with the reasons for the general interest in her career and life. She was not the first blind deaf-mute to learn communication, nor the only one available at the time for attention. The philosophical questions that had been raised by Victor, and later by Genie (see 9.3 below) did not apply: Keller had had speech and then lost it, and could not serve as a test of any language hypothesis. It is not clear on what base her celebrity rested in American society, or what ends that society used it for. Even her effective combination of the images of rarity, purity, and progress cannot fully account for her fame. Anagos, an early supporter, wrote of Keller that “Of sin and evil, of malice and wickedness, of meanness and perverseness, she is absolutely ignorant.” (quoted in Lash, 1980: 102) This purity fitted nicely into Anagos’s eugenic views, where

blind persons ought to exercise a certain degree of self-denial and abstain from matrimony: that it is very wrong for persons whose loss of sight is due to some organic disorder to marry any one: and that it is a terrible and unpardonable sin to encourage the union of two such persons. The community ... has a perfect right to expect that all educated blind persons should have proper respect for the eternal laws of nature. (Lash, 1980: 97)

Keller was, in any case, an effective advocate, although primarily for the blind rather than the deaf: and the fact that she learned to speak well gave oralism a considerable public relations success, especially as most of those who read (or wrote) about Keller did not realise the very different implications of innate and acquired deafness for language learning (Lash, 1980). While, furthermore, Keller was a noted radical and a powerful

advocate for people with disabilities, her work was largely done within the philanthropic organisations for blind people, and she could do little to empower people with disabilities to rebel against their carers. Such approaches had to wait until the general movement of revolt against authority in the nineteen sixties and seventies had provided a vocabulary of protest and of rights.

2.3. The development of manual communication techniques for the deaf

By the end of the eighteenth century the potential of many deaf children to benefit from education was widely accepted, but the medium and goals of this education were already contentious. Epée, a supporter of sign language, was confronted by his rival Pereire, who argued for the teaching of oral communication (Sacks, 1989). There were multiple issues. Was the production of speakers or signers the aim of intervention? Should any sign used in the classroom be the language of the deaf community, or a signed version of the dominant language? Should the instructors be deaf, or hearing? Whatever the answers, the questions were debated in speech, not sign. In this debate the advantage was with those who were able to interact with the wider society on equal terms—those who were not seen as disabled. The hearing teachers who had been necessary in the early days of deaf education had established their predominance and were constructing the profession (and their students) in their own image. The issue of how and what the deaf should be taught was to be decided by the hearing.

This decision was finally codified and delivered to the world at the 1880 World Conference for the Deaf in Milan which was “the single most critical event in driving the [sign] languages of the deaf beneath the surface” and, indeed, “the single most important cause—more important

than hearing loss—of the limited educational achievement of today’s deaf men and women” according to Lane (1984:387).

Douglas Baynton discusses the ideological underpinning of the oralist debate in his book *Forbidden Signs: American Culture and the Campaign against Sign Language* (Baynton, 1996). He points out that the oralist position of the late nineteenth century rested in large part upon the scientific consensus at the time in favour of evolution. Where the previous generation of evangelical Protestants had looked on sign language as closer to the language of the creation than speech, and therefore closer to god’s language, the evolutionists saw sign language as closer to the language of our ancestors than speech, and therefore a more primitive system.

To the manualist generation, “original language” meant “closer to the Creation.” It would hold quite different connotations for post-Darwin oralists, for whom it meant, instead, closer to the apes. For most it was simply the inferior language of inferior peoples. (Baynton, 1996: 40)

Sign was thus closer to the inferior races, and the deaf must renounce it or be tarred by the century’s pervasive racism:

The language used by deaf people became increasingly linked in the public mind with the languages of “savages.” References, such as Edward Tylor’s, to “the gesture-signs of savages and deaf-mutes” became commonplace in both popular and scholarly publications. (Baynton, 1996: 42)

By the end of the nineteenth century the issues were encapsulated in the struggle of Alexander Graham Bell to eliminate signing in favour of speech. Bell used his considerable fortune to campaign for the abolition of the sign language, saying “To ask the value of speech is like asking the value of life.” (quoted in Lane, 1984, 341). As well as its implications for the recognition of a ‘deaf culture’, Bell’s advocacy of speech as all important included an implied, but none-the-less severe, condemnation of the congenitally mute, who have no prospect of speech

under any method of instruction. As a fervent eugenicist, however, Bell took the position in such works as his *Memoir on the Formation of a Deaf Variety of the Human Race* (1883) that if deaf people found it easier to talk to other deaf people than to hearing people then they would tend to congregate together, and if they were thus brought into continual propinquity then they would intermarry and thus breed more deaf babies, which would represent a weakening of the American Race (Bell, 1883).

In the late nineteenth century several prominent deaf people seriously considered the establishment of a separate state for deaf people, where they could avoid society's prejudice (Winzer, 1986). On a more limited scale, if a relatively high proportion of the community was deaf, sign language could become a true community language, shared alike by deaf and hearing. In her significantly titled book *Everybody Here Spoke Sign Language*, Norah Groce describes one such bi-lingual—sign and English—community which existed on Martha's Vineyard in the eighteenth and nineteenth centuries. On the island deafness was a characteristic like blue eyes or black hair, which might or might not be mentioned when talking about someone, rather than a defining attribute (Groce, 1985).

Whatever the ideological underpinnings of oralism, its effects on deaf education were dramatic, especially in countries with a centralised education system. Seven years after the Congress of Milan there were no deaf teachers of the deaf employed in France. In future there would be no need for regulations to exclude the deaf from teaching—"the reduced intellectual achievements attainable under the new oralist regime" made it impossible for any profoundly deaf person to qualify as a teacher (Lane, 1984:398). In the 1970s the deaf schools in France and Australia did not

even teach the secondary syllabus. In Australia only elementary school teachers were allowed to train as teachers of the deaf.

The rise of oralism also brought about a consequent shift in power away from people who were deaf to hearing professionals. In the U.S. in 1858, 41% of teachers of the deaf were themselves deaf. By 1927, that proportion had fallen to 14% (Safford, 1996: 113). Many deaf adults have written about their experiences at oralist schools, schools which often tried actively to extinguish signing (see 11.3 below). In the nineteen seventies when Lou Ann Walker, both of whose parents were deaf and used sign, took a deaf education course at Ball State University in Indiana her professor gushed over her because she was “the only student she’d taught who’d actually known any deaf people.” A teacher in the model pre-school told her “We don’t sign here, of course. We want to prepare these children to enter the normal world” and Walker says she might have accepted that if the faculty had not treated their one deaf graduate student “condescendingly—almost inhumanly.” She concluded that theories of education “don’t matter a whit if you don’t consider your students to be human beings.” (Walker, 1987: 136-8)

2.4. The social progress of deafness

At its peak, the evolutionary model of ‘degeneracy’ all but restored the deaf to the body of the retarded from which they had been separated by the Enlightenment. The less deaf and the later deafened were as far as possible taught lipreading and speech: the profoundly developmentally deaf were almost written off. In 1890 the inspector assigned to Epée’s Institute for the Deaf recommended that

It should begin by purging itself of a dead weight of twenty-five per cent composed of the incapable and the semi-retarded....The idiots and the semi-idiots should be shipped out immediately....Everyone knows that the

deaf are inferior in all respects. Only professional philanthropists have said that they are men like everyone else....Similar to *homo-alalus*, to man without speech in prehistoric times, yet even more retarded because they cannot hear. (Lane, 1984: 401)

Lane points out that once more

the border between mere deafness and mental debility is determined by fluency in the majority language. Medicine, or more exactly the medico-psychological model, is the shield the oppressor holds in front of him as he advances. (Lane, 1984: 401)

Sign was seen as disturbing the relationships of gratitude and deference proper to the disabled.

The habit of full dependence, which the deaf-mute contract in catching what is said from the lips and communicating ideas by the orderly, rational and tranquil means of oral conversation, takes from them that indocile and wild spirit peculiar to those who express themselves by the fantastic and passionate method of gestures, and always renders them more obedient, respectful, affectionate, sincere, and good. (Lane, 1984: 401)

Deaf sign was, however, defended by a deaf community that had acquired an acquaintanceship with the mechanisms of political power. Congresses of teachers of the deaf were from 1889 countered by congresses of the deaf. In the main, their efforts were unavailing, and oralism became the official educational ideology, but the practical difficulties of the inferior oralist training methods and the continued opposition of a large element of the deaf community kept the issues, and manual sign, alive (Lane, 1984: 404). Edward Gallaudet, a hearing member of a family famous in the annals of U.S. deaf education, himself fought for the continuance of combined oral/sign instruction and the continued employment of deaf teachers, most notably at the international Congress on the Welfare of Deaf-Mutes held in Paris in 1900. Apart from the opening ceremony the Congress was split into hearing and deaf streams, with the deaf excluded from deliberations after Alexander Graham

Bell's view (quoted in Lane, 1984: 410) that "It goes without saying that those who are themselves unable to speak are not proper judges of the value of speech to the deaf" prevailed. Gallaudet tried unsuccessfully to have the Congress resolutions in favour of speech amended to indicate that they were in fact the resolutions of the hearing section alone (ibid., 412). Indeed, the hearing section even refused to hear the resolutions of the deaf section. Later the hearing were able to use their superior access to the journals to announce that "the oral method has been weighed in the balance—and it may be believed weighed conscientiously and with all fairness—and it is not found wanting." (Booth, 1900: 451) This exercise of authority by those who used typical means of communication over those who did not, presaged the response of speaking professionals to the use of augmentative communication, especially the subset known as facilitated communication, by congenital non-speakers some seventy years later (see 4.2 and 6.4 below).

Whatever effect the Congress resolutions had on educational practice they could not change the reality of deafness. Even hearing teachers of the deaf recognised the problems of oral instruction. At the Seventh Biennial Conference of the American Association of Teachers of the Deaf, in 1911, a Mr. Marten said

a deaf child learns much from the other children in the playground, (Hear, hear). I believe there are some schools—at least I have heard of such—in which the children don't sign in the playground. But I have never yet seen one. (Laughter and Applause). I have a teacher with me now, who has just come from the Mount Airy Institution, Philadelphia, which is one of the leading oral schools in America. She has been there three years, and she tells me that in the playground where there are no restrictions upon the children as to signing ... even a mentally defective child learns much from the signing of common facts. It is an education to them. (NATD, 1911: 72-3)

Marten's statement is of interest both because of its recognition that the children compensated for the deficiencies of their classroom education in the playground and its suggestion that mentally defective children learn much from the signing of common facts. The obvious question is whether these children were in fact "mentally defective", or whether they were, rather, as Lane suggests, simply those who found lip-reading and speech most difficult, possibly because of more profound deafness? In any case, children who could not learn by the oralist methods of the time were reclassified into a lower category. One oralist warned the Seventh Biennial Conference that "Children with all the signs of intelligence sometimes prove totally incompetent. After a year in our institution they have learned nothing." (Lane, 1984: 403) Consequently the conference voted for the establishment of special classes for the retarded.

This downgrading of deaf education after the Milan and Paris congresses was accompanied by pseudo-scientific abuse, often associated with the eugenics movement. In the 1880s and 90s Herbert Spencer repeatedly equated the capacities of deaf-mutes with that of brutes who think "only of things that can be touched, seen, heard (sic), tasted etc." (quoted in Best, 1943: 332) In 1911 they were described as the most frequent outcome of the "Mating of the Unfit", a category which included the insane, alcoholic, and syphilitic (ibid.: 334). In 1921 residential schools for the deaf were included in The Directory of State Institutions for the Dependent, Defective and Delinquent Classes along with facilities catering for "the blind, feebleminded, insane, epileptic, tubercular, inebriate, criminal, depraved and dependent." (ibid.: 333)

Ironically, it was during this time that Helen Keller, who was certainly not seen as belonging to any of those categories, became a

celebrity (Lash, 1980). And Mr. Singer, a deaf man isolated in a hearing world, was the dignified and able protagonist of Carson McCuller's *The Heart is a Lonely Hunter*, first published in 1940 (McCullers, 1961). Nonetheless, in advocating a changed attitude to the deaf, Best felt it necessary to state that they "are quite 'human' after all." He asked that the deaf "be regarded quite as other people, only unable to hear ... no longer as a distinct and different portion of the race, but entirely as normal creatures, equally capable and human as all other men." (Best, 1943: 338) That Best perceived that there was a need for such a plea indicates how parlous the situation had become.

The insistence on employing talking teachers to teach the deaf by oralist methods had by this time produced several generations with very limited literacy and academic skills (Best, 1943: 174-5). No significant change in this situation could occur without the rehabilitation of sign language, which had been down-graded to "a species of picture-writing in the air" (*Encyclopedia Britannica*, 14th ed., quoted in Sacks, 1989: 76). Appreciation of sign as a language was re-awoken by the work of William Stokoe, a linguist lecturing at Gallaudet, who collaborated with two deaf colleagues, Dorothy Casterline and Carl Croneberg, to publish a dictionary of American Sign Language in 1965 following on his 1960 text *Sign Language Structure*. In the seventies Ursula Bellugi and her colleagues at Harvard started to publish on the language of sign, the film *Children of a Lesser God* received wide distribution, and the American National Theatre of the Deaf toured internationally. The eighties saw regular sign language segments on *Sesame Street*.

Meanwhile the deaf had not given up their struggle for autonomy. They actively tried to recover power, a battle they fought alongside other

disability groups. After the end of the second world war a distinction began to be drawn between Societies *for* people with disabilities and Societies *of* people with disabilities. As one activist commented, “The organisations *for* the blind possess the resources and the emerging organisations *of* the blind the ideals.” (Driedger, 1989: 10) Influenced by her reading of Stokoe and her belief that American Sign Language is “the only thing we have that belongs to deaf people completely” (quoted in Sacks, 1989: 147), Barbara Kannapell founded in 1972 Deaf Pride, an organization dedicated to deaf consciousness-raising, which was followed before the end of the seventies by Deaf Power, an organization with a more overtly political agenda.

The vital issue of language control had to be addressed, and came to general notice in 1988 when deaf students at Gallaudet University refused to accept the Board of Trustees’s choice of a hearing President. The present acceptance of sign as a valid language of instruction can be said to have been ratified by the Gallaudet revolt in 1988. The Board’s selection of President Elisabeth Zinser, not herself a sign user, aroused a major campaign—DPN, or Deaf Prez Now. Several thousand protesters brought the campus to a standstill, marched on the White House, and obtained wide media attention, including the ultimate intellectual accolade of an article by Oliver Sacks in the *New York Review of Books* (Sacks, 1988).

The success of the DPN campaign rested on the existence of a network of Deaf community organisations across America. As Oliver Sacks explained,

the students ... have not done this alone: behind them there has been the active support of alumni, and of deaf organisations around the country....[The campaign] is not an order appearing from total chaos....Rather, it is the sudden manifestation of a latent order, like the sudden crystallization of a super-saturated solution.... This is a qualitative transformation from passivity to activity, and in the moral sense, no less

than the political sense, it is a revolution. Suddenly the deaf are no longer passive, scattered and powerless: suddenly they have discovered the calm strength of union. (Sacks, 1989: 174)

One of the protesters said later that

At Gallaudet, we had something not easily duplicated elsewhere: that sense of solidarity which comes from being a community with a long and cherished history. (Goldfarb, 1993: 30)

As the revolt at Gallaudet demonstrated to the world at large, arguments about deaf education had continued across the two centuries since Epée's arguments with Pereire (Sacks, 1988). In recent years these arguments have been framed within the discourse of liberation, the sign language movement making deliberate analogies with the black liberation and women's liberation movements (cf. the discussion of the concept of 'the deaf community' in 1.1.3. above) which had based themselves on the post-war movements of national liberation. A photograph of the protesters, for example, (Taylor & Bishop, 1991: 10) shows one carrying a sign "JEWS—CATHOLICS—BLACK—WOMEN—NOW IT'S TIME FOR DEAF". Opponents objected to the movement, saying that it was 'a reversal of civil rights' in that the protest itself constituted discrimination against the hearing. Jane Spillman, chair of the Board, said that "Deaf people are not ready to function in a hearing world." (Sacks, 1989: 126), a statement that did much to increase opposition to the Board's appointee. Five years on, I. King Jordan, the deaf President eventually appointed, described the Board of the time as having "a plantation mentality" and affirmed that DPN "both reflected and became part of the continuing struggle of different peoples to win the right to determine their own destiny." (Jordan, 1993: 65)

The Gallaudet protest added to the impetus for the passage of the Americans with Disabilities Act in 1990. It also raised in an acute form the

issue of the control exercised by a profession over its client group. While the deaf community (in part because of the language barrier) did not have much contact with the other factions of the disability rights movement, their success contributed to the growth of that movement and helped foster a conception of 'disability culture' that linked the oppression of the deaf with the oppression of other groups of people with disabilities. This more general movement gave the possibility of a forum to many groups.

The coalitions and organisations of disabled people that evolved in these decades [1960-1975] cut across medical-based disability distinctions to focus upon issues of common concern. Increasingly, disabled people have begun to perceive themselves as a minority group who have been denied basic civil liberties....This new movement resembles, in method and legal theory, movements by other disadvantaged and disenfranchised groups....Disabled people and advocates have started to call on the same clauses of the U.S. Constitution. (Funk, 1987: 14)

Whatever the acceptance of individual deaf people by the wider community, the deaf students at Gallaudet had raised the profile of the deaf as a group, and obtained recognition of their group identity. As it happens, it is traditional for each U.S. President to give a Commencement Address at Gallaudet at some time in his incumbency. In itself, this tradition shows a relatively high acceptance of the deaf, as opposed to other groups with communication impairments (who did not until recently have university graduates). Previous Presidents have presumably given their addresses with varying degrees of condescension and charity. Watching the television coverage of Bill Clinton giving the Commencement Address in 1995, it was evident that he saw himself as addressing equals, and in a gesture reminiscent of Kennedy's *Ich bin ein Berliner*, he gave a few words of his speech in clumsy sign.

It has taken the deaf two hundred years to get this far. The following chapters follow the progress of other groups with severe communication

impairments, to establish whether they are following the same path as the deaf and, if so, how far they have come.

Chapter 3. Finding a voice—recognition and treatment of muteness

Treatment of severe communication impairments other than deafness waited on their recognition. To provide appropriate treatment it was necessary for other groups to realise that at least some people existed who could hear but not talk, and who had good understanding, for if muteness was seen as inextricably linked with lack of understanding there could be little incentive to treat it. This chapter looks at the progress in the development of this recognition, particularly in regard to people with severe physical impairments such as cerebral palsy.

3.1. The care of muteness

Severe speech impairment not associated with deafness is best known in adults who have suffered strokes, and the first recorded case of such aphasia may be that in Luke chapter 1, verses 20-22 and 62-64:

And when Zacharias came out of the temple, he could not speak unto them: for he beckoned unto them, and remained speechless ... and he asked for a writing tablet, and wrote: and they marvelled all.

Zacharias was struck dumb but could still walk and communicate by writing, a pattern which may be seen after a transient ischaemic attack, or temporary interruption in the blood supply to a part of the brain. It should be noted that Zacharias had an advantage over most non-speakers of his time, in that he was literate. It should also be noted that the onlookers were surprised to learn that literacy could be independent of speech, a reaction that has remained consistent for more than two millennia.

The paucity of references to non-speakers may be because some mutes who could hear were assumed to be deaf. This is a probable hypothesis, if only because it is still a common presumption today that

someone who cannot talk cannot hear⁴. Those who were obviously able to hear may have been assumed to be idiots—again, a diagnosis of Severe Mental Retardation, the modern equivalent, is commonly applied to children who cannot talk (APA, 1994: 31). Another reason for the lack of references may well have been lack of human material. Many of the people who today suffer severe expressive communication impairments would not have survived without modern medicine. People with throat cancer died, rather than surviving with laryngectomies. Severe strokes and head injuries generally caused rapid death and anyone left in a weakened condition was easy prey for untreatable infection. Difficult births resulted in death, often of both infant and mother. Infants who could not suckle also died, reducing further the number of children with cerebral palsy or Down syndrome⁵. Children put into care died: the Dublin Foundling Hospital's records over the 21-year period 1775-1796 show that of 10,272 children only 45 survived, a mortality rate of 99.6% (Scheerenberger, 1984: 46). Before the twentieth century the problem of infants with severe physical impairments hardly arose. Babies with cerebral palsy tended to die young, being especially vulnerable to the respiratory problems and childhood illnesses of the pre-antibiotic, pre-immunisation age. The prevalence of Down syndrome was much less prior to the introduction of antibiotics:

the mortality of mongols decreased by 10% between 1944-8 and 1949-55, with the result that while the prevalence of mongolism among two-year-old children was 1 in 4,000 in 1929 it had doubled to 1 in 2,000 in 1949 and doubled again to 1 in 1,000 children in 1959. (Goodman & Tizard, 1962: 216)

⁴ When I tell people I work with people who cannot speak the most common response is on the lines of "Oh, people who are deaf. I suppose you use sign language."

⁵ As the likelihood of a Down syndrome birth increases with maternal age, the number of Down syndrome births may also have been less in eras where women tended to give birth early (and often died early).

doubled again to 1 in 1,000 children in 1959. (Goodman & Tizard, 1962: 216)

As late as 1963, however, 54% of children with Down syndrome still died before the age of 10 years (Krupinski et al., 1966).

For centuries almost the only references to non-speaking people were to the semi-mythical changelings or elf children. It was said that elves sometimes stole a human infant, replacing it with one of their own. Sometimes the replacement child was described as ugly, but often as attractive or elfin in appearance. Regardless of appearance, these 'changelings' shared some qualities—generally non-speaking but occasionally repeating what other people said, apparently to make fun of them, they were mischief makers, pinching and pulling hair, into everything, with no sense of danger. One legend speaks of “a changeling with a thick head and staring eyes who would do nothing but eat and drink” and another recounts that

On Lindheim Farm, in Nesherad, there was supposed to have been a changeling. No one could remember when he was born or when he had come to the farm. No one had ever heard him speak, but all the same they were afraid to do anything to him or make him angry. (Ashliman, 1997: 3)

Ashliman suggests that

We all want explanations for happenings that fall outside of our control, especially those that have a direct bearing on our welfare. It is only natural that our forebears wanted to know why some children fail to develop normally, and what our responsibilities are toward these handicapped individuals. The two stories quoted above are part of a vast network of legends and superstitions that give primitive but satisfying answers to these questions. These accounts—which, unlike most fantasy tales, were actually widely believed—suggest that a physically or mentally abnormal child is very likely not the human parents' offspring at all, but rather a changeling—a creature begotten by some supernatural being and then secretly exchanged for the rightful child. From pre-Christian until recent times, many people have sincerely and actively believed that supernatural beings can and do exchange their own inferior offspring for human children, making such trades either in order to breed

new strength and vitality into their own diminutive races or simply to plague humankind. (Ashliman, 1997: 1)

It is possible that some of these changelings were children with autism. Sometimes the condition we know as autism occurs quite suddenly, possibly as a result of brain damage caused by a viral infection, in young children who were previously apparently normal, producing behaviour which matches that ascribed to changelings.

The legends also describe how the parents should deal with the changeling: beat it until the Devil came to take back his own, throw it into water, leave it unfed and crying in an open field till the fairies retrieved it, or place it on a hot stove, or throw it into a fire till it turned into an alder stump. The legend was, essentially, a justification for infanticide, and there is ample evidence in court records that these legendary accounts do not misrepresent or exaggerate the actual abuse of suspected changelings.

The court records of Gotland, Sweden, for 1690 document [a case where] a man and woman were placed on trial for having left a ten-year-old “changeling”—a sickly child who was not growing properly—on a manure pile overnight on Christmas Eve, hoping that the elves who had made the exchange some years earlier would now return their rightful son. The child died of exposure. (Ashliman, 1997: 3)

In the sixteenth century Martin Luther supported this intolerance of severe disability when he saw a twelve-year-old in Dessau who “had the use of his eyes and all his senses” but who did not speak or walk:

So I said to the Prince of Anhalt: ‘If I were the prince I should take this child ... and drown him.’ But the Prince ... refused to follow my advice. Thereupon I said ‘Well, then the Christians shall ... pray that the dear Lord take the Devil away.’ This was done daily in Dessau and the changeling died the following year. (quoted in Wolfensberger, 1975: 7)

When he was asked why he sought the death of the child Luther said “The Devil sits in such changelings where their soul should have been!”

(Wolfensberger, 1975: 7-8)⁶ An example of the extended use of the term to mean ‘idiot’ occurs in the play, *The Changeling*, in 1623, where the changeling of the title is a (pretend) fool being admitted to an asylum, which contained “but two sorts of people ... and both under the whip—that’s fools and madmen.” (Middleton & Rowley, 1623: 273)

Ashliman proposes that as theological explanations for retardation gave way to medical explanations, “community values and personal attitudes changed to such an extent that the very word ‘changeling,’ its synonym ‘killcrop,’ and their equivalents in other languages now have become historical curiosities.” (Ashliman, 1997: 7) However, as he also says, “Views held firmly for a thousand years do not die easily, especially when they appear to answer some of life’s most troublesome questions” (Ashliman, 1997: 1), and an alternative way of looking at the matter would be that many of the values and associations of the old legends were simply carried across into the medical diagnosis of retardation.

Whether or not their condition was attributed to the devil, the few mentions of hearing but mute children prior to the eighteenth century certainly did not suggest any way in which their lot might be improved. The men of the Enlightenment, however, no longer believed in the direct intervention of the devil, and correspondingly reconceptualised severe communication disability in the terms of the debate over Rousseau’s noble savage.

⁶ Blatt (1987) draws attention to variant accounts of Luther’s words, but the differences do not appear to be significant.

3.2. Establishment of a diagnosis of severe physical handicap separate from idiocy

As far as we can tell from the scant records, a general consensus has always related physical disability to intellectual disability. There has also been a strong tendency to link disability to moral delinquency⁷. The German philosopher Jakob Engel, for example, saw movement and gesture as a reflection of the intrinsic relationship between soul and body; in 1785 he presented a depiction of an idiot that emphasised his posture—the dropped head, the unclosed lips, the hanging chin, the half-open eyes, the hands in the pockets—commenting that all could recognise

at first glance the weak, inactive mind, incapable of attention or interest: a mind, which never can bring even the limited energy to create a tension in his muscles so that the body carries itself correctly, that the limbs are held correctly. Only the most stupid and lazy can assume such a meaningless, mindless position. (quoted in Gilman, 1982: 72)

As this consensus remains influential, it is perhaps necessary to say at this point that many alternative explanations exist for muscle tone and postural abnormalities apart from a diagnosis of mental retardation; the characteristics commented on by Engel, for example, are all typical of low muscle tone, a symptom of neuromotor dysfunction.

Almost at the same time, however, an alternative stream of thought based on the philosophy of Locke and Condillac (Scheerenberger, 1984: 76) was developing that saw science as all-powerful, man as plastic, and all mental conditions therefore theoretically responsive to intervention⁸ as

⁷ An alternative tendency, towards seeing sinless innocence in the holy fool, has persisted side by side with the delinquency model.

⁸ An interesting example of this attitude can be seen in Mary Shelley's *Frankenstein* (1817), almost contemporary with Itard's work, where the monster represents the ultimate tabula rasa and learns to speak from first principles and from listening to an isolated family.

Jean-Marc-Gaspard Itard suggested in the introduction to his detailed account of his attempts to educate a mute but hearing child:

Lighted by the torch of analysis and lending each other a mutual support, the two sciences [metaphysics and medicine] have in our day laid aside their old errors and made immense progress. So it was reasonable to hope that if there ever appeared a creature similar to those of whom we have spoken ['wild' children] the sciences in question would bring to bear all their resources to develop him physically and morally. (Itard, 1801: xxiii)

Itard went on to describe his attempts to educate Victor, a child who had been found in the forests of Aveyron in 1799 aged about eleven. Initially it was thought that Victor lacked speech either as a result of his isolation or because he had suffered an injury to his throat: this remains a possibility, but the cause of his muteness cannot now be established with any confidence. Today many of Victor's symptoms appear similar to those of children now diagnosed as autistic, who may have apraxia affecting the acquisition of speech and handwriting.

Victor could hear, and appeared quite adept physically. Over several years, however, Itard never managed to teach him to speak more than a few words. Itard's patient and imaginative teaching of Victor was to inspire Seguin and lead to the first systematic program for educating 'idiot' children. Ironically, Itard himself saw the outcome as a failure:

This long preparation resulted in nothing but the emissions of unformed monosyllables sometimes shrill, sometimes deep....Nevertheless, I persisted....Finally, however, seeing that the continuation of my efforts produced no change, I resigned myself to the necessity of giving up any attempt to produce speech. (Itard, 1801: 86)

And it was speech that Itard wanted. Victor did in fact learn to spell,

to make use of his writing, entirely unformed though it was and has remained, to express his wants, to solicit the means to satisfy them and to grasp by the same means of expression the needs or will of others. (Itard, 1801: 84)

Itard did not regard this as real communication. Real communication was speech. If speech could not be produced there was no point proceeding, and Itard “abandoned [his] pupil to incurable dumbness.” (Itard, 1801: 86)

Lane writes that,

In teaching Victor to understand and produce written language, Itard inexplicably left off once Victor had mastered strings of verb plus noun....If Itard had been less committed to oral language, Victor might have realised [his original sponsor's] ambition for him and gone on to master the written language. (Lane, 1979: 170)

To non-specialists Itard is probably best known through the François Truffaut film *L'Enfant Sauvage* (1970), in which he is portrayed as an ornament of the Enlightenment, a humanist of scientific bent in an era which believed “the proper study of mankind is man”. In fact, Itard did not simply abandon Victor. He also went on to work with children who were deaf, and his obsession with achieving spoken communication led to some of the cruelest treatments in the history of communication impairment. As full speech is largely dependent on hearing, Itard devised a number of procedures to make the deaf hear. One of these, administered to 120 pupils (including Laurent Clerc) at the National Institution for the Deaf, involved repeatedly pushing a probe through the nose into the Eustachian tube and irrigating the tube—this in the days before anaesthesia and antiseptics. Harlan Lane also describes other unlikely treatments, one of which involved fracturing the skulls of pupils by striking the area just behind the ear with a hammer (Lane, 1984: 133-4). Dr. Meniere, Itard's successor at the Institution commented that “A host of pupils were subjected to the most painful, barbaric, absurd and useless treatments” (1853: quoted in Lane, 1984: 433-4). As Lane (1984, 134) has Clerc say, the deaf “were clearly not Itard's brothers but his materials.”

This is an early example of the need of some non-disabled professionals to make people with disabilities the same as everyone else, both rejecting whatever accommodations the people themselves have made (in the case of the deaf students their fluent sign language—Itard himself knew no sign), and seeing any advance other than cure as not worth having.

3.3. The stigma of degeneracy

Itard's work with Victor was considered significant in its testing of the blank slate theory of education—one that offered the possibility of unlimited improvement—and his apparent failure contributed to the eclipse of that approach. As the idealistic optimism of Rousseau passed into the commercial conservatism of the nineteenth century the attitude towards disability changed again. Even by 1807, only eighteen years after Itard's work, a commentary on Lavater's *Physiognomy* describes a picture of Victor as showing

the dominant expression of savagery, of astonishment mixed with uneasiness in it, and above all an expression of excessive mobility, lack of attention, and mental deficiency, which show in the extent, the protrusion and convexity of the upper lip. (Gilman, 1982: 75)

The picture itself is somewhat distorted by the consistent habit of illustrators of showing idiots with their heads extended forward rather than erect. This corrected, it shows nothing except a slightly receding chin falling well within the normal range.⁹ The accuracy of the diagnosis, however, is less significant than the perception. The possibilities that had

⁹ Stephen Jay Gould has highlighted the strong tradition of scientific racism that highlighted the supposed deficiencies of presumed inferiors by tilting their pictured heads (or skulls) to bring out (or create) features such as prominent jaws that were thought to support a contention of primitiveness (Gould, 1981: 30-72).

presented themselves to Itard were already being closed off by the belief that anatomy was destiny.

This ideological predisposition fitted well into the evolutionary theory of the later nineteenth century:

Down's syndrome used to be called 'mongolism'....Down's work ... embodied a deadly earnest attempt to construct a general, causal classification of mental deficiency based on the best biological theory (and the pervasive racism) of the age.

Down's namings, including the term 'mongolian idiot', were explanatory as well as descriptive. They worked from the theory of recapitulation, which postulated that

- (i) higher animals in their embryonic development passed through a series of stages representing the adult forms of their lower ancestors, and
- (ii) higher human races had passed through and developed beyond the stages now represented by the existing civilisations of the lower races.

The evolution of animals and races were two comparable ladders, with lower forms stopping their climb at lower levels. Some recapitulationists added to this a further ladder:

- (iii) within a race, some individuals might slip back down to ancestral levels—'throwbacks', or 'atavisms'.

Down realised that the last two ladders could be merged into one through a theory connecting personal atavism to racial backwardness. It is in this context that Dr. Down had his flash of fallacious insight: some Caucasian idiots must represent arrests of development and owe their mental deficiency to a retention of traits and abilities that would be judged normal in adults of lower races. (Borthwick, 1996: 405)

These ideologies led to a general equivalence of backward traits. If sign was evolutionarily an indication of backwardness, the absence of sign and speech alike was even further down the ladder: both, however, were similarly based and similarly undesirable. Deafness and blindness were grouped with idiocy and criminality as 'the stigma of degeneracy'. The general position of such conditions is particularly illustrated by their use in the American debate on race. In the 1840s Vice-President Calhoun defended slavery on the grounds that blacks in slave states enjoyed an unsurpassed degree of health and comfort while of the free blacks of

Massachusetts “one out of every thirteen was either deaf and dumb, blind, idiot, insane, or in prison,” and in 1851 the *Journal of Insanity* claimed that “every fourteenth coloured person in the state of Maine is an idiot or a lunatic.” (Gilman, 1982: 112) These figures were, of course, totally unfounded:

the returns of the census were grossly perverted in the interests of slavery, to create the impression that a far greater proportion of the free blacks of the North suffered from various physical infirmities than the slaves of the South. (Lane, 1984: 444)

But their accuracy is less important than what they say about the collective stigma attaching almost indifferently to blackness, idiocy, criminality and dumbness.

Gould’s *The Mismeasure of Man* (1981) covers in detail the social significance of nineteenth (and twentieth) century comparisons of women, blacks and the poor on physiologico-evolutionary scales: he does not mention, however, the extension of these scales down to idiots, as in Carus’s *Cranioscopy* of 1841:

in presenting the skull of a twenty-four year-old idiotic girl he concludes his description with the comment that ‘It is striking how similar the pronounced jaw line is to the skull of a Black. For it is evident that decadent structures among civilised peoples are often similar to the typologies of uncivilised peoples.’ (Gilman, 1982: 111)

The skull shows a pronounced orthodontic problem having little bearing on any issues of either ethnicity or idiocy¹⁰. Again, it is the perception that counts, and it is clear that the pervasive nineteenth-century belief in ladders or stages of development placed people with intellectual impairment into a

10 Any such expression of iconographic stereotyping can be linked directly to communication impairment only when sufficient diagnostic information is available—that is, from texts written after physiognomy had become linked to the case study method (itself a development of the late eighteenth century) rather than being an independent discipline.

fixed slot very little amenable to education or culture. It must also be remembered that this evolutionary tradition is closely connected with the origins of our present concepts: as Safford notes, “Mental testing emerged from the confluence of Darwinism, child study, and efforts to establish psychology as a science, the dominant concerns of which ... came together in psychometric conceptions of intelligence.” (Safford, 1996: 175)

Significantly, the question of Victor’s intellectual and communicative status continued to evoke similar prejudices relatively recently: a 1941 article by Denis in *The American Journal of Psychology* demonstrated the circle of association between the intellect and communication in his proof that Victor was retarded:

Feral man is ordinarily mute...Deficiency in language is an outstanding trait of the lower-grade defective also...Tredgold says of mute idiots “Their utterances mostly consist of inarticulate grunts, screeches, and discordant yells.” (cited in Lane, 1979: 175)

A proof that shows the Wild Boy of Aveyron to be retarded because he was mute in the same way as people labelled retarded, must also be capable of being interpreted in the other direction—people labelled retarded, if given similar levels of attention, should be capable of attaining similar levels of literacy. The fact that the more optimistic association was not made shows how strongly the negative stereotype had fixed itself within the professional imagination.

3.4. Unsystematic intervention and individual expedients—introducing non-speech communication techniques

Where there was no incentive to look for the stigma of degeneracy, attempts could be made to provide a partial remedy for disability. In *The Count of Monte Cristo* (1845), Dumas described a man who had lost speech and writing skills but who was still able to communicate by using

eye movements to accept or reject letters and words spoken by his daughter. This may be the first recorded use of a communication system specifically devised for a person who had severe communication impairment that was not caused by hearing loss.

Monsieur Noirtier, “one of the finest Jacobins of the French Revolution”, has ruptured a blood vessel in his brain and is paralysed. He is wheelchair-bound and has no speech. He can, however, use his eyes. Today he would probably be diagnosed as having had a brainstem stroke and his condition would be described as locked-in syndrome, which means possession of intact comprehension and cognition without a means of expression.

It had been arranged that the old man would express assent by closing his eyes, refusal by blinking them several times, and a desire for something by looking at the ceiling. If he wanted to see his grand daughter Valentine, he would close his right eye only: if he wanted his servant, he would close his left eye.

Using the yes and no signals, much can be communicated.

Valentine entered a few moments later....

“Oh, grandfather!” she cried. “What’s happened? You’re angry about something, aren’t you?”

“Yes,” he said by closing his eyes.

“With whom are you angry? Is it my father? No. My stepmother? No. Are you angry with me?”

Noirtier closed his eyes.

“You’re angry with me?” cried Valentine, astonished.

“Yes.”

As Dumas knew, however, free communication required access to the full resources of language. The system that Valentine and Noirtier had devised is sophisticated and powerful. Adapted to computers, it is still used today.

“What do you want, grandfather?” asked Valentine. She began to recite the letters of the alphabet, stopping to watch his eyes at each letter. At N he signalled, “Yes.”

“Ah, it begins with an N.” said Valentine. “All right, is it Na? Ne? Ni? No?”

“Yes.”

“It begins with No?” said Valentine. “Good.” She went over and took out a dictionary, opened it before Noirtier and began to run her finger up and down the columns. At the word ‘notary’ he signalled her to stop.

“Is it a notary you want, grandfather?”

“Yes.”

And so a lawyer is summoned. Noirtier’s son Villefort, who was on bad terms with his father, tries to discourage the lawyer from staying:

“You have been sent for by Monsieur Noirtier here,” said Villefort after the first exchange of greetings with the notary. “His paralysis has deprived him of the use of his limbs and his voice. It’s hard even for us to grasp a few scraps of his thoughts.”

Noirtier appealed to Valentine with his eyes, an appeal so serious and imperative that she immediately said to the notary, “I understand everything my grandfather wishes to say.”

She explains the code, and tells the lawyer

“And however difficult it may seem for you to discover his thoughts, I’ll demonstrate it to you in such a way that you’ll have no doubts on the subject.”

Valentine named all the letters of the alphabet until she came to W, where Noirtier’s eloquent eyes stopped her. Then she began to ask him “Wa-We-Wi-” He stopped her at the third syllable. She opened the dictionary under the notary’s attentive eyes. “Will,” said her finger, stopped by Noirtier’s eyes.

“Will! Monsieur Noirtier wants to make his will! It’s quite clear. This is marvellous!” exclaimed the notary to the amazed Villefort. “Nothing now seems easier to me than what I regarded as impossible only a few minutes ago. This will be a valid will.”

And so Monsieur Noirtier goes ahead and makes his will (Dumas, 1845: 205).¹¹

Dumas was using the weight of plausible detail to give a veneer of probability to an implausible plot where, for example, Noirtier is disinheriting Valentine to protect her against the poison of her stepmother, Valentine is about to marry the son of a man Noirtier killed some years ago, and Villefort is being hounded by the Count because he (Villefort) had imprisoned him (the Count, in the days when he was Edmond Dantes) to protect Noirtier (in the days when Noirtier was a prominent Jacobin). Because of these flagrant absurdities it was important that the detail was plausible, and Dumas has given a textbook account of successful communication with a person with locked-in syndrome.

The technique Dumas describes is very similar to that used today in enlightened intensive care units for people in the same situation as Monsieur Noirtier (Andrews et al., 1996). It was recently used by another Frenchman, Jean-Dominique Baudry (ironically, at work on a biography of Dumas when he was struck down by a brainstem stroke), to write a book, *The Diving Bell and the Butterfly* (Baudry, 1997). It is perhaps unsurprising that people who have been normal find it easier to establish their competence than people who have never been normal, regardless of the severity of the disability, but it is nonetheless perplexing that the experiences of the former are not thought to have more relevance to the problems of the latter.

¹¹ This example was also given in *Speechless* (Crossley, 1997: 42-45).

3.5. The social progress of cerebral palsy

The classic example of a developmental disability in which severe physical impairment is often associated with severe communication impairment is cerebral palsy, in which muscle control is impaired by damage to the developing brain (typically, but not always, damage to the motor cortex) which produces the abnormal muscle tone or spasticity characteristic of the most common form of the condition.

Cerebral palsy was first categorised in 1862 by Dr. William Little, visiting physician to the Asylum for Idiots at Earlswood, and was for the next eighty years known as Little's disease. In the nineteenth century most severely affected infants used to die young, as the result of untreatable epilepsy or pneumonia. In the twentieth century the number of teenagers and adults with severe cerebral palsy has increased with improvements in baby care, the decrease in childhood diseases due to immunisation and, after 1945, the use of antibiotics (Borthwick, 1994). It was well into this century before attempts were made to educate even the less disabled, those who made recognisable attempts to speak. Little himself had said that people with cerebral palsy were "probably of low-grade mentality and little or nothing could be done to improve their condition." (quoted in Schonell, 1956:14) In the first half of this century, children with cerebral palsy were usually placed in large institutions with a diagnosis of 'congenital idiot' or 'idiot cripple'; the term 'cerebral palsy', which has gradually displaced the English label of 'spastic', was popularised in America in 1938 by Phelps (McNaughton, 1996b:8).

Little's pessimism continued to be the rule till at least the second world war, although some teachers did begin to work with children with the milder forms of cerebral palsy earlier. Still, as McNaughton says,

“Prior to the forties, one’s motor capabilities were used as the measuring stick for one’s mental abilities.” (McNaughton, 1996b: 9) Progress began to be made in the nineteen forties, when people who had received some of this professional help began to enter the workforce. Earl Carlson, a person with cerebral palsy, became a doctor and went on to write a book on the condition (*Born That Way*, 1942) that advocated holistic and individual training methods for people with cerebral palsy. The change in perceptions was fuelled by the publication of two more popular books about people with cerebral palsy—*My Left Foot* (Brown, 1954) and *Karen* (Killilea, 1952)—and by the late fifties Leaning (1958: 20) was able to comment that the pendulum had swung over time from the point where all persons with cerebral palsy were regarded as having mental defect to the point where isolated groups sought to reject any association between cerebral palsy and mental impairment, a view he plainly regarded as bizarre.

My Left Foot, the autobiography of the Irish writer Christy Brown, which described his desperate efforts as a child to overcome his communication impairments and win recognition of his intelligence, was especially important in opening doors for those who could not talk clearly (Earl Carlson and Karen Dulea could both speak quite well). McNaughton (1996a) attributes the recent attention paid to communication for people with cerebral palsy to the rise in their numbers caused by antibiotics developed in wartime and to the post-war baby boom. Zangari et al. (1994) also credit some spillover from the therapies (and expectations) devised for casualties of the war, and the changes caused by the ‘normalisation’ movement and the rise of parental advocacy for people with disabilities.

Nonetheless, recognition of the capabilities of people with cerebral palsy has not come easily, and much prejudice still exists today: They have suffered, and suffer, from a continuing belief in the close connection between motor skill and intelligence, including a widespread belief among speech therapists and teachers “that ‘good’ speaking skills were a prerequisite to reading instruction” (Koppenhaver et al., 1991) and hence to academic education. Correspondingly, until the late sixties

few special provisions were made for those children who had cerebral palsy and lacked the ability to speak. Some children were scheduled for ‘maintenance’ therapy and the odd lucky child received a wheelchair tray, with magazine pictures related to basic needs, from a sensitive occupational therapist. (McNaughton, 1990: 3)

To sum up, by the end of the sixties there was some recognition of communicative capacity in those whose muteness was associated with severe physical impairment, but very little had actually been done to provide communication for this group. The next chapter outlines the introduction of new communication techniques and technologies to address expressive problems which commenced in the seventies.

Chapter 4. The development of non-speech communication techniques

Unless someone makes a jump by going outside the handicapped person's previous stage of communication, there is no way the speechless person can do so. Failure is no crime. Failure to give someone the benefit of the doubt is. (Anne McDonald in Crossley & McDonald, 1980: 76)

This chapter takes the history of intervention for people with severe expressive communication impairments primarily but not solely associated with severe physical impairments from the nineteen sixties till the present, in terms of the developmental stages outlined in the prologue: correct identification of the impairment, intervention leading to the establishment of effective communication, recognition of learning capacity, and provision of appropriate educational options leading to employment and citizenship rights. It also examines the involvement of professionals in the new communication interventions.

4.1. The development of augmentative and alternative communication

Augmentative communication includes any communication strategy needed to make an individual's speech more functional: 'Rebecca' lives with her parents, who understand her speech, but when she is away from home she augments her speech by using an electronic diary containing proper names and personal details, on which she can type any words not understood. Alternative communication includes any communication strategy used when a person has no comprehensible speech at all. In fact, the strategies used to augment speech are the same as those used instead of speech. The difference between augmentative and alternative communication is merely the difference between partial and total dependency on non-oral communication.

Sign and gesture systems originally developed for the deaf were eventually adapted for use with people with physical handicaps, aphasia, or autism (Creedon, 1973). Initially the introduction of any non-speech communication strategies for individuals who were not deaf generated considerable controversy, and intervention was undertaken primarily by parents, teachers and therapists without academic connections (McNaughton, 1990). Much early work in this field sprang from Canada in the 1970s and involved the use of Blissymbols, an artificial ideographic communication system that its inventor, Charles Bliss, had designed as a universal language—a kind of visual Esperanto—which was taken up by Shirley McNaughton and her colleagues, who were looking for a way to represent concepts for use by non-speaking, non-reading children with cerebral palsy (McNaughton, 1975). The term ‘language’, in fact, Bliss would have regarded as too confining: he actually looked forward to “ultimate victory ... the day ... when the symbolic logic, semantics and ethics of my symbols will be taught to all the children of the world.” (Bliss, 1976: 142)

Blissymbols were first used only with children with severe physical handicaps, others being thought to have too little learning potential. Complicated, opaque and cumbersome, Bliss’s *Semantography* was successful largely because it was the first non-speech communication system that the students had been offered. Ideographic language systems were seen at the time as a less advanced form of communication than verbal language¹² (Myklehurst, 1960) and consequently Blissymbols were perceived by some educators and therapists as a simplified form of language that was suited to slower and less linguistically able clients. It

12 One wonders whether any Chinese scholars were ever asked their opinion on this point.

seemed as if language was able to make an entrance into the client population only when it came in a form that was seen as entirely new and thus implied no blame on carers for not having used it before. Any language form, however, constituted an advance over the practices of the day, where the ability to read (and, at the ages where decisions as to future education were taken, that meant to read aloud) was regarded as a necessary prerequisite to communication training, and where those unable to achieve this were offered only very limited picture boards (McNaughton, 1996a).

Once language had gained a foothold, it expanded the area of its operations. While some work had been done with communication boards for people with disabilities as part of the Non-Oral Communication Project at Iowa University in the late 1960s, the first journal article on their use (McDonald & Schultz, 1973) did not come out until 1973. The use of Blissymbols encouraged the use of many types of communication board:

Speech-language pathologists who had previously been told that the use of communication boards was unethical, and who had sometimes been fired for applying them, suddenly found such approaches to be the only rational mechanisms for helping severely speech-impaired individuals communicate independently. For ambulatory mentally retarded individuals various sign systems were introduced with real success. (Vanderheiden & Yoder, 1986: 12)

Opposition came primarily from speech therapists who felt that speech should be the only goal of intervention (and that speech therapists should control the field), and from people from all backgrounds who felt that offering children who could only speak with great difficulty any alternative would make them 'lazy' and stop them speaking altogether (Creech, 1993: 3). Much of the opposition to augmentative communication appeared to be the result of ingrained belief that speech was the only acceptable form of communication and that anything else was

not just less desirable but not worth having at all, opposition which echoed the opposition to sign in deaf education.

One might speculate that the negative attitude towards the use of special augmentative communication components in the early years was greatly influenced by the oralist movement in the United States. (Vanderheiden & Yoder, 1986: 11)

There were two situations in which non-speech communication programs were implemented with little opposition—in primate research (which was, however, controversial in other ways: see 6.1 below) and with institutionalised deaf people.

4.1.1. Unaided communication—Makaton signs

The first sign language program used systematically with people who could hear but not talk originated in England in the late 1960s. At around the same time as signing was moving from the primate laboratory to the special school classroom in the U.S. three British speech therapists developed a communication training program using a restricted vocabulary of manual signs for people with hearing impairments who had been assessed as having significant learning difficulties (Cornforth et al., 1974). It was a simplification of British Sign Language and the original selection of the Makaton sign vocabulary was arbitrary, to meet an immediate need. The personal nature of the program is shown in the name, MAKATON, standing for MArgaret Walker, KATHERine Johnson and TONY Cornforth. Like other communication technologies developed to meet a particular need,¹³ Makaton signing programs extended beyond the group and

¹³ The QWERTY keyboard layout is the best known. Originally developed to slow down ten-finger typists to stop the little hammers on an early manual typewriter from jamming up it has become the industry standard and is used on almost all electric keyboards, including those on pocket computers which can only be used with one finger.

situation for which they had been devised, and became an industry standard for non-speech residents in mental retardation institutions.

The influence of the primate and Makaton programs, combined with the obvious practical utility of communication strategies which required no equipment, meant that initially non-oral communication programs for people who could use their hands used unaided formats—signs and gestures. By the eighties there was a move towards aided systems, both because many of the first group to have their expressive needs recognised, those with severe physical impairments, could not use their hands, and because appropriate technology was more readily available. Aided communication systems were defined as “those systems requiring some type of external assistance or an aid or device such as paper, pencil, pictures, charts communication boards and electronic devices, including, of course, computers.” (Rabush et al., 1984, Introduction) Unaided systems continued to be used with and by people without major physical impairments who lived in segregated settings (see 6. 1 below).

4.1.2. Aided communication—communication boards to computers

Some work with communication boards (Feallock, 1958) was documented prior to the teacher Shirley McNaughton’s use of Blissymbols as an alternative to sign for children with cerebral palsy in Toronto in the late sixties. Nonetheless,

it was not until such pioneers as McDonald, Murphy and Husky made their 1974 presentation at ASHA [the American Association for Speech and Hearing, the speech therapists’ professional organisation] on language boards ... that some minimal [professional] focus was directed on aided communication systems. (Rabush et al., 1984, Introduction)

Fortuitously, developments in technology took place at the same time as developments in the theory of non-speech communication. The Canon

Communicator, a mini-typewriter designed in Holland for people who were deaf and blind, was speedily taken up by people with severe expressive impairments, as had been the Possum scanning typewriter, designed in England for speaking people who could not use their hands to type. The Autocom (U.S.) and the Carbalinguaduc (Switzerland) systems were the first developed specifically for people with SCI. Technical restrictions meant that all but the simplest of the early electronic communication aids required their users to be literate, a requirement which relatively few people with cerebral palsy could then meet, given their restricted educational opportunities.

Interest in non-speech communication was fuelled by the advent of affordable, portable personal computers in 1975, which made it possible to utilise computer-based technology to compensate for the output problems of individuals who were severely physically disabled.

In an attempt to take some of the burden off classroom teachers and aides, more automated means for communication were also sought, particularly for physically handicapped individuals. (Vanderheiden & Yoder, 1986: 12)

The first personal computers appeared at exactly the right time, when the field of non-speech communication had developed sufficiently to be able to make use of them. Many people knew what they wished to do for people who could not talk, and here, at least hypothetically, was the technology which would allow them to do it. Eugene McDonald attended the first workshops on Non-Vocal Communication Techniques and Aids held at the Trace Center of the University of Wisconsin in Madison in 1975, and he and Gregg Vanderheiden started to use the term 'augmentative communication' for non-vocal communication techniques, to address the concern that introducing a communication board implied that the user would never achieve any functional speech. (McDonald,

1996: 12) Rick Creech, a well-known aid user even in the 1970s, commented later,

We have come a long way since the early conferences on augmentative communication back in the late 70s! Because I was one of the first users of a portable voice output aid, I attended these conferences. The questions asked at those conferences would astound us now. Some people even opposed the use of all electronics, suggesting more articulation therapy was the answer. (Creech, 1993: 3)

The potential of the new technology was shown in 1979 when Jim Brooks, a university graduate with cerebral palsy who could not walk, talk intelligibly, or use his hands, used a speech synthesiser controlled with his foot to tell the Michigan State Legislature to “never forget their obligation to protect the right of all citizens of this state to freedom of speech and human expression” (Danjuma, 1980:11)

4.2 The professionalisation of non-speech communication

Following Martyr, the use of the term ‘profession’ in this thesis is flexible:

it accommodates those groups which have been recognised in the past as professions, those which have identified themselves as professions, and those which have apparently made a transition from ‘trade’ or ‘occupation’ to ‘profession’ in popular definition or self-definition. (Martyr, 1994: 5)

The main professions concerned with the population of people with severe communication impairment are medicine, psychology, education, the paramedical therapies of occupational therapy and speech therapy (or speech-language pathology), and the technical disciplines of rehabilitation engineering and computer science.

Non-oral communication’s path to professionalisation was in some ways a recapitulation of the path taken by deaf communication, but traversed more quickly in an age of speedier communication. Initially there

were personal accounts of individuals who could not speak using idiosyncratic communication strategies successfully—*The Count of Monte Cristo, My Left Foot*. These were followed by the accounts of workers in the field who had implemented new communication strategies with a number of people—Makaton, Blissymbols, Yerkish. At this point academics saw the potential for research and publication, and produced papers on the new communication strategies (Larson, 1971). Postgraduate students looking for new fields to conquer wrote theses on the new interventions and engineers looking for new applications for their technologies saw the potential for using the latest computer technology with people with communication impairments (Silverman, 1976).

There are no hard-and-fast criteria for establishing when a new field of endeavour has become professionalised (Johnson, 1979: 22-29), because “there is no universal or unilineal process of professionalisation which is of universal applicability.” (ibid.: 29) Some indicators of professionalisation are the existence of university courses in the field (professionalisation is well under way when there is an entire degree available on the field or university departments solely devoted to it), the publication of academic papers and the delivery of conference papers on related topics, the establishment of registration requirements for practitioners or teachers in the field, the establishment of professional associations, the publication of journals (especially refereed journals) in the field and the holding of national and international conferences solely devoted to the field. How quickly these occur will depend in part on whether the people who are in the field at the beginning come from academic backgrounds. An offshoot from an established academic discipline is likely to become professionalised more quickly than a field which has its genesis completely separate from academia. In the case of non-speech communication, which involves people from many disciplines, the

first practitioners were technicians, teachers or clinicians rather than academics, and initially they “either stayed within their own disciplines or shared information with colleagues from other fields on an informal basis.” (Zangari et al., 1994: 47)

The new field of non-speech communication arose when teachers, speech therapists (as they then were) and occupational therapists addressed the problems of a new population of clients. It was (and is) thus handicapped by having no firm location in any single existing discipline. The therapies were themselves in their origins seen as handmaidens to medical professionals (Johnson, 1979: 58), were to a large extent staffed by women, and were thus not granted high status. Their status, as Johnson suggests, was also affected by the status of their clients, in the same way as “the low status of the child-as-client” affects the status of the teaching profession (Johnson, 1979: 30). The courses that trained people to be therapists or teachers were not initially offered by universities, but rather by lower-status colleges. The courses were not academic in approach, stressed practical competence, and did not emphasise research. Laboring under all these handicaps, non-speech communication has had many difficulties establishing its credentials. Perhaps as a result, it is very concerned with respectability and the preservation of appearances—possibly rather like a lower-middle-class family eager to move up in the world.

Another indicator of professionalisation is the development of an exclusive jargon, a specialised vocabulary which serves both to elevate the topic and to exclude the uninitiated from the new club (a Professor of Nutrition Science, not a Professor of Food). People who cannot talk prefer to be called non-speech people. Correspondingly, one might expect the

communication strategies non-speech people use to be called non-speech communication, or, perhaps, given that many of them use communication aids which do speak, non-oral communication. Augmentative and Alternative Communication or AAC was ratified as the term for non-oral communication at an inter-disciplinary meeting in the early 1980s (Zangari et al., 1994: 37). It is a title which mystifies and confuses all but the initiated (giving the field a title no-one outside the field understands may be an early indication of professionalisation). Nonetheless, there is still no name for people who provide AAC: there is no qualification of 'AAC therapist' after the manner of 'occupational therapist'. practitioners refer to themselves as 'AAC specialists' without specifying what discipline they are generalists in, and they are still unable to exclude unapproved practitioners (although this last factor may be about to change as a practicing certificate is now being mooted in the U.S.).

The population of AAC clients was and is as heterogeneous as their instructors. Deaf education had been inextricably linked with a specific impairment and a specific community, who retained the naming rights. Non-speech communication's boundaries were relatively unclear, as it was needed for members of many different diagnostic groups, and no one diagnostic group could 'own' it. Users of deaf-sign may share little more than their deafness, but at least they share that. People who use other non-speech communication strategies do not share a common diagnosis—they may, for example, have cerebral palsy, Down syndrome, autism, motor neurone disease (ALS), intellectual impairments, or acquired brain damage. Another difference which inevitably hindered the development of common cause among non-speech people was that their associated impairments generally made it impossible for them to communicate with each other prior to professional intervention. Geb Verburg, an early AAC

worker, speaks of a new grouping as being brought into being by the therapists rather than arising from the demands of the clients. “The late seventies and early eighties were interesting times because a lot of new things were created for a population that was in a sense discovered and defined.” (Verburg, 1996: 21)

While the Abbé de l’Epée took deaf signs and systematised them to provide a means of instruction, a local sign language had existed before his intervention. Among people who could hear but not talk, however, signing did not spring up naturally, and the only communication available (and then only to a few people) was dysarthric speech, speech which was rendered almost unintelligible by muscular impairment, often associated with severe cerebral palsy. While people with dysarthria could sometimes understand each other even if their speech was incomprehensible to outsiders, as the institutionalised Arthur was understood and his stories passed on in the novel *Skallagrigg* (Horwood, 1988) based in part on *Tonguetied* (see 5.2 below), their physical dependency and lack of mobility precluded any communal action. Forming even small groups, let alone a network such as that that had supported the deaf students’ action at Gallaudet, would be much more difficult for this population, at least until their communication impairments were addressed. The first recorded cross-diagnosis association of non-speech people was established in Victoria in 1981 under the acronym BUG, for Board Users Group, and later metamorphosed into CAUS, the Communication Aid Users Society. The Society did not hold its first Australian conference until 1995 (Communication Aid Users Society, 1995).

Zangari and her colleagues have reviewed the social and technical developments which were pre-cursors to the emergence of AAC as a

“legitimate area of specialization” in the nineteen seventies, highlighting the role of the Iowa Non-Oral Communication System Project which started in the U.S. in 1964 and the development of the POSSUM hands-free typewriter in the U.K. in 1963. (Zangari et al., 1994: 27-33) In the early seventies the first books solely devoted to AAC were published by Copeland (1974), McNaughton (1974), and Vicker (1974). Soon there was enough technology available to fill a book (Vanderheiden & Grilley, 1975). The first periodicals devoted to AAC also commenced publication during the decade—*Communicating Together* in Canada, *Communication Outlook* in the U.S., and *Communication Matters* in the U.K.—and by the late seventies sufficient articles had appeared to warrant the publication of two bibliographies—Silverman (1976) and Brown et al. (1977). The *Communication Enhancement Bibliography* published by *Communication Outlook* in 1984 contained 758 items (Rabush et al., 1984).

The late 1970s saw short courses being given at major conventions, such as the first ASHA short course on non-speech communication symbols and systems (Fristoe et al., 1977). By the end of the seventies the aids used had started to change from “simple communication boards to elaborate electronic prostheses with artificial speech.” (Rabush et al., 1984) The first international conference on non-speech communication was held in 1980. In the eighties a number of texts designed for university use were published (Schiefelbusch, 1980; Silverman, 1980; Musselwhite & St. Louis, 1982; Blackstone, 1986; Montgomery, 1987). A group of professionals and consumers from seven countries met in East Lansing, Michigan in May 1983 to establish ISAAC, the International Society for AAC. An indication of the extent to which the field was already professionalised appeared in the first issue of the new society’s refereed journal, *AAC Augmentative and Alternative Communication*, when Shirley

McNaughton wrote, “The establishment of a reviewed journal for the field of augmentative and alternative communication had highest priority within our list of specific goals.” (McNaughton, 1985: 2)

While professionalisation proceeded apace, there was (and is) still a long way to go before most non-speech people had appropriate communication intervention. The first issue of *AAC* contained Matas et al.’s 1984 survey of AAC in Washington State which found that in the west of the state (Pacific seaboard) only half those with SCI used AAC and only a third of those used communication aids. The remaining two thirds used sign or facial expression to augment their speech. In the interior, eastern part of the state, the situation was worse, with only 18% of those with SCI using AAC.

At the time, the provision of AAC was dependent on a child meeting ‘minimal criteria’ for using an augmentative communication system. The minimal criteria, according to Matas et al., were:

Should have a severe speech problem that prevents independent communication.

A. Should be able to establish and maintain eye contact for 3 seconds.

B. Should be able to attend to task for approximately 3 minutes.

Should demonstrate an ‘intent’ to communicate in some observable manner. (Matas et al., 1985: 28)

The theory of minimal criteria, which if applied to newborns would have excluded them from exposure to speech, was gradually discarded after publication of an important article by Kangas and Lloyd in *AAC* in 1988, where it was noted that

descriptive data regarding child development have been overextended to a prescriptive sequence of precommunication and communication intervention for individuals with disabilities. Furthermore, a model of child development may not be a sufficient framework for children and adults who experience severely disabling conditions and are functioning

at early levels with respect to cognitive norms. (Kangas & Lloyd, 1988: 211)

(The use of ‘cognitive norms’ rather than ‘developmental norms’ in the final sentence indicates just how pervasive was the link between physical ability and cognition.)

However, while the concept of minimal criteria held sway it had effectively ensured that many of the people who were later to be candidates for facilitated communication training were excluded from standard AAC intervention. Indeed, the criteria for exclusion from AAC almost matched some of the criteria for diagnosis of autism: lack of eye contact, short concentration span and apparent lack of interest in communication. Like the establishment of communication with the deaf, communication with people with SCI

- arose in the aftermath of the decay of previous paradigms (such as degeneracy),
- employed techniques that had long been available if anybody had felt a need to use them,
- was seen as a test of popular contemporary theories of the nature of humanity (tabula rasa theory, primate language),
- was carried out by people who themselves had no handicap and who
 - were paid by the state or by charity (i.e. by people who had no handicap),
 - exercised power over people who had speech handicap,
 - were not accountable to people who had speech handicap.

4.3. Establishment of a diagnosis of severe communication impairment separate from idiocy

In 1985 correct identification of the nature of the non-speech child's impairment and provision of intervention leading to the establishment of effective communication were still issues. A decade later the situation has improved somewhat. In developed countries funding for electronic aids is more readily available and the technology both caters for a wider range of users and meets more needs of those users. Despite these advances, as a service provider in a first world country I am still seeing both adults who are either mute or have virtually no intelligible speech but who have never been offered any alternative communication system, and children whose education is being placed at risk because of unaddressed communication impairments. In Victoria, government funding for communication aids is now readily available to adults and almost unobtainable by children (Crossley, 1996). Without a voice it is almost impossible for these children to have their learning capacity recognised. While it is possible for them to attend mainstream schools which offer appropriate educational options, they cannot take advantage of these without a means of communication.

Rick Creech spoke at the First Annual Pittsburgh Employment Conference for Augmented Communicators in 1993 and pointed out that since the seventies, "conferences on augmentative communication have focused on a variety of issues such as interaction and literacy. However, very little has been written or said about employment and augmentative communication." (Creech, 1993: 4) Creech himself has been notably successful in gaining education, employment and citizenship rights. Born with severe cerebral palsy he uses a 'unicorn' headpointer to replace his speech and hands. He recently added a Masters in speech pathology

(becoming the first non-speech speech pathologist) to his other tertiary qualifications, is employed by a communication aid manufacturer as a consultant, and is married with children.

Creech is not alone—many non-speech people have graduated and, indeed, completed postgraduate degrees, in virtually every field from which they are not excluded by their other impairments. Gaining employment is another matter, and most non-speech people with developmental disabilities who have jobs are probably employed in the disability field. The irony is that John, who has a Ph.D., may be living next to a residential unit housing people who have cerebral palsy similar to John's, but whose academic potential is completely unknown because they cannot speak and no-one has offered them an alternative means of communication. This is a situation comparable with that of the deaf community in the 1790s, where relatively few deaf people had as yet had a chance to be educated, and the way forward was pointed by the favoured few (Lane, 1984: 107-8).

The best known AAC user in the world is probably Stephen Hawking, author of *A Brief History of Time*. His undoubted intellectual achievements have shed a little reflected glory over other non-speakers, especially those with the same condition, Motor Neurone Disease or ALS, who were once seen as not worth bothering about because they were going to die quite quickly. Now that high-power communication technology is available, many people with acquired impairments such as Motor Neurone Disease who would previously have left their employment are staying on or resuming their old jobs. As they were usually educated prior to becoming disabled they have not had to battle to receive an appropriate education as both deaf and non-speech children must, and they are found in

a wider range of occupations. They have raised the profile of non-speakers and non-speech communication substantially.

One important demonstration of this raised profile occurred in 1993 when Bob Williams was appointed Commissioner of the U.S. Administration on Developmental Disabilities in the Clinton Administration. Bob is probably the first senior administrator in the world to use a spelling board, and was himself almost placed in an institution for people with intellectual impairments. Ten years before his current appointment Bob, who has severe cerebral palsy, very little intelligible speech, and uses a wheelchair, was visiting an institution as a member of the President's Committee on Mental Retardation. At the conclusion of the visit Bob was wheeling along behind the rest of the group when the security guard at the gate stopped him, saying, "No you don't, feller. You can't follow them. You belong here." (Williams, personal communication, 1990)

AAC users are now at the point where it has been demonstrated that some non-speech people can benefit from education, obtain employment, marry and have families and contribute to their communities. It is, however, doubtful whether this sequence is accepted as achievable by all, or even most, group members (one parent of a four-year-old with severe cerebral palsy told me recently that when she told professionals working in the field that she wanted her son to have an education which would allow him to attend university if he wanted to they had simply laughed). It is obvious that the accommodations which make it achievable are not in place for all.

While successful users of AAC, people like Rick Creech and Bob Williams, have created a strong advocacy base in the field of

communication handicap, there remains in the textbooks and in the hospitals a continuing belief that while conditions such as cerebral palsy do not necessarily involve mental retardation they nonetheless imply a much higher than usual probability of retardation. This means that any given child with cerebral palsy is still likely to be viewed as guilty of mental retardation until proven innocent, rather than the reverse, as would be the case with a deaf child. The release of some people with a certain physical condition from the category of mental retardation, that is, has not been applied to all people with that condition. There has been no single general removal of people with cerebral palsy from the category of mental retardation but, rather, a gradual extension of acceptance of ability as new communication techniques offer new possibilities to more severely handicapped individuals.

When I was working in St. Nicholas Hospital, an institution for children diagnosed as severely and profoundly retarded, in the early 1970s, considerable concern was raised by the discovery that one of the young residents was deaf, and hence may have been incorrectly diagnosed as retarded. One hundred and fifty of the one hundred and sixty residents had cerebral palsy, but that raised no concern about the possibility of a misdiagnosis of retardation. While there are still many non-speech people with cerebral palsy in retardation institutions or custodial classrooms, expectations today are generally more positive. In 1992 I accompanied Anne McDonald, once a St. Nicholas resident labelled profoundly retarded, to the United States. Looking at her flailing around in her wheelchair the immigration officer asked, "What's wrong with her?" "She's got cerebral palsy." "Oh good—she'll understand everything I say."

That this acceptance is still not universal was indicated by another incident, also involving McDonald, which introduces the next chapter. Taken together, these incidents suggest that severe cerebral palsy, which usually entails severe communication impairment, is in transition, fluctuating between the general presumption of competence applied to spinal quadriplegics who can speak (but who nonetheless still suffer occasional incidents of devaluation) and the general presumption of incompetence suffered by people with conditions such as Down syndrome, which have been universally associated with severe cognitive impairment. The past and current situations of two such diagnostic groups are discussed in the next chapter.

Chapter 5. Mute = Dumb—speech and intelligence—the special relationship

5.1. “This is Dopey. He don’t talk none”¹⁴—the perception of intelligence in people with severe communication impairments

In January 1996 I accompanied my friends Chris and Anne to the film *The Madness of King George*. Anne, who has athetoid cerebral palsy and cannot talk intelligibly, is in her thirties and is a university graduate. The theatre had no proper wheelchair spots so Anne had to sit in the only accessible space at the back of the theatre. The slope her chair was on made her involuntary movements worse than usual which meant that she generated some noise, though certainly much less than a (presumably non-disabled) woman elsewhere in the theatre who laughed loudly and frequently.

During the movie the man sitting closest to Anne made disparaging gestures and moved to another seat. At the end of the film he approached us in the foyer and said that, while he was very sympathetic, Anne’s presence had ruined the movie for him and everyone else. “You shouldn’t bring her to films that she couldn’t possibly understand” he said repeatedly, adding that we should get a baby sitter. He referred to Anne as our charge and when Chris said she wasn’t our charge, she was our friend, he said we were in charge of her. In response to his reiterated denigration of Anne’s understanding I said something about her having a degree, to which his response was, “Oh yes, I’m sure”. At this stage Anne got into the act with her voice output communication aid and said, “I’m sorry”.

¹⁴ *Snow White*, animated feature film, Walt Disney Studios, 1935

Hearing her 'speak' seemed to non-plus him and he said, "Go on—tell me to piss off", to which she said "Shut up!", and he left in some confusion.

While this incident exemplifies the continuing ignorance of some people about cerebral palsy, it is also interesting because of the way the man changed his tone when Anne 'spoke' to him, and because some members of the audience came up to Anne later and apologised for his rudeness. It reinforces the conclusion of the previous chapter that cerebral palsy is a diagnostic group which already has some community acceptance as competent and that individual members can extend this by using communication technology. This situation may be contrasted with that of other diagnostic groups whose members have severe communication impairments.

This chapter examines professional beliefs about the intellectual functioning of individuals with severe communication impairments, particularly as they are reflected in the past and current situation of the two diagnostic groups who have often been seen as exemplifying developmental and acquired cognitive dysfunction: people with Down syndrome and people diagnosed as being in a persistent vegetative state.

The pervasive stereotype applied to people with communication impairments has been that mute = dumb, as in stupid.¹⁵ The *Oxford English Dictionary*, Compact Edition, 1971, in discussing the permutations of the meaning of 'Dumb', shows this transmogrification:

In Gothic, Old Norse, and OE, only in sense 'mute, speechless': in Old High German it shared this sense with those of 'stupid' and 'deaf': in the

¹⁵ The word 'idiocy', by contrast, for many centuries shared its common meaning of 'fool' with the alternative meanings of 'ignorant person without learning', 'layman' or (from the Greek) 'private (as opposed to a public) man' (*Oxford English Dictionary*, Compact Edition, 1971).

other languages and periods, generally in sense ‘stupid’, though early modern German also had sense ‘deaf’....These diverse applications suggest as the original sense some such notion as ‘stupid’, ‘not understanding’, which might pass naturally into either ‘deaf’ or ‘dumb’.

1. Destitute of the faculty of speech

c1000 Ags. Gosp.Mat. ix 32; hyn dumbne man

1532 Skelton, Garl. Laurel., Better a dum mouthe than a brainless scull.

‘Dummy’ has related meanings:

1. A dumb person (colloq.)....

3. A person who has nothing to say or takes no part in affairs: a blockhead.

In ancient Greek, similarly, the same word, ‘kophoi’, was used for both the deaf and the dumb. This led, among other things, to an interpretation of Aristotle’s statement “Men that are deaf are in all cases also dumb: that is, they can make vocal sounds but cannot speak,” as “Those who are born deaf all become senseless and incapable of reason.” (Lane, 1984: 92) This judgement flowed from Aristotle’s general position on language:

To explain how people interpreted information, then translated it into speech and action, he posited a *sensorium commune*, a concept with profound ramifications for beliefs about deafness, for it ascribed to hearing, speech and reason a common source. (Safford, 1996: 7)

Aristotle’s influence in medieval and renaissance Europe was so great as to give this judgement immense weight.

The common view has historically been that people’s knowledge and understanding is exhibited through their speech and actions. Esquirol, in 1838, divided up the intellectually impaired into two main groups of imbecile and idiot with subcategories based on speech and, to a more limited extent, language:

Imbecile level 1: speech is free and easy

Imbecile level 2: speech is less easy and vocabulary more circumscribed

Idiocy level 1: uses merely words and short phrases

Idiocy level 2: uses only monosyllables and certain cries

Idiocy level 3: no speech. (Esquirol, 1838, quoted in Scheerenberger, 1984: 81)

The idiot's lack of speech was attributed to absence of mind: "Having no ideas, and thinking not, they have nothing to desire: therefore have no need of sign, or of speech." (Esquirol, 1845, quoted in Safford, 1996: 168)

It is only in the last century that a 'scientific' basis for matching speech and intelligence has been devised—the intelligence test. Such tests, however, were designed to make the same distinctions as the previous measures. Binet, the begetter of intelligence testing, also supplemented his testing by speech measures:

An idiot is any child who never learns to communicate with his kind by speech—that is to say, one who can neither express his thoughts verbally nor understand the verbally expressed thoughts of others, this inability being due solely to defective intelligence, and not to any disturbance of hearing, nor to any affectation of the organs of phonation.

An imbecile is any child who fails to learn how to communicate with his kind by means of writing—that is to say, one who can neither express his thoughts in writing, nor read writing or print, or correctly understand what he reads, this failure being due to defective intelligence, and not to any defect of vision or any paralysis of the arms which would explain his inability.

A moron¹⁶ is one who can communicate with his kind by speech and writing, but who shows a retardation of two or three years in his school studies, this retardation not being due to insufficient or irregular attendance. (Binet, 1909, quoted in Scheerenberger, 1984: 142)

The three-part division was also expressed later in educational terms as 'educable, trainable, and custodial' (Safford, 1996: 169). It surfaced

16 The coining of the term 'moron' was attributed to the American Goddard in 1910. Binet died in 1911 in Belgium and so could scarcely have heard of it, but Binet's term covered a similar area. In Goddard's system, idiots had a mental age of two or less, imbeciles between three and seven, and morons between eight and twelve. (Safford, 1996: 177)

once again when the presumptive relationship between overt language production and cognitive ability was built into the definition of mental retardation. In the American Psychiatric Association (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV, 1994), mental retardation is defined in the first instance in terms of intelligence quotient or IQ, “significantly subaverage general intellectual functioning (defined as an intelligence quotient of 70 or below on an individually administered general intelligence test) resulting in or associated with deficits or impairments in adaptive behaviour ... with onset before the age of 18.” In the Diagnostic Features section, however, the degrees of severity are differentiated partly by language skills. Mildly retarded people “can learn academic skills up to approximately sixth-grade level” including, presumably, literacy. Moderately retarded people “can acquire communication skills ... [but] are unlikely to progress beyond the second-grade level in academic subjects.” Severely retarded people in their early childhood years “acquire little or no communicative speech...During the school-age period, they may learn to talk.” With profoundly retarded people, “communication skills may improve [from an unspecified base] if appropriate training is provided.” (American Psychiatric Association, 1994: 41) Speech is referred to as if it were identical with language—despite the advances in non-speech communication during the eighties, no mention is made of alternative communication strategies.

The presumption about speech matching intelligence is not new. Only minor changes have been made between the 1994 manual and that of fourteen years earlier (DSM-III, 1980) which stated that “mildly retarded people ... can learn academic skills up to approximately sixth-grade level,” moderately retarded people “can talk or learn to communicate ... [but] are unlikely to progress beyond the second-grade level in academic subjects,”

and severely retarded people “develop little or no communicative speech during the pre-school period...During the school-age period, they may learn to talk.” With profoundly retarded people, “Some speech ... may take place during adult years.” (American Psychiatric Association, 1980: 32-3) It was assumed that someone who could not speak would not be able to spell. DSM-III did not say specifically that every child who did not learn to talk was profoundly retarded, but nonetheless that was and is a common presumption.

Fawcus & Fawcus (1974), in reviewing twentieth-century studies which linked disorders of communication and mental retardation, have noted Cyril Burt’s report that in London in the 1920s severe speech defects occurred in 1% of normal children, 5% of backward children, and 15% of mentally deficient children speech (quoted in Fawcus & Fawcus, 1974: 593).¹⁷ In 1930 an American, Kennedy, found that 42% of 249 feeble-minded patients and 71% of 27 imbeciles had speech disorders ranging from slight to severe, while none of the 32 idiots studied had meaningful speech (*ibid.*: 594). In a 1941 study of 2,522 institutionalized people, Sirkin and Lyons found similar speech defects in 47% of feeble-minded and 74% of imbeciles (*ibid.*: 594), and in 1968 Sheehan et al. stated that:

Of 216 patients examined at Porterville State Hospital ... 50% had no speech at all or else severely delayed language development ... dental abnormalities and articulation disorders were common, and only 12% of patients seen had normal speech. (quoted in Fawcus & Fawcus, 1974: 595)

More recently, a 1984 study of school-age nonspeaking students in Washington State found that 12.3% of 1,405 students diagnosed as

¹⁷ Burt has been exposed more recently as having had a tendency to make up his data to suit his biases (Hearnshaw, 1979), and this study may never have been done: it does, nonetheless, represent evidence of those biases.

moderately and mildly mentally retarded, 100% of 74 students diagnosed as severely and profoundly retarded, and 100% of 276 multi-handicapped students were nonspeaking (Matas et al., 1985: 20).

Studies over the years have shown similar statistical associations between communication disorders and diagnosed intellectual impairment. The issue is not the percentage of people in any group—the incidence figures for speech impairment in each diagnostic category may well be accurate—but what came first, the speech impairment or the (presumed) intellectual impairment. Only recently has there been any attempt to separate the effect of intellectual defect from that of other possible causes of speech defect. This change in the nature of common assumptions was fostered by the rise of the profession of speech therapy. For therapists to be useful, remediation must be possible. For remediation to be possible, speech problems must arise from causes other than mental retardation. Even so, many speech therapists practising today were taught that it was pointless to offer speech therapy to children who were mentally retarded (personal communications, 1980-96).

This is despite the first studies addressing this issue appearing in the nineteen forties, when a study of 50 children with delayed speech found that there were a number of constitutional, environmental and psychological factors, other than mental retardation, to explain the retardation of speech (Fawcus & Fawcus, 1974: 595). In the fifties a paper by Kastein pointed out that a child's "label of gross (mental) impairment does not necessarily indicate the cause for his language and speech deficiency", and a paper by Mathews said that the "well-trained speech and hearing therapist should recognise that there may be many explanations of delayed or defective speech which have no relation to intellectual

retardation” (both quoted in Fawcus & Fawcus, 1974: 595). Another paper asserted that:

Despite the very high incidence of speech defects among the feeble-minded, low intelligence is probably not a direct cause of defective speech production, though it is undoubtedly directly associated with poor linguistic ability. There are many organic conditions, such as cretinism, mongolism and brain damage, which are responsible at once for the lowered intelligence and the defective speech of the individual. The amount of intelligence needed for the correct production and control of speech sounds is not great. (Berry & Eisenson, 1956, quoted in Fawcus & Fawcus, 1974: 596)

Thus in the fifties some researchers had moved from stating that speech problems were caused by retardation to stating that the problems and the retardation had a common cause. The next step was to suggest that “the speech disorder itself may be largely or in part responsible for the retarded intellectual development” (Fawcus & Fawcus, 1974: 596), and that lack of speech “may even limit the development of the thought processes, and hence intelligence.” (ibid.: 597) This statement still accepted that retardation was inextricably connected with lack of speech, in contrast to Berry and Eisenson, who, in reporting an increase in IQ in children who had been “taught to speak”, suggest that this could be because the speaking child “generally makes a more adequate adjustment to his environment, and to the taking of intelligence tests.” (Berry & Eisenson, 1956, quoted in Fawcus & Fawcus, 1974: 600)

The psychiatrists who wrote the Diagnostic and Statistical Manuals appear to be thinking of language as a skill which has to be learned, and whose learning depends on the kind of mind you have. Language studies in other fields are now moving towards a consensus that language, in the words of one recent book title—*The Language Instinct* (Pinker, 1994)—is not a thing to be learned, as one learns the rules of poker, but rather a fundamental element in the composition of a human mind: and that, while

the expression of language may be disturbed or disrupted, this does not necessarily relate to the continuing existence of the basic structures of language in the mind, still less to degrees of intelligence. Regardless of one's view of this theory, as Borthwick (1996) points out, this consensus has until now been held at bay at the boundaries of intellectual impairment. Texts on intellectual disability discuss exercises for 'pre-lingual', 'pre-symbolic', or even 'pre-intentional' adults (Bloomberg & Johnson, 1990b), as if there is a form of mind common to most adults that involves language, and an undeveloped form of mind common to babies and people with mental retardation that does not.

These important issues are, however, almost irrelevant to the question of assessment. Whether or not one agrees with Pinker, and whatever one thinks about the organisation of the human brain, there is a fundamental injustice in giving people who cannot talk tests requiring spoken answers. It makes language, or the lack of one form of it, into a barrier in the same way as the notorious dictation test administered by Australian immigration officers in the heyday of the White Australia policy. The immigration rules provided for the administration of a dictation test if there was doubt about a potential immigrant's educational standard, but did not specify the language of the test. Immigrants whose colour was considered undesirable were given tests in languages they did not know—in 1950, for example, two Muslim Indians were given the test in Italian. The immigration officer reported, "Neither man managed to write one word", and they were sentenced to three months imprisonment before being deported (Knightley, 1997: 2/5).

5.2. Assessment of atypical communicators

As was said above, to be officially mentally retarded you must have an IQ score below 70. The two most widely-used standardised tests from which IQ scores are derived are the Stanford-Binet and the Weschler (in its various forms). While the tests ask different questions they have one important thing in common—they require spoken answers and some manipulative ability. No alternative verbal scales are provided for people who cannot speak or have limited speech.⁷ Slow responses (and all augmentative communication strategies are significantly slower than speech) are equated with intellectual incapacity, and the astrophysicist Stephen Hawking would both be penalised on the verbal items which give bonus points for speedy responses and fail the elephant jigsaw (and everything else) in the performance scale.

Mental retardation is diagnosed not by a test of brain matter but on the basis of performance, which is where the difficulties of the concept begin. Diagnosing mental retardation is not unlike a dog chasing its tail. Very, very few people have mental retardation diagnosed for the first time after an intelligence test administered blind. Rather the tests are given to people who are already believed to be 'retarded', with a view to ascertaining just how retarded they are. Someone whose performance is not up to par is given tests which require the use of functions that are not up to par, then the results are used as an explanation for why the person's performance is not up to par.

The basic conceptual flaw in the diagnosis of mental retardation is that it depends on the premise that one's behaviour is an accurate reflection of internal mental processes—in particular, that

general delays or deficits in language function are closely related to
 general delays or deficits in intellectual development ... the everyday

facility with which people with autism or mental retardation use a language (eg. spoken, written, or pictorial) is an accurate depiction of their ability to do so ... there is no clinically significant phenomenon that inhibits the overt production of communication and “masks” normative communication skills (i.e., actual production is representative of “internal” speech skill)...That there is a strong presumptive relationship, in general, between overt production and actual ability is a cornerstone of psychological assessment methodology, statistics, and psychometrics. (Jacobson et al., 1995: 755)

In the most obvious sense, what you do does reflect what your central nervous system does—a person with severe athetosis cannot talk because s/he has brainstem damage—but our ability to go beyond this kind of crude equivalence is very limited.

The most widely read book of the last few years to focus on IQ testing is probably *The Bell Curve* (Herrnstein & Murray, 1994), which caused great controversy in the U.S. with its thesis that the people (or races) at the bottom of the social pyramid were there because of intrinsic genetic differences, which could not be addressed by equal opportunity programs. The authors’ main concern was social engineering rather than the assessment of intelligence, and the book focussed on variations in mean IQ scores between racial and social groups. Interestingly, it was not at all concerned with the people who are currently viewed as having significant intellectual impairments. This disregard is one of the few things *The Bell Curve* shares with Stephen Jay Gould’s *Mismeasure of Man* (1981). The books are written from very different perspectives, but both are concerned with the accuracy and applicability of intellectual assessment, and it is perhaps surprising that they do not investigate the situation of those people whose lives are most affected by IQ tests—people who have obvious impairments. While Gould does review some examples of misdiagnosis and mistreatment from early this century, he does not discuss the current situation of this group, and *The Bell Curve* omits them totally.

As many people have pointed out, *The Bell Curve*, along with all other books which rest their arguments on IQ scores, has to prove two points. First, that it is valid and meaningful to reduce all the mental abilities of an individual to a single figure, an IQ score. Second, that an IQ score is validly derived from tests which accurately measure individual mental abilities without bias.

Typically, bias¹⁸ in IQ testing has been envisaged as relating to class, race or education. As I have argued above, more easily demonstrable bias due to disability is usually disregarded. It is as though prejudice on the basis of disability is unimportant.

The central question of intellectual assessment is how to measure something which cannot be accessed directly. The general assumption used to be that mental retardation was like the mark of Cain. It, or its accurate reflection, could be seen in the awkward movements of cerebral palsy and the epicanthic folds of Down syndrome. Until very recently most people admitted to institutional care because they were mentally retarded were given the 'eyeball test'. They were looked over and if the 'stigmata' associated with mental retardation were evident then that was sufficient.

Most 'mentally retarded' children were so classified on the basis of five criteria:

1. Physiognomy ("You need only look at him to see that he is ... stupid")
2. Use of age ("He acts like a two-year-old")
3. Quality of school work
4. Physical co-ordination ("He's slow and clumsy")

18 The word 'bias' here is used in its everyday sense rather than the technical, statistical meaning given it by Jensen in his 1979 book *Bias in Mental Testing*.

5. Physical signs, such as premature ageing (or, “He’s a funny-looking kid”) (Scheerenberger, 1983: 65¹⁹)

Of 403 children admitted to British ‘Hospitals for the Subnormal’ in one 1967 study, only 155 had been given a standard intelligence test (Mittler & Woodward, 1967). Even more strikingly, a 1987 survey of Caloola Training Centre, an Australian institution at Sunbury for people labelled intellectually impaired, found that of 624 clients 0.46% had a severe intellectual disability, 1.83% had a moderate disability, 2.29% a mild disability, 0.15% a borderline disability, and 95.27 an unassessed disability (Client Information Centre, 1988). Anne McDonald was not given an intelligence test before as a three-year-old with severe cerebral palsy she was admitted in 1964 to St. Nicholas Hospital (an institution for people with severe or profound mental retardation); she was given one before she was allowed to leave. At St. Nicholas the intelligence of only 3.4% of the residents had been tested, the other 96.6% being ‘estimated’ (Health Commission of Victoria, 1982). Not one resident had anything approaching normal speech, and more than 90% had no intelligible speech at all (personal observation, 1980). While these speech problems might explain why IQ tests were not administered, the assumption that all these untested non-speaking children had IQs below 35 confirms the hypothesis of this chapter—that mute equals dumb.

The choices made when the institution was asked to have Anne McDonald assessed in 1978 at the age of 17 were very informative about the presumptions still operating in the Victorian health system at that time. Firstly, the hospital pediatrician was asked to conduct the assessment.

19 Scheerenberger implies that these methods were used only before the introduction of IQ tests, but the institutional records discussed below show clearly that this is not the case.

Secondly, the pediatrician used the Denver Developmental Scale (Frankenberg & Dodds, 1967). The Denver is a screening tool designed to check whether pre-schoolers without obvious physical or sensory impairments are developing normally, and if you use it for anyone older that means that you have decided in advance that the person you are assessing has no skills beyond those expected of a 4-year old. Thirdly, the pediatrician refused to allow McDonald to use a communication board and refused to be told how she signalled 'yes' and 'no' because that might bias his assessment (Crossley, 1997: 18). He later reported that he had dangled a plastic ring on a string in front of her when she was lying in her cot and that she had looked at it but made no effort to reach for it. Apart from the fact that McDonald is a quadriplegic how many 17-year-olds had the pediatrician met who would reach for plastic rings? His finding was that she had at best the potential of a 12-month old.

That was the sixties and seventies, and today a child with a disability would be given an intelligence test before admission to residential care. That might not, however, change anything. If a hypothetical Anne Two were to turn up for assessment at the age of three without speech, fine motor skills, gross motor skills, head control, or eye movement control, and therefore without any ability to perform any existing intelligence test, she would fail her developmental examination, whatever her intelligence, at best achieving a 3-6 month level. The only certain thing that anyone could say of her would be that her knowledge (if any) was inaccessible and she was therefore unassessable.

The hypothetical Anne Two is only an extreme example of the general problem. Tests of intelligence purport to assess how well you take information in, and what you are able to do with it, on the basis of what

comes out. If nothing quantifiable comes out you are untestable. If anything quantifiable comes out you may be tested as though you have no disability, so that a six-year-old child with ten words of speech may be given a test requiring spoken answers and a teenager with no speech who cannot point accurately may be given a test to be answered by pointing. Obviously neither the child nor the teenager will do well on their tests, and that is not surprising. What is surprising is that the results are frequently assumed to reflect what the child and the teenager are thinking and what they are able to learn, and are used as a basis for decision-making about their futures.

Unfortunately many children with severe communication impairments are still denied the therapy they require, along with access to educational opportunities, because the results of inappropriate testing appear to show that they have such significant intellectual impairments that their ability to benefit from training is limited.

Accurate assessment of people with severe communication impairments is far from easy. There may be individuals for whom no valid assessment measure can be found. More commonly, individuals may require special training or equipment before they can be assessed accurately. Choosing an appropriate test or assessment strategy is difficult. The measure used has to be appropriate for the age and disability of the person. Developmental screening tests, such as the Denver (Frankenberg & Dodds, 1967) or Bayley (Bayley, 1969), which are designed to screen infants without major impairments for signs of developmental delay are sometimes used inappropriately with older people who have severe or multiple impairments, and their results are then wrongly interpreted as indicating mental age. Most importantly, it is necessary to separate the

communication disability from tests of comprehension, knowledge or cognitive processing. A regular reading test may effectively become a speech test if reading aloud is included for a student with a severe speech impairment.

Performance on tests requiring oral responses (such as the Wechsler Intelligence Scale for Children, or WISC) is adversely affected by speech impairments. People who have some clear speech which is nonetheless unreliable due to word-finding problems, aphasia or dyspraxia have special difficulties here, in that the true nature of their impairments may not be recognised by the tester. A person with word-finding problems or aphasia may say the wrong answer, often using a related word, despite knowing the correct answer (Bannister, 1985: 134). Not surprisingly, a person with such a problem may be unwilling to respond to questions at all, and this lack of response may be confused with stubbornness or ignorance, as may be the sporadic responses of a person with dyspraxia.

Echolalia is a specific word-finding problem in which the sufferer repeats the last word or words their communication partner says. Spoken responses to questions are correspondingly unreliable, and will depend on how the question is put. An echolalic conversation might go, for example,

Q. Is the capital of Australia Canberra or Melbourne?

A. Melbourne.

Q. Is the capital of Australia Melbourne or Canberra?

A. Canberra.

Q. What is the capital? Do you know?

A. No (know!)

Non-speech tests (such as Raven's Matrices and the Peabody Picture Vocabulary Test) and the performance items of tests like the WISC require manual responses. Obviously these cannot be used with people who have severe physical impairments precluding hand use (at least not without significant adaptation of the test presentation). Unfortunately, many people with severe communication impairments who can use their hands for gross motor activities still have neuro-motor impairments which affect their pointing or fine manipulative abilities (Crossley, 1994). In fact, the block design tests which are included in the performance scales of the WISC and Stanford-Binet had their origin in tests for apraxia, a neuro-motor disorder which is not uncommon in people with severe communication impairments—as Ayres has noted, “Among the tests used by investigators [of apraxia], the most popular have been designs with Koh's blocks, such as those used in some intelligence tests.” (Ayres, 1985: 110) Correspondingly, if an individual performs badly on a block design test, this may be caused by apraxia as much as by any problems of understanding or reasoning. Only a neuro-motor assessment will disclose where the difficulty lies. This is particularly relevant to the ranking of people with SCI, in that because of their lack of speech they are exactly the group who are likely (if they use their hands at all) to be assessed on performance or multiple-choice tasks that avoid the difficulties of administering verbal tests. Furthermore, non-speaking test-takers can neither explain their problems nor complain about the test.

Assessment, however insecurely based conceptually, tends to override observation: observations are interpreted in the context of an immobilising belief system. The case of Joseph Deacon is instructive. Deacon, who had severe athetoid cerebral palsy, was thought to be severely retarded and unable to communicate other than through noises and body language. He was

institutionalised as a child in England in the late 1920s. When he was a young man a new resident, Ernie Roberts, whose speech was clear, found that Deacon could talk and that he could understand him. Towards the end of his life Deacon, who was physically unable to write or type, wrote his autobiography, entitled *Tonguetied* (Deacon, 1968), with the assistance of three friends. He dictated it to Roberts, who was illiterate, but could understand his words and repeat them to a second friend, who could write. Deacon then reviewed the handwritten text and relayed it letter by letter to a third friend, who could not read but recognised letters and could operate a typewriter. Almost incredibly, the psychiatrist superintendent of the institution regarded the production of Deacon's book not as evidence of his intellectual capacities but rather as an example of what could be achieved by a person who was severely mentally retarded. In his introduction he said, "This is the first time that a severely physically and mentally handicapped resident of an institution has written a book." (Deacon, 1968: ix)

This judgement is hardly consistent with the definition of severe mental handicap, under which Deacon would not have been expected either to be able to spell or to compose, but the psychiatrist's overriding belief system obviously overrode this inconsistency. Deacon was subjected to many IQ tests before and after writing the book. These have been described by psychologist David Ellis (Ellis, 1982), who finally decided that both Deacon and Roberts were "not mentally handicapped": justice at last, although it would have been preferable if this conclusion had been published while Deacon was still alive.

5.3. Intelligence and etiology

While most people with severe communication impairments have probably had their abilities under-rated at some time or other, people with Down syndrome and people diagnosed as being in a persistent vegetative

state (PVS) are incompetent virtually by definition. I shall argue that the assessment of both these groups has been inappropriately based on speech, and partakes of the general prejudices against people who cannot speak. If it can be demonstrated that the assessment of these prototypical incompetents is defective, by extension the assessment of other groups who have severe communication impairments is suspect.

5.3.1. Down syndrome

Down syndrome is the name given to the cluster of physical and neurological impairments caused by certain chromosome abnormalities, most commonly a third copy of the twenty-first chromosome, Trisomy 21. The physical effects of the chromosomal abnormality are variable—about 40% of babies with Trisomy 21 have heart defects, up to 80% have (correctable) visual impairments—and may include almost every organ of the body. Of those who can speak 90% have severe articulation disorders and may not be understood by people outside their immediate families (Turner et al., 1990).

Publication of *The Bell Curve* (Herrenstein & Murray, 1994) stimulated a flurry of interest in ‘racial’ differences in IQ. Down syndrome used to be called ‘mongolism’, and the relationship between racism and views of Down syndrome has correspondingly received some attention.

Dr. Down was medical superintendent of the Earlswood Asylum for Idiots in Surrey when he published his “Observations on an Ethnic Classification of Idiots” in the *London Hospital Reports* for 1866. In a mere three pages, he managed to describe Caucasian ‘idiots’ that reminded him of African, Malay, American Indian, and oriental peoples. (Gould, 1980: 135)

Nonetheless the relation between IQ testing and people with Down syndrome has not been analysed in the same terms as the relation between IQ testing and blacks, presumably because people with Down syndrome

are regarded even by liberals as being intrinsically different from the ruling culture. The issue is whether these differences are due to differences in underlying cognitive functioning, or whether they can be accounted for (in whole or part) by particular social (or physical) deficiencies unrelated to what DSM-IV describes as 'significantly subaverage general intellectual functioning'.

The significance of Down's paper is now generally reduced to its having been the first paper to describe Down syndrome. As Stephen Jay Gould makes clear, this underestimates both the intention and effect of Down's work.

In his time, it embodied a deadly earnest attempt to construct a general, causal classification of mental deficiency based on the best biological theory (and the pervasive racism) of the age. (Gould, 1980: 135)

Even in the nineteen-twenties a British doctor could write of Down syndrome that

It is the 'Mongolism' rather than the idiocy that it is important to stress ... a kind of physical and psychical makeup that is coarsely and brutally displayed and accentuated in certain idiots and imbeciles. (Quoted in Kevles, 1985: 160)

Attitudes to people with Down syndrome can thus be seen to draw from a collective reservoir of racial prejudice.

Down syndrome is usually diagnosed at birth (if not before, through amniocentesis). Depending on the age, training and experience of the diagnosing doctor the parents may be told within a few days of the child's birth that their baby is severely, moderately or mildly retarded. The other professionals with whom the parents come in contact are also likely to have a definite opinion on the intellectual attainments to be expected from a child with Down syndrome. Their views will vary depending on their experience or the reference sources they consult. Goddard (1916) claimed

that the ultimate mental capacity of a person with Down syndrome was equivalent to that of a 4-year-old. Dr. Benjamin Spock's influential book *Baby and Child Care* (1946) suggested that babies 'born mongoloid' should immediately be institutionalised based on the premise that if the infant "merely exists at a level that is hardly human, it is much better for the other children and the parents to have him cared for elsewhere." (Spock, 1946: 478) Heaton-Ward and Wiley (1984) underline the fact that disparagement of the abilities of people with Down syndrome begins even earlier than for other people with intellectual impairment:

The diagnosis of mental handicap is rarely possible and, with few exceptions, unwise in the first 6 months of life. The most important exception is Down's syndrome ... [where] the ultimate presence of some degree of severe mental handicap can be forecast with certainty. (Heaton-Ward & Wiley, 1984: 7)

Generalist reference sources may be quite out of touch with more recent developments. *The Oxford Companion to the Mind* (Gregory, 1987: 201), for example, states that intelligence is "limited to an IQ of between 20 and 60" and "most die young". In a discussion of language development as recently as 1993, Professor Rondal, a Belgian psychologist, states that "a mental age of 4 to 5 years is the upper limit of mental growth for the majority of individuals with Down's syndrome" (Rondal, 1993: 167), a judgement based entirely on oral language.

In fact, views on the extent of the intellectual impairment have changed significantly since the syndrome was first delineated in 1866. In 1986 Graham Clunies-Ross wrote:

Up to the early 1900s people with Down syndrome were typically viewed as being profoundly mentally retarded. Surveys of children and adults during the first half of this century classified most people with Down syndrome in the severely mentally retarded category. Kirman's (1944) review suggested that the majority of Down syndrome children fell in the moderately to severely retarded range, with 2-3% achieving at the mildly retarded level. In the 1960s there were reports of up to 10% of cases

being educable or mildly retarded. By the mid-70s it was suggested that perhaps as many as 20-50% of older children and adults with Down syndrome were in the mild range, with a small number even achieving within the normal range. (Clunies-Ross, 1986: 167)

This revision is the equivalent to a jump of 30 to 40 points in average IQ scores over a sixty-year period. The pattern has been that people with Down syndrome have tended to approach the level of expectations that their parents and teachers have for them, and these expectations have been based on marginally surmounting the upper limits of professional expectation in each generation. While encouraging, this is a slow and incremental process, and involves no questioning of the basic paradigm, where “Down syndrome = mental retardation”. Introductory special education texts such as Fishler and Koch (1991: 341) still say “Retarded mental development is found universally [in individuals with Down syndrome]” and Patton and Payne (1989: 112) note that for many the term mental retardation “conjures up the image of a Down’s syndrome individual.”

The paradigm has until recently remained utterly unquestioned in its broad outline. In this area, at least, there has been no conceptual gulf between radicals, liberals and conservatives. In *Communication Unbound* (1993) Douglas Biklen, a radical in the field of educational integration, describes his early encounters with people typing to communicate at the DEAL centre in Melbourne, Australia. Biklen notes that when observing young people with Down syndrome typing, he assumed their conversational abilities would be more limited than those of other people whose communication was facilitated:

the fact that I was ready to believe (people with Down syndrome) might be more limited than other people was testimony to my disability blinders, to my attributing mental retardation to the condition of Down syndrome, and to my retrieving its associated stereotypes. (Biklen, 1993: 177)

Kliewer, who does question the paradigm, describes the 'text' of Down syndrome which "exists within the parameters of the imagery of mental retardation." (Kliewer, 1995: 29)

The changes that have been recorded in the IQ profile of people with Down syndrome represent a general shift in the Down syndrome mean of some 30 IQ points, from an average IQ of less than 20 to an average IQ of (depending on the study) between 40 and 60. The difference remaining after these adjustments between recent estimates of mean IQ scores for people with Down syndrome and the general population norm is approximately fifty points. *The Bell Curve* debate was concerned with the fifteen or twenty points between those black and white IQ means. Despite the differences in magnitude, however, a fundamental question in both cases is whether the initial assumption should be that the underlying cognitive levels of the two groups are similar but that other factors intervene to prevent equivalent levels of test scores, or that the differing score levels represent different levels of cognitive functioning.

Most people with Down syndrome have physical, sensory and communication impairments. A 1990 study of children with Down syndrome found that 38% had heart problems, 77% had visual defects, and 62% had hearing loss (Turner et al., 1990). Very little work has been done dealing with the extent to which level of cognitive functioning can be masked by physical disability. Hearing loss and visual defects can affect test-taking both directly, in that they impair operations on the actual test, and indirectly, in that they handicap the student in acquiring the information needed to take the test successfully. There are no studies of the intelligence of people with Down syndrome that control for these

factors, much less for the speech impairment which may actually prevent a person with Down syndrome responding to the tests altogether.

Today many people with Down syndrome are doing things which challenge the accepted wisdom about the inevitable effects of Trisomy 21—writing books, graduating college, holding down regular jobs, driving cars, even writing grants and conducting research projects. Indeed, accounts of people with Down syndrome who did not fit the pattern of idiocy described by Langdon Down have appeared regularly over the past century.

In 1955, under the unlikely title “The Sage: An Unusual Mongoloid”, John Buck, a psychologist, discussed the case of Benjamin Bolt. Mr. Bolt had been “committed to a hospital for the mentally deficient in the early 1940s” after the death of his parents. Bolt, who was in his forties, was described as “about as defective a Mongoloid as one could expect to find locomoting without active assistance.” Nonetheless, his “courtly acknowledgment” of Buck’s introduction “would have done justice to a seasoned diplomat.” Mr. Bolt, who had been educated by his mother, did not have significant impairments of speech or hand use and had little difficulty convincing Buck that he did not belong in a state hospital. Buck describes in some detail the tests he administered which led him to conclude that Bolt was not “mentally deficient”:

His answer to the third similarities question (In what way are a dog and a lion alike?) is noteworthy: ‘They are in two different classes: the lion is in the cat class, and the dog is in a class by himself.’ Then, after a brief pause, he added as if in afterthought, ‘But of course they are both carnivorous!’ (Buck, 1955: 457)

Despite such responses it took some years for Buck to convince the medical administration that Bolt should be allowed to leave the institution. Buck concluded his account by saying,

For many years the term ‘Mongolian idiot’ was freely used in the literature. Later it was conceded—grudgingly, to be sure—that Mongoloids under optimal circumstances might even function with the efficiency of morons. Then Pototzky and Grigg reported two Mongoloids whose intelligence might be termed ‘borderline’.

This changing trend and the case of the Sage compel one to speculate that before too long it may well be demonstrated that Mongolism need not inevitably be accompanied by mental retardation. (Buck, 1955: 481)

Buck’s hopes were not to be realised in the next forty years.

In 1964 Seagoe described Paul Scott, a person with Down syndrome who learned to write at the age of 6 and kept a diary until his death at the age of forty-seven. Scott’s teacher had initially thought he was intellectually hopeless because

he spoke no intelligible words or sentences and asked no questions. He made incoherent sounds as he played, pulling out the drawers of her desk, taking the chalk and erasers from the blackboard and laughing with joy as he threw them at the ceiling. (Seagoe, 1964: 12)

But through a process of “kinesthetic teaching” (Seagoe, 1964: 10), where Scott’s motor ability was initially the focus, he learned to read and write. Scott’s father was rich, and Scott travelled around the world. He described a visit to the Soviet Union:

We rode on the new underground called the metro. We saw Cossack soldiers in long overcoats to their ankles....The patriarch of the Greek Catholic Church is a prisoner of the Soviet, picking cotton on a collective farm in Asiatic Russia. The ‘Hidden Church’ we attended were all aged people. The hymn books were threadbare. Secretly, 30,000 Bibles were printed and distributed in the last several years. (from Seagoe, 1964: 102)

Interestingly, despite Scott’s obvious literary abilities, even Seagoe never questioned his diagnosis of mental retardation. She did, however, attempt to have the diary published, but was unable to get any publisher to believe that the diary was in fact the work of an individual with Down syndrome.

The stereotype of Down syndrome has persisted in the face of this contrary evidence, and it is necessary to ask why. Burton Blatt, a powerful

force in the American disability rights movement, initially doubted Seagoe's claim. When twenty years later he asked himself why, he concluded that "the answer to that question perhaps lies in the deeply embedded hopelessness associated with virtually everything connected with mental retardation." (Blatt, 1987: 102) This is, however, only taking the question back through one regression—back to the question of why, in the face of contrary evidence, has there been this hopelessness?

Individual differences between children with Down syndrome are often overlooked because of their superficial similarities of appearance, and the similarities between children with Down syndrome and other children are often ignored. The teacher of a ten year old with good speech and writing skills, who had been attending her local elementary school without an integration aide, and who was not by any means bottom of her class, recently asked me for a book on how to teach children with Down syndrome. Her student was a child who had no disability apart from her facial evidence of an extra chromosome.

A few years ago I spoke with a psychologist about the somewhat unexpected competencies found in people with Down syndrome who were given access to non-speech communication, and he said, "Yes, I know what you mean. Last year I gave a five-year-old Downs girl [who could speak] a full Stanford-Binet, and she scored an IQ level of 115." I asked the psychologist where he had published this. He looked at me rather oddly. "Oh, I couldn't publish it. People would think I was mad." (Clunies-Ross, personal communication, 1991) I told this story to another researcher shortly afterwards, and he said, "That's interesting. The highest I've ever had one of my Downs subjects score is 99." (Shattock, personal communication, 1992) He too had not published the test result. Such

examples suggest that the stereotype of Down syndrome persists partly because anomalies that would challenge it are simply discarded as embarrassing.

This thesis will not cover in any detail the debates over paradigm shift that have agitated the history and philosophy of science in recent years, nor will it lean any great weight on the 'scientific revolution' model of rapid and thorough change. I do accept, however, Thomas Kuhn's concept of the paradigm (Kuhn, 1970) as a consensual boundary to the kind of questions that can be asked within a discipline, a boundary that has a powerful if unformulated constraining influence, not just on the asking of questions, but also on the interpretation and handling of evidence which is in conflict with a currently accepted paradigm.

Many people believe that IQ tests are not good measures of ability, but they are the tests that purportedly provide the basis for the existence of retardation institutions and special education programs. The system's response to unexpectedly good test results may indicate that the test results of people with known disabilities are seen more as a means of quantifying prejudice than as a reliable indication of competence.

The girl with a test score of 115 had entered school with her teacher having been told nothing other than that she had Down syndrome. What the teacher thought that label meant depended on the teacher's information and prejudices, but it was certainly unlikely to lead her to expect the above-average performance suggested by that test score. Our multicultural society means that these days possession of epicanthic folds is more likely to indicate your ethnic origins than possession of an extra chromosome, and for the first time Down syndrome cannot be identified purely on the basis of appearance. Nonetheless, something about Down

syndrome still excites prejudice. The boy who scored 99 lives in Canberra, which does not have a strong integration program, and the regular school system continued to try and exclude him because he had Down syndrome and therefore must be intellectually impaired, regardless of his IQ score.

As DEAL Communication Centre, where I work, provides services for people with communication impairment, it is not surprising that the students with Down syndrome who attend the Centre all have very severe speech impairments (even though such impairments are not inevitable). As well as obvious articulatory problems, however, we have found that most of these students have significant word-finding problems which lead to their being unable to say words or answers that they in fact know. We have also found that these students have major problems with handwriting associated with significant motor-planning problems (Crossley, 1994: 19).

Typically, students with Down syndrome score far higher on tests of receptive language and reading comprehension than on tests of expressive language and handwriting. As has been found in research in Australia and overseas, reading comprehension is often a real strength for these children (and adults). Butterfield, in an article titled “A Provocative Case of Over-Achievement by a Mongoloid”—a title that in itself speaks volumes as to the effect of expectation—writes of an adult who had a measured IQ of 28 (and thus a mental age of approximately four) and a reading age of 10 (Butterfield, 1962). Carr mentions three studies in which reading age was higher than would be predicted from IQ scores.

Potozky and Grigg give results on nine young people, mean CA 20, mean IQ 55, who ... [had] an average level of about 8 1/2 years. Dunsdon *et al.* [after testing] ... eight children, mean CA 11 and IQ 54, obtained a mean reading age of 8 yrs 8 months. In a study from Macquarie University (Pieterse and Treloar, 1981) eight children who had been in an early intervention program and had gone on to ordinary schools, at a mean age

of eight and Stanford Binet IQ of 59 had a mean reading age of 7.2 years.
(Carr, 1988: 424)

Similarly, in a review of the literature on the literacy abilities of preschool children with Down syndrome, Buckley notes that numerous studies demonstrate “Down’s children are showing reading skills as good as or more advanced than would be expected even for normal children [of the same chronological age].” (Buckley, 1985: 325) Buckley does at least raise the idea that “mastering a written language is in some way easier than mastering a spoken language for Down’s children” (Buckley, 1985: 322), and in fact makes the interesting suggestion that, unlike nondisabled children, who learn to read as a second language, children with Down syndrome may learn to read as if it were a first language. Having said this, nonetheless, she makes no criticism of the fact that the demonstrated reading ability of the preschool children involved in the numerous studies she cites has not prevented them from being diagnosed as mentally retarded on the basis of their IQ scores.

Written language may be used to cue speech or to substitute for speech, though motor planning problems mean that keyboards usually have to be substituted for pens. As the low muscle tone and impulsivity (pointing without looking or taking time to think) found in many children with Down syndrome may complicate use of keyboards, communication aids, and even assessment using multiple choice tests, a therapist’s first task is often to teach the child to point effectively. Hearing and vision problems are also common and must be carefully monitored and remedied as they would be for any other student. Once all sensory, neuro-motor, and expressive problems have been addressed, then—and only then—is it possible to find out what the child has learnt and is capable of learning.

'Paul' exemplifies some of the problems that people with Down syndrome who cannot speak may have in demonstrating their competence. Paul attended a regular primary school, but because he could not read aloud or write more than a few words he was not thought to be learning anything. Indeed, his lack of speech put him in the 'low functioning' category of Down syndrome. When he was eleven Paul's mother thought it 'so sweet' that Paul imitated his sisters by sitting and pretending to read for an hour when he came home from school each day, and by insisting on taking a book to 'read' in bed each night. He chose age-appropriate books, held them the right way up, turned the pages one-by-one, and moved his eyes from left to right and down the page, but because he could not speak well enough to say what he had read his family presumed he was not understanding the words on the page. At the age of twelve Paul was given a chance to type for the first time. He revealed good reading comprehension and an excellent vocabulary. Later he was to score above the 90th percentile on the Peabody Picture Vocabulary Test, a standard vocabulary assessment. In the 1996 Victorian Certificate of Education he scored an A in Mathematics and good passes in other subjects and is now enrolled in a Business Studies course at a TAFE college (Paul's early history is discussed in Crossley, 1994: 124-128).

The academic achievements possible for most children with Down syndrome cannot be known until the first group of students who have had all their expressive impairments addressed since infancy and who have attempted the regular syllabus at regular schools has proceeded through the school system. They will be the first group for whom the playing field has been levelled. They are already showing that Trisomy-21 produces a variable range of physical and neuromotor problems, which, like cerebral

palsy, may include but certainly does not necessarily include learning difficulties.

People with Down syndrome have only seldom attained the level of personhood demonstrated by people with hearing impairment in the time of Massieu and more recently by people with physical handicap. To date they have written very few books and have been involved in relatively little self-advocacy. Nigel Hunt, an Englishman, wrote the first book by a person with Down syndrome in 1967, published as *The World of Nigel Hunt*. The book came with a patronising foreword by a professional downplaying the complexity of the work, saying, for example, that “his manner of thinking ... is entirely concrete. He never makes a generalisation.” (Penrose, in Hunt, 1967: 11) As Booth comments, however,

One might suppose that intelligence is revealed not simply by a capacity to make generalisations but by an ability to make them when appropriate and refrain from making them when they are inappropriate. The literature about people with Down’s syndrome is littered with inappropriate generalisations. (Booth, 1985: 12)

Furthermore, Hunt does in fact generalise, and Penrose’s comment represents an expression of ‘diagnostic overshadowing’ (see 9.2 below) where the diagnosis is taken as determining the person’s life absolutely in all its aspects. Similarly, Gibson comments that,

There is no evidence in *The World of Nigel Hunt* or in any of the “bringing up our mongol” books that the fundamental performance limits of the syndrome have been surmounted or that nurture can influence these performance limits. (Gibson, 1978: 58)

Denial of the evidence could scarcely be taken further, until, that is, we enter the hospital wards occupied by people diagnosed as being in persistent vegetative state.

5.3.2. Persistent Vegetative State

Most people have been unconscious at one time or another—after a hit on the head or during a medical or dental procedure. Sometimes people who sustain brain damage remain unconscious for days and are described as being comatose. If after a length of time they open their eyes but do not speak or move they are likely to be diagnosed as being in a Persistent Vegetative State (PVS). It is only recent advances in resuscitation and life support that have made a term like Persistent Vegetative State necessary. Fifty years ago few of the patients now described as being in PVS would have survived long after their initial injuries. The term was devised in the early seventies by two neurologists to describe patients with brain damage surviving in a state that was neither coma nor recovery—who showed “wakefulness without awareness”.

In our view the essential component of this syndrome is the absence of any adaptive response to the external environment, the absence of any evidence of a functioning mind which is either receiving or projecting information, in a patient who has long periods of wakefulness. (Jennett & Plum, 1972: 736)

In the medical system PVS serves as the post-coma holdall. Conventional wisdom is that, despite apparently being awake, patients in a persistent vegetative state have no consciousness and no understanding (which does make their care very much simpler). One therapist wrote,

Vegetative patients are not ‘locked in’ [aware but unable to express their awareness]: we know they have suffered very extensive brain damage. The pathophysiology of such damage precludes the sparing of cognitive abilities against a background of severe physical impairment. (Snow, 1991: 25)

The assumption appears to be that these people have severe physical impairments caused by brain damage, so it is inevitable that they will also have severe cognitive impairments.

An assumption of unawareness has significant treatment implications. Painkillers may not be administered, even to patients who appear to be screaming in pain, once practitioners read statements such as,

The PVS patient may 'react' to painful stimuli, but he or she does not 'feel' pain in the sense of conscious discomfort of the kind that doctors would be obliged to treat or of the type that would or should seriously disturb the family. (Mitchell, Kerridge & Lovat, 1993: 72)

Procedures which would normally be done with a local anaesthetic may be done without. Therapy is unlikely to be provided and entertainment will be considered irrelevant, so patients may be left looking at the ceiling for months or years. As dignity will not be considered an issue a PVS patient may be left naked for nursing convenience. Medical staff and visitors may talk in front of a patient in a way that they would not if they thought the patient could understand (Personal experience, 1985-97).

In 1993 a number of American neurological associations established a Task Force to investigate aspects of PVS. Its criteria for PVS included :

- 1) no evidence of awareness of self or environment ...
- 2) no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to ... stimuli:
- 3) no evidence of language comprehension or expression.
(Multi-Society Task Force, 1994: 1500)

The fundamental problem with this formulation has been obvious from the time the condition was named:

there is a group of patients who never show evidence of a working mind. This concept may be criticized on the grounds that observation of behavior is insufficient evidence on which to base a judgment of mental activity. (Jennett & Plum, 1972: 737)

The concept is indeed vulnerable to just this criticism. Behaviour is observable; awareness or unawareness is a deduction. Behaviour may not in all cases be a reliable guide. Brain damage frequently destroys the

neurological structures that normally support volitional actions. In locked-in syndrome, in which consciousness is generally conceded,

consciousness and cognition are retained but movement and communication are impossible because of severe paralysis of the voluntary motor system....Patients with this syndrome can usually establish limited communication through eye-movement signals. (Multi-Society Task Force, 1994: 1502)

Locked-in syndrome thus consists essentially of PVS with the addition of purposive eye movements. There are many forms of neurological damage that can affect the control of eye movements. The Task Force is uneasily aware of the possibility of such errors.

By definition, patients in a persistent vegetative state are unaware of themselves or their environment. They are noncognitive, nonsentient, and incapable of conscious experience. There is, however, a biological limitation to the certainty of this definition, since we can only infer the presence or absence of consciousness in another person ... an error might occur if a patient in a locked-in state ... was wrongly judged to be unaware. Thus, it is theoretically possible that a patient who appears to be in a persistent vegetative state retains awareness but shows no evidence of it. In the practice of neurology, this possibility is sufficiently rare that it does not interfere with a clinical diagnosis carefully established by experts. (Multi-Society Task Force, 1994: 1501)

Later in the Task Force Statement the possibility of undiagnosable locked-in syndrome appears to move slightly further away from the theoretical to the possible:

In rare cases, it may be difficult to distinguish a persistent vegetative state from a severe locked-in state. Under such unusual circumstances, a patient may not be able to express behavioral responses to painful stimuli or the responses may be extremely difficult to detect: the absence of a response cannot be taken as proof of the absence of consciousness. (Multi-Society Task Force, 1994: 1576)

In the face of this possibility, it is impossible to prove, in any specific case, that the subject is not sentient. If it is not possible to prove this, there is no justification for assuming it. The fundamental question is not, "Can cases of locked-in syndrome be confused with cases of PVS?" but, "Is it possible

that PVS is the same thing as locked-in syndrome, but without purposive eye movement?”

The reliability of a diagnosis of PVS is poor. One study of patients in nursing homes who had been identified by nursing home personnel (nurses and physicians) to be in a PVS was obliged to discard 11 out of 62 subjects (17%) on the grounds that they “were considered by us to have some awareness of their environment, with some of the patients demonstrating volitional movement.” (Tresch et al., 1991: 930) That 17% error rate, while high, is much lower than the error rate found in the only pre-1996 study addressing the question directly (Childs et al., 1993), where 18 out of 49 people (37%) were found to be inaccurately diagnosed. A 1996 study reported that 30 of 40 patients diagnosed as in PVS demonstrated awareness, an error rate of 75% (Andrews et al., 1996). In every case in the Andrews study the reversal of the preceding diagnosis occurred after non-speech communication intervention.

A diagnosis of PVS is typically taken to preclude communicative intervention. In one Australian study the most commonly cited reason for not offering non-speech communication to people with acquired problems was their lack of cognition (Russell & McAllister, 1995). The uncertainties inherent in the diagnosis of PVS suggest that decisions regarding intervention should not be dependent on medical judgements of cognition.

Based on this evidence, I suggest that intervention aimed at establishing communication should be mandatory for the PVS population, as non-speech communication strategies now available may be able to make use of controlled movements not evident at a traditional neurological examination. Andrews et al. reported that, in their unit, “the patient’s

awareness is nearly always identified first by the occupational therapists ... and only later is communication achieved by the other members of the team” (Andrews et al., 1996: 15), and relate this to the patients’ severe physical impairments and the need for appropriate positioning and adaptive equipment to elicit responses.

Between 1986 and 1990 DEAL Communication Centre staff saw 17 people who had been described as being in a persistent vegetative state. Their outcomes add to concern about the reliability of diagnosis of PVS. Of the 13 survivors, seven now communicate through speech or spelling, and the other six have demonstrated awareness. (Crossley & Borthwick, 1996) In almost every instance, the doctors and therapists involved in the initial diagnosis of PVS sturdily resisted any suggestion that their patient might have preserved abilities.

One client, ‘Carolyn’, was sixteen when she was knocked off her bike and suffered a major head injury, fracturing the base of her skull and sustaining massive frontal lobe damage, especially on the left side. When first seen by DEAL staff she was a tube-fed quadriplegic without speech living in a rehabilitation hospital. Carolyn had been assessed as not suitable for therapy—the medical director concluding that

the patient’s condition has not improved since admission ... at no stage has she given a consistent cognitive response to stimuli, confirming the impression of a chronic vegetative state with a very poor prognosis. It was not considered that rehabilitation had anything to offer this unfortunate patient. (Hospital records, 1985)

Despite these findings, Carolyn’s mother sought a non-speech communication assessment for her daughter. By using a headpointer Carolyn was able to demonstrate preserved literacy skills. She went on to spell out her opposition to the hospital’s plan to move her to a nursing home. Unfortunately, all of the professionals who had previously assessed

Carolyn agreed that it was impossible for her to be spelling and in consequence none would come and observe her use of the headpointer. A month after she had started to communicate she was transferred to a geriatric nursing home—an extraordinarily depressing environment for anyone, let alone a seventeen year old. Fortunately, after battling the medical establishment, her mother succeeded in taking Carolyn home (Crossley, 1997: 61).

While it is not unusual for there to be disagreement about the communicative abilities of people with severe brain damage, in Carolyn's case the matter was settled conclusively. About twenty months after the accident, and nine months after she had started using the headpointer, DEAL had a phone call from Carolyn. Her speech had come back the previous day. Her voice sounded a bit rusty and lacked intonation, but it was quite clear. Any doubts about her literacy skills could now be resolved, because she could read aloud or give spoken answers to written questions. Professional staff at the rehabilitation hospital initially refused to believe reports of Carolyn's speech. A letter from the Chair of the Equal Opportunity Board, who had conversed with Carolyn, and a psychologist's report together eventually forced a revision of their attitudes towards her. Nonetheless, their attitudes to other people left in similar situations showed no sign of changing (the statement that the pathophysiology of PVS precluded the retention of cognitive abilities, for example, was made by a member of the rehabilitation hospital assessment team several years after Carolyn had recovered speech).

The case of PVS is perhaps the clearest demonstration of the potentiality for total dehumanisation of people who are unable to

communicate. Richard Dworkin, Professor of Jurisprudence at Oxford, who writes on medical ethics, says

Some accidents and diseases leave their victims either in comas or in what doctors call a persistent vegetative state. In either case they are unconscious and the higher centres of their brains have been permanently damaged in a way that rules out any return to consciousness. They are capable of no sensation and no thought...[nonetheless] The relatives of a patient in a vegetative state often treat him as still alive. (Dworkin, 1993: 187)

The true situation, as Andrews et al. make very clear, is not only that these people are indubitably alive, but that many are conscious and aware, only waiting on a means of communication to make their opinions known:

patients can regain awareness after more than four months in the persistent vegetative state. Some of the patients reached a high level of functioning in daily activities and mental state...Others remain severely disabled, though recovering sufficient mental ability to make decisions for themselves. Even the most profoundly disabled were able to take pleasure in their surroundings. (Andrews et al., 1996: 1599)

Down syndrome and persistent vegetative state may at first sight appear to have little in common, but both share a presumption of cognitive incompetence founded on the communication and motor impairments which are integral to each condition. There is evidence that this presumption has often led those professionals who have observed signs of competence to disregard the evidence of their eyes, or to keep such evidence to themselves. This may in part be because the prevailing paradigm is so strong that to question it is to invite ridicule. The situation of these representative diagnostic groups exemplifies that of the third main class of non-speakers—people with a primary diagnosis of intellectual impairment. As might be expected from the histories of Down syndrome and PVS, communication intervention which allows people with such a diagnosis to demonstrate unexpected competence provokes disbelief. It is appropriate that the next chapter is introduced by the words of a girl with

Down syndrome, who asks the central question: "Can anyone hear the voice inside?"

Chapter 6. Treating expressive impairment: challenging intellectual impairment

Can anyone hear the voice inside?

Give me some light and I can see.

Give me some pain and I can feel.

Give me a call and I will hear:

But give me credit -

That's for some too hard.

Remember:

My words, like pearls,

Are found in an oyster. ('Jan', quoted in Crossley, 1997: 286)

'Jan', the author of this poem, has very limited speech caused by Trisomy 21, otherwise known as Down syndrome. She was a teenager when she typed the poem with facilitation. Giving her credit was indeed hard, so hard that her family and teachers did not believe she had written it. This was partly because they did not expect a person with Down syndrome to have the literacy or conceptual abilities needed to write poetry and partly because the poem was produced with facilitation, a communication strategy which invites scepticism. Both in what she wrote and how she wrote it Jan encapsulated the main controversies surrounding the use of non-speech communication by people labelled 'intellectually impaired'.

This chapter outlines the development of non-speech communication for people diagnosed as intellectually impaired, from the initial provision of limited-vocabulary communication systems through the production of potentially-unlimited spelt communication by people using facilitation. The history of facilitated communication is taken from its initial use by numbers of people with disparate diagnoses who were isolated from each other to the establishment of facilitator training programs in the tertiary sector and the publication of textbooks about the method in the 1990s.

These developments have been associated with intense controversy and acrimonious debate, only rivalled by the oralist/sign debates in deaf education. While oralist/sign debates continue, they started in the eighteenth century and today reflect the experiences of two centuries of deaf education. The controversy about communication for people like Jan only started in the 1980s, after non-speech communication was first offered to people whose primary diagnosis was intellectual impairment but who did not have severe physical impairments, and, as outlined in this chapter, it illuminates many facets of current societal attitudes to people who cannot talk.

6.1. A very few words—limited communication for people labelled intellectually impaired

In the early years of augmentative communication, people who were regarded as mentally retarded “were ignored ... as we [therapists] focused on people with motor impairments and normal/near normal cognition.” (Blackstone, 1992: 1) Communication systems reached people diagnosed as having intellectual impairment from two directions—down from the top, as methods that proved effective in people with physical handicaps who were thought ‘higher functioning’ were applied to them, and up from the bottom, as work done with chimpanzees was applied to them.

Yerkish, a ‘computer-controlled language system for investigating the language skills of young apes’, had been devised in the Yerkes Primate Center in the sixties (as it happens, the Yerkes after whom the centre was named was a past president of the APA and a force in the development of IQ testing: see Gould, 1981). The late sixties and early seventies saw the introduction of restricted sign vocabularies and artificial ‘laboratory’ languages such as Yerkish to hearing non-speaking children in the United States (Rumbaugh et

al., 1973). These programs were directly based on the use of such communication by chimpanzees—the title of one book on the topic, *Language Intervention from Ape to Child* (Rabusch, 1984), reflected the attempts to use these strategies with non-speaking ‘retarded’ human infants which followed the animal experiments. A number of researchers thought that,

If nonvocal response modes provide an alternative for chimpanzees who do not have the physical ability to produce speech, it seems possible that such an approach might have applicability for communication development in low level retarded [humans]. (Kuntz et al., 1978, 35)

The authors appear to be suggesting, by analogy, that ‘low level retarded’ are like chimpanzees—that is, that they lack the physical ability to produce speech. If this were true, however, what would that then imply about the label of retardation? The proposition in fact appeared to be founded on fuzzy reminiscences of evolutionary theory: the lowest humans might overlap with the highest animals and might be able to learn similar skills. Such a study was in fact carried out comparatively recently.²⁰ Ronski and her colleagues claimed that the establishment of a conditional association between food and its symbol had formed the foundation for symbolic communication skills in two chimpanzees, and went on to describe “the successful adaptation of this language-relevant research effort to language intervention in five case studies of adolescents with severe retardation.” (Ronski et al., 1988: 95)

²⁰ Ironically, the research with people diagnosed as retarded took place well after primate communication studies themselves had fallen into general disfavour and the notion of symbolic communication among primates was increasingly regarded (correctly or incorrectly) as a mirage. The transfer of communication efforts from apes to people with disabilities may have been an attempt to salvage something from the wreckage, or may have been an attempt to convince potential grantmakers that the primate work had redeeming social value.

Given that a perceived relationship between limited speech and limited intelligence underlies the construction of mental retardation (see 5.1 above), it is not surprising that people diagnosed as retarded were initially offered limited vocabulary non-speech communication systems:

Only facets of the Blissymbolics and Signed English programme were appropriate for intellectually-impaired students. Picture sets provided the best means for labelling and choice-making. This group proved to be less motivated to learn how to communicate and take control over their own lives. (Rush, 1996: 5)

The issue of how much control students could take over their own lives using a set of pictures chosen for them by the researchers is not addressed. It is unlikely, for example, that the pictures included a hand with two raised fingers and the appropriate accompanying message.

“After all, even if they were able to speak clearly and fluently they still wouldn’t have much to say”, still seems to be the rationale for providing adults with the vocabulary of infants:

We use a few gestures, signs and picture sets for labelling and choice-making purposes. But since all are at the pre-symbolic stage of communication, we do not get into any serious literacy activities. (Rush, 1996: 6)

If Rush were correct, and the students were indeed pre-symbolic—that is, not able to associate symbols with their referents—the signs and pictures used (which are of course symbolic) would be meaningless to them. If the students were using signs and pictures, they were not ‘pre-symbolic’. It appears that Rush’s presumptions about these students and about literacy have over-ridden observation.

The forms in which this limited vocabulary was provided were dictated by the physical characteristics of the people, often described as ‘the trainable mentally retarded’, for whom speech augmentation was seen as especially desirable. These people, whose speech was by definition

limited in fluency or intelligibility, were seen as having more potential to learn than those described as severely or profoundly retarded, who often had severe physical and sensory impairments in addition to their SCI, and were seen as more needy than those assessed as 'educable', whose relatively fluent speech was generally judged to meet their needs. Typically, the trainable mentally retarded were able to walk and feed themselves, and had physical skills in advance of their speech (Love, 1968).

As indicated in 4.1 above, first attempts to provide communication for hearing people without speech focussed on the needs of people with severe physical impairments who were seen as having able minds trapped in disabled bodies. Ironically, it was easier to provide communication aids to people with severe physical impairments than it was to provide them to walking non-speakers, regardless of their intellectual capacity: people with severe physical impairments used wheelchairs, which went everywhere with them, on which the large communication displays and heavy computers of the seventies could be mounted. Non-speakers who walked had difficulty carrying cumbersome communication aids. Consequently the first attempts to help ambulant non-speakers communicate focused on the sign language used so successfully by the deaf, and from the mid-sixties sign language programs using the Makaton vocabulary were widely implemented with students with a range of developmental disabilities (Grove and Walker, 1990).

Makaton met the portability requirements of walking non-speakers, but it had other disadvantages. Sign language required good hand skills, but many of its potential users who can hear have hand function impairments and may find manual signing no easier to use than speech

(Crossley & Remington-Gurney, 1992: 31). While hearing non-speakers had similar expressive needs to the deaf, the cause of their expressive problems was neurological impairment affecting some of the motor systems involved in speech and/or language. Whether they walked or not, people who had neurological impairments affecting their speech typically also had difficulties in reproducing the sequences of fine movements necessary for signing and handwriting (Crossley & Remington-Gurney, 1992). For many, learning to use hand signs appeared to be only marginally less difficult than learning to talk. Most ended up with a very small expressive sign vocabulary, despite being known to recognise and understand many more signs than they produced²¹. Unfortunately, as Deich and Hodges (1977:145) make clear, students who ‘fail at signing’ risk being seen as having ‘no language skills’.

Furthermore, another inherent problem with limited vocabulary sign language programs for non-speakers is that they are just that—limited vocabulary ‘languages’, which arbitrarily restrict what even the most fluent user can say. The expectations held for Makaton users can be deduced from the size of the original vocabulary, which was set at only 200 signs. To place this in context, Kendon (1988) cites 300 signs as the minimum required for a signing system to be called a sign language, and speaking children aged 5 have been recorded as using more than 5,000 words (Pinker, 1994: 150).

21 There is one important exception here: some infants with Down syndrome who were introduced to hand signs in early intervention programs have developed sign vocabularies as extensive as the spoken vocabularies of other children of the same age, and have gone on to speak relatively fluently (Crossley, 1997: 167).

Makaton was initially used in institutions for people labelled mentally retarded, firstly with deaf residents and later with non-speaking residents (Grove and Walker, 1990). Whatever its vocabulary limitations, its introduction into the institutions was something of a triumph given the virtual exclusion of sign from the education of the deaf in England at this time (Sacks, 1989: 162). Because the retardation institutions were closed communities it was possible either to set up signing wards or to teach most residents and staff at least some signs. However, if sign language training is not emphasised strongly and repeated regularly, even the hearing impaired residents of intellectual disability institutions can be left without communication owing to staff changes.

In 1994 the Community Visitors to Janefield, a large residential institution in Melbourne for people diagnosed as intellectually impaired, described the problems in a unit in which most of the residents had hearing impairments and had been taught a limited vocabulary of Auslan (Australian sign language) signs:

On visiting the unit it was obvious that the staff on duty had little, if any, understanding of what the residents were 'signing'. Not one staff member was able to introduce Community Visitors to residents who were hearing impaired. Whilst the Janefield Special School was open, hostel staff had received some training from the instructors in Auslan....However, staff changes after that time left few of those staff in the unit, and other staff had little understanding of Auslan. Community Visitors noted that the residents themselves did not have any problem with communication. The lack of skills was on the staff side. **It was incomprehensible to Community Visitors that DH&CS would staff a unit without one member of the staff being able to communicate with the residents.** (OPA, 1994: 89, emphasis in the original)

Because these sign users did not live in signing communities, there were only a limited number of people in the world with whom they could communicate. While this disadvantage of course also applies to deaf signers, and has been main prop of oralist arguments over the years, the

circumstances of the two groups are, of course, different, in that the deaf need a way to receive messages as well as a way to express them. As most developmentally disabled sign language users can hear, their carers, friends and families do not need to use sign to talk to them, reducing still further the exposure to sign that learners receive.

There was both a difficulty in extending use of Makaton into the world outside the institution, and a need to provide some communication for people with poor hand skills. To meet these needs, in the 1980s the use of communication displays was extended to people labelled mentally retarded (Crossley & Remington-Gurney, 1992). On these communication boards or books, words were represented by pictures or specially drawn symbols. Initially the most popular symbol system was the Blissymbols used by children with cerebral palsy and supposedly no literacy skills. As with the Makaton signing, symbolic communication was intrinsically limited, not just in topic but also in grammatical complexity. An individual with a communication board could only say what the person who assembled the board thought was necessary or suitable, and practical limitations meant that few walking symbol board users had even 200 symbols at their disposal.

The prevailing perceptions of mental retardation as inextricably linked with restricted communication skills presumably affected the complexity of the communication systems provided to non-speakers labelled mentally retarded. Correspondingly, the fact that these people had difficulty becoming fluent in whatever system they were offered only appeared to provide confirmation of the link between mental retardation and language impairment. The all-encompassing construct 'mental retardation' was sufficient explanation for any incapacity, making any

differential diagnosis of specific sub-impairments unnecessary. In fact, even fluent users of Makaton signs or Blissymbols and subsequent pictorial communication systems would be hard put to challenge prevailing perceptions of their abilities given the limited vocabulary and structures at their disposal.

It was not, however, the linguistic limitations of Makaton and communication boards which led to the use of keyboards with facilitation, but rather the physical limitations of many of their users. People who find signing difficult do not automatically acquire the pointing and selection skills necessary to use communication boards effectively, either (Crossley & Remington-Gurney, 1992). There were no communication options suitable for people who could not sign, type or write fluently, could not carry eye-pointing displays or enlarged keyboards or scanning systems, and could not wear headpointers. The most practical option was to teach them the hand skills needed to use portable communication boards or small electronic communication aids. This in turn gave rise to facilitated communication training (Crossley, 1994: 12).

6.2. Mute does not equal dumb—the development of facilitated communication training

Facilitated communication training is a strategy for teaching or enabling people with severe expressive communication impairments to use communication aids with their hands. To facilitate communication a facilitator makes it easier for a non-speaker to make selections from a communication aid by providing physical support. Facilitation differs from co-active guidance, a more generally accepted training technique, in that students using facilitated communication make their own choices rather than pointing at items nominated by their facilitator. In facilitated

communication training this support is combined with exercises designed to improve the communication aid user's hand use, with the aim of enabling him or her to use communication aids independently (Crossley, 1994).

The records of facilitated communication date only from the last three decades. Its short history can be split into two parts: before and after the opening of the DEAL Communication Centre in Melbourne in 1986. While a number of teachers and parents used facilitation to assist non-speakers before 1986, they worked with single individuals or small groups and their use of facilitation was seen as case or situation-specific, rather than as a technique which had broader application. Consideration of the early use of facilitated communication points to the reasons which prevented wider application of the technique prior to 1986.

From early 1986 facilitated communication training was used with hundreds of non-speaking people with varying diagnoses attending DEAL Communication Centre, whose only common feature, apart from their SCI, was their previous lack of success with sign language and communication aid use (Crossley, 1992: 16). From DEAL, use of facilitated communication has spread to virtually all countries in which any form of communication augmentation is used. In its short history, facilitated communication has received an extraordinary amount of media attention and has often been the focus of controversy. Because this controversy is amply documented and on-going, it is relatively easy to identify the stakeholders and the attitudes fuelling it; however, because the controversy has not yet been resolved, its final effect on society's attitudes to non-speakers remains unknown. The systematic use of facilitation and the associated controversy is discussed in the latter section of this chapter.

6.3. Unsystematic intervention and individual expedients—facilitating communication prior to 1986

It would be incorrect to give the impression that facilitated communication followed sequentially the development of non-speech communication strategies for people with physical impairments, or that its use has been restricted to non-speakers who could walk. The early use of facilitation overlapped the early use of other forms of AAC by people with cerebral palsy and in the seventies and early eighties facilitation was used by people with varying diagnoses who did not know of, or could not access, other forms of non-speech communication. Use of facilitation by individuals with severe physical impairments who for one reason or another cannot compensate for their impairments through technology will inevitably continue, though the specific technique called facilitated communication training is now primarily associated with the use of spelt communication by people diagnosed as autistic and/or intellectually impaired²².

Possibly the first attempt to use spelling to extend the communication of children with autism occurred in the late 1960s when two pediatricians in upstate New York employed the Edison Response Environment (ERE), “a cubicle enclosing a multiphase electric typewriter, projector, and programming device that could respond to or direct the user in a variety of ways,” also called the “talking typewriter,” to teach children with disabilities (Goodwin & Goodwin, 1969: 557). Sixty-five of their students had been diagnosed as autistic. Some students, who had only

22 While autism is a diagnosis separate from mental retardation, most people with autism are said to have significant intellectual impairments (Gregory, 1987: 63), and a diagnosis of autism may be taken to imply intellectual impairment without any specific testing being undertaken, especially if the person has no speech or disfunctional speech.

repetitive or echolalic speech, typed words they could not say. Sometimes the typing was followed by speech development. One young child is described as using the ERE

in a sporadic and explosive fashion, often dashing up the stairs and into the booth in which it was installed, sometimes falling down en route, jumping up on the chair, lifting up the plastic lid and typing a few keys, then tearing off the paper and rushing downstairs. This continued over a period of several months. Efforts to slow him down were only partially successful. (ibid.: 558)

Eventually this child showed that he could recognise letters and words. After he started to type words at the age of four, he also began to talk. “At eight, he has a large vocabulary, speaks intelligibly with slight articulation defect, and is doing well in the second grade of a home instruction program.” (ibid.: 558) The Goodwins argued that the ERE did not change the children’s intelligence but, rather, gave them a means of expressing their intelligence: “The ERE was the instrument that showed us abilities not measured by conventional psychological tests.” (ibid.: 562) While the Goodwins do not appear to have used facilitation, the account of their use of electronic devices and written language to augment the communication of children with autism highlights a strength—literacy in advance of spoken language—and a weakness—impulsivity, which were to feature in later accounts of facilitated communication. Given the Goodwins’ excellent credentials, it is somewhat surprising that no-one appears to have followed their lead (at least, I have found no reference to the use of the technique after the time of the Goodwins). People may perhaps have thought that the ERE was integral to the children’s success, and in the absence of access to that costly purpose-built technology thought that there was no point in trying regular typewriters with autistic children.

The first substantial account of the use of facilitation to assist communication was published in 1974. Rosalind Oppenheim, a teacher and mother of a boy with autism, documented in detail the procedures she used in the sixties to teach her son and other children with autism to communicate through facilitated handwriting.

Most of the autistic children whom we have taught have learned to read without difficulty, often before they develop speech. Writing, however, is another story. Many autistic youngsters have major problems in controlling pencils, chalk or crayons. This disability appears to be more pronounced in nonverbal children ... we usually teach writing by manipulating the child's hand, and thus feeding in the motor patterns. We believe that the autistic child's difficulties stem from a definite apraxia....There seems to be a basic deficiency in certain areas of his motor expressive behaviour. So, in teaching writing, we find that it is usually necessary to continue to guide the child's hand for a considerable period of time. Gradually, however, we are able to fade this to a mere touch of a finger on the child's writing hand. We're uncertain about precisely what purpose this finger-touching serves. What we do know is that the quality of the writing deteriorates appreciably without it, despite the fact that the finger is in no way guiding the child's writing hand. "I can't remember how to write the letters without your finger touching my skin' one nonverbal child responded....The problem is not recognition, but rather execution, in retaining the mental image of required motor patterning. Ultimately, however, the finger-touching can be eliminated, and the child does write without it, although some children want the touch of a finger on some other bodily surface, such as the head, in order to write. (Oppenheim, 1974: 54)

The clarity and freshness of Oppenheim's writing is reminiscent of Itard's, and her findings should have aroused both interest and replication, but her finding of neuro-motor dysfunction, at a time when autism was still being seen as an emotional disorder caused by 'refrigerator mothers' (Bettleheim, 1967) so at variance with prevailing notions that it appears to have sunk without trace. Similarly, her use of facilitated handwriting as a communication strategy was not widely adopted, despite its requiring no technology more complex than pencil or paper. There is no sign that Oppenheim's work caused so much as a ripple in academic attitudes or educational practices, even though her book was reprinted in 1977. Part

of the explanation for this neglect may be that not being an academic, Oppenheim did not publish in refereed journals and her work was correspondingly not picked up in data bases or citation indexes. Current interest in facilitated communication has led to her work being quoted more in the 1990s than it ever was in the 1970s (for example, in Biklen, 1990, and Crossley, 1994).

At about the same time as Oppenheim started facilitating the writing of children with autism in the United States, the parents of Helen Fox, a girl with autism living in England, found that her scribbles became intelligible if her arm was supported while she wrote. Over the next decades Helen Fox filled shelves of exercise books with large round writing. These books are an extraordinary record—they contain every word Helen Fox communicated over more than twenty years, during which time her output was ignored or dismissed by most of the professionals with whom she came in contact. In the face of on-going professional disinterest or scepticism, the Foxes did not try to publicise Helen's communication, only mentioning it publicly for the first time after facilitated communication received notice in the U.K. (Fox and Fox, 1994, personal communication).

Separately from Oppenheim and the Foxes, facilitated handwriting was also used as a communication strategy by students with autism at Sofia School in Denmark in the early seventies. There was a controversy about “the existence of ‘hidden knowledge’—including reading and spelling—among autistic and psychotic children” (von Techner, 1994: 126), and the procedure apparently fell out of favour between 1975 and 1985, at which time staff in another Danish institution discovered that

some residents, who were described as ‘knowledge-concealing’, could use communication boards and keyboards with support (Johnson, 1989).

The first recorded use of facilitated communication aid access by non-speakers with cerebral palsy occurred after the first use of facilitated handwriting by non-speakers with autism. Both strategies developed independently. There is an obvious reason for handwriting taking precedence over communication aid use, in that the first communication boards and electronic communication aids were only introduced in the seventies and took some time to spread. It may have been purely accidental that facilitated handwriting was not first used with students with cerebral palsy—after all Christy Brown first used writing, in his case writing with his left foot, as a non-speech communication strategy in the thirties (Brown, 1954)—or it may have been due to the nature of cerebral palsy. Most non-speakers with cerebral palsy probably do not have sufficient control of their hand movements to achieve legible handwriting with facilitation, as opposed to writing with co-active assistance, and consequently could not have expressed themselves through facilitated handwriting if it had been tried.

As far as is known, the first facilitated communication aid use by a non-speaker with cerebral palsy occurred in April 1977 when I supported the arm of a socially responsive sixteen year-old with athetoid cerebral palsy and no intelligible speech while she pointed to Blissymbols to answer questions. This use of facilitation had at the time no theoretical basis. It was a measure forced upon me by circumstances. After teaching children with cerebral palsy for five years I was required to devise a simple communication strategy for a non-speaking child as part of my practical work for a Diploma of Education.

The child I chose to work with was Anne McDonald, a girl with extremely severe physical impairments who had been labelled profoundly intellectually impaired (see 5.2 above). Anne had been living in St. Nicholas Hospital, a state institution for children labelled severely and profoundly mentally retarded (IQ less than 35 and less than 20 respectively, in the terms used in 1964 when the institution opened) since she was three and was still the size of a three-year old. She had no wheelchair and could not sit on an ordinary chair so she lay on the floor during the day. Severe extensor spasm had caused her body to arch in a bow shape, with her head pushed backwards towards her heels. She could be seated in a baby buggy major (a larger version of a baby's umbrella stroller) but her head and shoulders retracted to the extent that she had to twist sideways to avoid suffocation. In order for her to look at anything placed on a table in front of her it was necessary to flex her hips forcibly and push her head forward. In order for her to point to anything on the table it was necessary to internally rotate her right arm and push it forward and up from its retracted position behind her right hip. With this support Anne pointed correctly to named objects, pictures and Blissymbols before going on to learn to read and spell (Crossley & McDonald, 1980).

My first experience of professional rejection of unexpected competencies in a non-speaker came just after I started to teach Anne McDonald to spell. I informed the Superintendent of St. Nicholas about the work we were doing. I told him that the speed of Anne's learning was at least as good as that of the non-disabled children I was also teaching as part of my practical work.

The word 'normal' broke the Superintendent's composure. He said that if I ever suggested again that any child of normal abilities was living in St. Nicholas he would take action against me under the Public Service Act. He said that he remembered Anne McDonald from the day of her

admission [on the day the hospital opened, nearly thirteen years previously] and that what I was suggesting was just not true. He said I was not to mention the work I was doing with Anne to anyone. I asked him to come and see her for himself. He refused. (Crossley & McDonald, 1980: 69)

In 1979 McDonald turned eighteen, the age of majority in Australia, and left the institution, still in a baby buggy, after instructing a lawyer and winning an action for Habeas Corpus in the Supreme Court of Victoria refused (Crossley & McDonald, 1980: 227). She completed a degree in humanities in 1993.

While Anne McDonald's use of facilitated communication caused considerable local controversy in the seventies, and while it was certainly suggested that any purported 'communication' must originate with her facilitators, McDonald was by no means the first individual with athetoid cerebral palsy to have shown academic abilities (see 3.5 above). Therapists experienced in working with people with cerebral palsy were not surprised that a child with no speech could have been mis-assessed and could have had considerable untapped potential. *Annie's Coming Out*, a book we co-authored which described McDonald's communication in detail, was published in 1980. Despite this, there was no rush to try facilitating communication with other children with cerebral palsy. While the book sold quite well in Australia, by the end of the eighties we had heard of only one child whose family had decided to emulate McDonald's program (and who was then accessing a computer keyboard with facilitation).

While many disability professionals read *Annie's Coming Out*—I was told it was on the syllabus for many courses—they seemed more interested in what it said about institutional care than in applying any of the material on communication to the residents or students in their care. It

appeared that Anne was viewed as unique, rather than as representing a class of people who, on the basis of their severe communicative and physical impairments, had been labelled intellectually impaired (Crossley, 1993b: 11). It was unclear whether this attitude was adopted because people were put off by the controversy or the amount of work involved, or whether they found it impossible to believe that the children with severe disabilities they knew could ever learn to read. A contributing factor, at least for teachers, may well have been the ubiquity of Piaget's work on child development (Piaget, 1954), quoted in almost every course I took for my Diploma of Education in 1976-7 as showing that children's development moved in an orderly sequence from walking to talking to reading. If one believed that this sequence was inviolable, then it would be impossible for a child who could not walk or talk to read.

Another concept which may have had impact was that of 'critical periods' in neurological development during which specific skills had to be acquired. Anne McDonald started to spell shortly after the first articles appeared about 'Genie', a neglected child who was said to have had minimal language exposure prior to coming to the attention of the California authorities when she was six, and who despite being subjected to intensive remedial programs had never acquired fluent speech (Rymer, 1993). Some psychologists suggested that because Anne was sixteen when she started to communicate, and had long passed the critical period for language acquisition, it was impossible for her to develop sophisticated language (Vant, personal communication, 1978). The sophistication of Anne's language was consequently evidence that it must have been produced not by her but by her facilitators. What these psychologists had overlooked was that Anne was not language-deprived. She could not talk

and had no access to education, but her hearing was excellent and people were talking around her, if not to her, all the time.

Shortly after Anne McDonald left St. Nicholas Hospital the newspapers printed stories about Christopher Nolan, a gifted Irish boy with severe athetosis and no intelligible speech who communicated by typing with a headpointer while his mother stabilised his chin. *Damburst of Dreams*, his first book, appeared in 1982. Like McDonald, Nolan unavailingly sought independence through technology, and in the early eighties he and McDonald exchanged information on computer options. Unlike her, Nolan had supportive parents and was never in conflict with the medical bureaucracy. Compared with McDonald and other users of facilitated communication, Nolan had little trouble with scepticism about his abilities (although in his second book, *Under the Eye of the Clock*, published in 1987, he expressed the distress that he felt when a lone American journalist questioned the authenticity of his writing).

The first electronic communication aids used by McDonald and Nolan were not easily portable. In the late seventies two mini-typewriters became available, the Canon Communicator made specifically for people with severe communication impairments, and the Sharp Memowriter designed for general use. Both were easily portable and suitable for use by walking non-speakers. The first person with autism reported to use a communication aid with facilitation was David Eastham, a Canadian teenager who started to type with facilitation in 1979. *Understand*, a collection of poems he typed on his Memowriter, was published in 1985.

HELL IS WHERE YOU'RE IGNORED
 THIS IS TRUE I SAY
 HOPE
 YOU UNDERSTAND
 YOUR YOUTH HAS GONE AWAY (Eastham, 1985: 11)

David Eastham drowned in 1988, aged 24. His mother Margaret documented the teaching procedures she used with David, together with many unsuccessful attempts to teach him to speak and to use sign language, in *Silent Words*, which is the most detailed account of the development of typed communication by a person with autism yet published (Eastham, 1992). The photographs in the book show David progressing from typing with his hand held to typing with a partner's hand on his shoulder.

Across the border in the United States another young man with autism, Arthur Schawlow junior, was also starting to communicate by typing with facilitation. Arthur Schawlow senior was in Stockholm to receive the Nobel Prize for physics in 1981 when he heard of a man with autism using a Canon Communicator to type messages. His wife obtained a Communicator and tried it with Art junior, along with a computer and a range of software. Art would only use the keyboards with physical support from a partner. While the support was initially offered as a teaching strategy, Art continued to seek support after he started generating his own messages. Ironically, the book in which the Schawlows described Art's communication contained a chapter by Douglas Biklen, who was later to popularise facilitated communication in the United States (Schawlow & Schawlow, 1985). At the time Biklen did not see the import of Art's communication: unaware of David Eastham, like everyone else he saw Art's typing as an idiosyncratic communication strategy used by a Nobel laureate's son (Biklen, personal communication, 1993). Before Biklen realised that Art's typing was of wider significance, the Schawlows were to link up with Carol Berger, a teacher working in special education classes in Oregon who independently started to use facilitation in 1987. She later described her first experience of facilitated typing:

One day, after stewing in my own frustration over how to help these students communicate, I selected a 7-year-old boy and sat him in front of the computer....Fearful that the child would throw the monitor or printer to the floor or that I would be hit, I placed a chair in front of the computer for the student and a second chair behind him for myself. This gave me the ability not only to control his arm movements by placing my arms around him, but also to take his hand and point his index finger to the keyboard....Instead of me moving his hand, however, he moved his own hand, along with my own, to the first letter of his name. (Berger, 1992a: 6-7)

My own first attempt at using facilitation with a child with autism took place in 1985 when I was babysitting 'Jonathan', a 7-year-old boy with autism who was completely mute, and who had been judged to be profoundly intellectually impaired. His mother was interested in the communication equipment Anne McDonald was using and I took along a Communicator and an early speech synthesiser. My use of facilitation had, again, no theoretical basis but was the product of circumstances. I wanted to explore the devices with Jonathan, and unless I held onto him he ran away. Unexpectedly he showed that he was able to spell simple words while I was holding him, and indeed corrected my spelling of his name. What later happened to Jonathan exemplifies both the potential of non-speech communication to change the lives of people without speech, and the difficulty non-speakers may find in maintaining those changes in an unsympathetic society.

Jonathan attended DEAL Communication Centre in Caulfield regularly after it opened at the start of 1986. While he remained mute, he progressed to typing with minimal or no facilitation. After attending an ordinary primary school Jonathan made his Bar Mitzvah, becoming the first non-speaking autistic boy known to do so, and topped his regular secondary school class before being expelled for aggressive behaviour. Sadly, by this time his mother had died. In Victoria admission to government-funded residential care is available only for neglected children

or children diagnosed intellectually impaired. In order to get access to a residential placement for his son, his father took Jonathan, presumably without his communication aids or his school reports, to two doctors who labelled him severely retarded²³, because of his obvious autism and lack of speech (DEAL case notes). He now lives in a unit for teenagers labelled significantly intellectually impaired and attends a school for students with IQs less than 50²⁴.

Ironically, prior to his institutionalisation, Jonathan's success in communicating with facilitation was directly responsible for the international spread of facilitated typing as an augmentative communication strategy for people with autism. Biklen, who knew him and his family well, featured Jonathan in his 1990 article and his book *Communication Unbound* (Biklen, 1993) and showed videotapes of him typing in conference presentations.

6.4. Facilitated communication post-1986—a new DEAL

The development of a formal communication training program using facilitation was fostered by the 1986 opening of DEAL, Australia's first centre devoted solely to meeting the communication needs of individuals with severe communication impairments not caused by deafness. It had been expected that the centre would cater for the people with severe physical impairments who constituted the majority of AAC users, and that

23 I use the term 'labelled' in relation to intellectual 'assessments' made primarily on the basis of appearance. Jonathan was not tested—his lack of speech and challenging behaviour were regarded as sufficient evidence of severe intellectual impairment.

24 IQs, or in the case of children are unable or unwilling to do standard IQ tests their eye-ball equivalent, are used in Victoria as the basis for deciding which children with disabilities should attend which segregated schools. Special Schools are attended by children with IQs greater than 50, and Special Developmental schools by children with IQs below 50.

the clientele would be largely people with cerebral palsy or acquired brain damage. Accordingly, prior to opening, the centre purchased an up-to-date selection of communication aids suitable for mounting on wheelchairs. In fact, from 1986-90, only 213 (32%) of DEAL's 666 clients with developmental disabilities were diagnosed as having a severe physical impairment, and 636 (95 %) were labelled as either intellectually impaired or autistic or both. Of the DEAL clients labelled as intellectually impaired or autistic, two-thirds were reported as having some exposure to manual signing programs but only 4 had acquired more than 100 signs. Of those aged over 10, fewer than 5% could write a simple sentence to dictation, and fewer than 50% could write their names (Crossley & Remington-Gurney, 1992: 33).

During assessment of hand skills some 90% of the 452 individuals labelled as intellectually impaired who did not have cerebral palsy showed neuro-motor problems which adversely affected their ability to make accurate selections from a communication display. The most common were eye/hand co-ordination impairments, disinhibition, perseveration, low muscle tone and inability to isolate an index finger (often associated with more general motor planning problems or apraxia). Facilitation was used when necessary to provide temporary remedies for these problems while academic skills were assessed (Crossley & Remington-Gurney, 1992: 32).

The results of academic assessment were surprising—some 70 % of the 431 aged over 5 showed the ability to type a short comprehensible sentence without a model to copy (*ibid.*: 36). Unlike Anne McDonald, who had to learn how to read before she could communicate by spelling, most of these people were living in the community and had attended schools; they could all walk and pick up books and magazines, and had

considerable exposure to ambient print on television, signs, and packaging. Their speech and hand function impairments, however, had apparently prevented them from using any literacy skills they had acquired. Initially all but two of those with previously unused spelling skills required some facilitation in order to use keyboards successfully.

The occupational and physical therapists at DEAL suggested strategies that could be used to improve specific hand functions, and the combination of facilitated communication and motor training was called facilitated communication training (Crossley, 1988). Not all users of facilitation had literacy skills: facilitation was also used when necessary to assist individuals in pointing to symbol and picture boards, or choosing from real objects, such as toys.

Facilitated communication training was never problem-free. The most obvious concerns were the need for facilitation, the dependency that this could produce, and the risk of facilitators unduly influencing communication. Facilitated communication training was essentially an ad hoc solution to some of the communication problems of ambulant school-age children or adults with both severe speech and hand function impairments whose communication could not be put on hold while they undertook a lengthy occupational therapy program (Crossley, 1992: 16). It excited attention because the communication produced with facilitation was unexpected in both style and content, and challenged previous assumptions about the language skills of specific groups, especially people with autism (Biklen, 1990: 22). It aroused controversy when people who typed with facilitation complained about their treatment, especially when some of these people failed tests designed to resolve questions of authorship (Cummins & Prior, 1992: 229).

The first report of DEAL's use of facilitated communication was made to the Australian therapeutic community in an article in the *Australian Communication Quarterly* (Batt et al., 1987). A more specific report, highlighting the use of facilitation with people diagnosed as autistic, was made to the biennial conference of the International Society for Augmentative and Alternative Communication (ISAAC) in Anaheim, California (Crossley, 1988). However, an article based on the ISAAC conference paper was rejected for publication in the journal *AAC* and facilitation aroused little interest in the international community prior to the involvement of Douglas Biklen.

Biklen, a Professor of Special Education at Syracuse University, and author of many books on the inclusion of people with disabilities, was occasionally invited to lecture in Victoria. When DEAL first started finding unexpected competencies in people with autism, a member of DEAL's committee of management wrote to Biklen asking for suggestions for future research. In *Communication Unbound* Biklen described his reaction:

I had been ... shocked by a [1987] letter from Australia that described Crossley's success in using a new technique to allow people with autism to communicate. The letter claimed that Crossley was eliciting "high-level" communication from her students. "Sophisticated written (typed) communication at sentence level," I was told. I did not know what to think about this claim. It seemed conceivable to me that Crossley and her colleagues had happened on a *few* people with autism for whom such communication was possible. But it made no sense that people with autism who had been classified as severely intellectually disabled would have normal or even near-normal literacy skills. By definition, people with autism who do not speak or who speak only a small range of phrases are referred to as "low-functioning" and are thought to have a severe intellectual disability as well. Of course, one possible explanation was that Crossley's students were actually mildly disabled: in other words, perhaps they had autism but were among the group commonly called "high-functioning." This term is often applied to those people with autism who have useable, easily understood speech. Yet the letter described the method as working with students who typically might be called "low-

functioning,” including some who were previously thought to be severely intellectually disabled. The letter about Crossley was baffling, so much so, that, whether consciously or not, I put it out of my mind for a year and a half. But when I knew I would be in Melbourne I arranged to visit DEAL. (Biklen, 1992: 323)

Biklen came to visit DEAL late in 1988 and saw Jonathon, whom he had met on previous visits when he had appeared to be a typical mute, low-functioning, hyperactive youngster with autism, typing with a partner's hand on his shoulder. On his return to the U.S. Biklen obtained funding to return to Melbourne and spend a month at DEAL observing therapy sessions during July/August 1989. In 1989 Biklen went back to the U.S. with quantities of observational data and copies of DEAL videotapes and printed teaching and therapeutic materials. The data became the basis for an article in the *Harvard Educational Review* (Biklen, 1990), and the teaching materials served to instruct some of Biklen's colleagues and graduate students in facilitation and to start introducing some non-speaking students with autism who were attending Syracuse schools to facilitated communication. In the United States word about facilitated communication spread quickly. When I attended the national conference of the Association for People with Severe Handicaps in Chicago late in 1990, I spoke to an audience of 1,500 people, and the workshops on facilitation, held in rooms seating 400, were packed out.

Facilitated communication could allow non-speakers and non-writers with significant neuro-motor problems to use keyboards or letter boards, and FC, as it became known in the U.S., became synonymous with the production of unexpected spelt communication (Crossley, 1993b: 3). Children diagnosed as autistic were said to be typing that they were lonely. Non-speakers who had been diagnosed as severely retarded and shut away in institutions for twenty years were said to be spelling out complaints

about the treatment they had received. Unsurprisingly this generated both enthusiasm and controversy.

In August 1992 I went to Syracuse University to teach a course in augmentative communication. This gave me the chance to observe the FC phenomenon at first hand. Parents whose children could not speak, and who had been told nothing could be done, were desperate for help. Teachers and therapists working with people who could not speak wanted to help. They all flocked to lectures and workshops, and they went home and tried to facilitate communication. Those who could not get to workshops picked up what they could from the newspapers or the television coverage and improvised. It is scarcely surprising that their lack of detailed information on what, why, how and with whom led to mistakes and misapprehensions.

The media ran a stream of 'miracle' stories: 'Shattering the Silence' (Martin, 1991), 'The Magic Touch' (Kim, 1992), 'The Miracle of Arthur Wold' (Macdonald, 1992). As portrayed in such stories, FC appeared deceptively simple. Write out the alphabet on a sheet of paper, put it in front of a non-speaker, hold his or her hand, and wait for words and sentences to be spelt out. This was a description, of sorts, but it was not an explanation, and there is only a short step from the unexplained to the inexplicable. What was surprising was not the scepticism which such media reports often aroused but, rather, that so many people were prepared to embrace reports of spelt communication without having any explanation for them. If you did not have any information about the reasons for using facilitation, and if you did not know how literacy skills could be acquired outside the classroom, you just had to accept FC on faith: and many people did.

This faith was buttressed by the erroneous belief that facilitated communication was the only communication strategy available for people without speech. Therapists who worked with people with cerebral palsy or acquired brain damage knew better; however, services in the disability field are typically provided for a diagnosis and not a need—non-speakers with cerebral palsy received communication aids, non-speakers with Down syndrome did not—and the therapists knowledgeable about AAC were not in contact with the people who had taken up FC with such enthusiasm. Few caregivers or teachers had any familiarity with other non-speech communication techniques, and so they saw facilitated communication training as the alternative to speech (Crossley, 1993b: 4).

They were encouraged by a rapidly developed myth that most non-speaking individuals have a mysteriously acquired ability to spell (Crossley, 1993b: 4-5). Expecting literacy skills in non-speakers was certainly a positive change from the earlier negative mythology that people who could not talk could not learn to read, but it was absurd to suggest that literacy skills were innate—if not specifically taught they might be picked up from exposure to written language in newspapers, magazines, junk mail, product labels, TV commercials, and greeting cards, but only by sighted individuals who had the necessary exposure.

It was not dangerous to believe that everyone had the potential to acquire literacy, but it was dangerous to believe that literacy was innate. A belief in universal literacy led to absurdities such as people who were blind and had not been taught to read ‘spelling’ sentences by pointing to letters with facilitation.²⁵

25 People who have always been blind cannot have learnt to read from incidental exposure to print and can only acquire reading or spelling skills through formal instruction. This does

At a conference in the U.S. a woman brought up her son to talk to me. She held his hand over a card containing the letters of the alphabet but no DELETE, NO, or THAT'S NOT WHAT I MEANT. The boy's eyes were on the ceiling while his hand moved around the board. After a few minutes silence his mother said, "He spelt 'I want to thank you for discovering FC. I use it all the time.'" Judging by appearances, it was not clear whether he had ever used it—used it, that is, to communicate his own thoughts. This kind of facilitation created understandable scepticism.

People who accepted inexplicable literacy and typing without looking were equipped to accept even more implausible things. Many people seemed to believe that everything typed with facilitation was true, however far-fetched, up to and including claims of guidance by the divinity in person (a rather strange set of writings put together by a 'facilitator' who claims that his students are messengers from God was available on the Internet early in 1997 under the name 'QIM Tunes'). This willingness to believe may have been bound up with the stereotype of people with disabilities—innocents, 'holy fools', people who did not participate in the wickedness of the world and who therefore could not be telling lies—as seen in, say, the emphasis on purity in the public image of Helen Keller (see 2.2 above). Inexperienced communication aid users with a history of dependency had emotional (and practical) difficulties in correcting misunderstandings, and misinterpretation was always a more likely explanation for inherently implausible communication than either miracles or mendacity, but that appeared to be too prosaic for many people.

not mean blind non-speakers who are illiterate cannot express themselves. They can either use sign language or select from options presented in auditory or tactile form. In the early nineties many families were unaware of these strategies, presumably because the professionals with whom they were in contact were also uninformed.

Such credulity would probably have produced problems whenever it arose, but the U.S. in the early nineties was possibly the worst time for it. Sexual assault, and especially sexual assault by caregivers, was the subject of immense interest. Any communication from a non-speaker that could possibly have a sexual connection produced an immediate reaction. This reaction was intensified when the communication was typed. Written language is generally taken as more serious, more considered, than speech, and it certainly stays around in a way that speech does not. Some allegations of abuse were based on a few gnomic typed words, which were passed around, mulled over and analysed in the search for meaning as if they were utterances from the Delphic oracle. As with the oracle, reality often did not match the interpretation (Crossley, 1993b: 6).

The obverse of the belief that everything typed with facilitation was gospel truth was that if something was proved to be untrue then that was taken to mean that the person could not communicate at all. It was politically incorrect to suggest that a non-speaker might tell lies, exaggerate, or make mistakes just like other people, so if the communication was wrong then the blame must rest with the facilitator (Heinrichs, 1992: 1). This was then usually taken to involve complete self delusion involving the manufacture of all communication from scratch. A more rational explanation would have considered the difficulties inherent in non-speech communication and allowed for the possibility of error on both sides. The typical FC user was a novice communicator—even experienced, competent AAC communicators and partners get it wrong sometimes, and by no means all facilitators were either experienced or competent. Some apparently unjustified allegations of abuse were made with facilitation, and lawyers in these cases attacked Biklen for the uncontrolled spread of FC (see, for example, *Storch v. Syracuse*

University, 1995, 629 New York Supplement 2nd. Series 958-965). To an outsider this seemed absurd. Biklen had published his article in the *Harvard Educational Review*, after all, not the *National Enquirer*.

While Biklen's 1990 article in the *Harvard Educational Review* drew immediate criticism (Cummins & Prior, 1991), the lag time for academic journals meant that it was 1992 before many papers on facilitated communication training appeared. The flood of articles that followed could be divided into three groups; instructional and theoretical pieces (such as Duchan, 1993), qualitative research and case studies (such as Biklen & Schubert, 1991), and quantitative research and test results (such as Wheeler et al., 1993). The qualitative articles were generally positive and the quantitative articles were predominantly negative. A detailed examination of facilitated communication and the law is contained in 8.5 below, and further discussion of the attitudes, explicit and implicit, revealed in the testing of facilitated communication follows in chapter 10.

In brief, after the 'miracle' stories came the 'hoax' stories. The latter group originated with professionals, usually psychologists, who had tested people using facilitation and found them wanting. The presumption behind the testing was that if these people could spell at all they would be able to do the same kinds of tasks that non-disabled spellers were able to do. If they could not that was taken as proof that they could not spell. Expectations of instant competence may have been encouraged by the unexpected literacy skills reported in many FC users. The naive view held by both critics and supporters was that if these people really were spelling then they should have all the other skills of people who could spell. In effect, this view saw starting to communicate as equivalent to getting the telephone connected, as if all that had been missing from the non-speaker's

life was a technology. This view ignored both the primary effects of the disability that had left the non-speakers mute and the secondary effects of having been treated differently all their lives.

The FC users tested, whatever their ages, had just started to communicate. Any ordinary test taker—any non-disabled child or adult who could spell well enough to do the psychologists' tests—would have been talking for five or six years at least, and would have had many thousands of conversations to practise the necessary language skills. All of the FC users had severe speech/language impairments. The typical child speaks fluently. All FC users had difficulties in generating text which necessitated the involvement of a facilitator. The typical child writes with relative ease, and all of the FC users had had atypical life experiences due to their disabilities.

One research project took 21 students aged between 11 and 21 who had been diagnosed as autistic and mentally retarded, only two of whom were believed able to spell words, and sat them at keyboards with 'facilitators' whose only training came from the researchers. The students were allowed twenty hours to acquire literacy and keyboard skills. They were then given a test which required them to type the answers to questions asked while their facilitators heard white noise played through headphones. Somewhat surprisingly, six students did answer at least one question correctly, including the two students known prior to the study to have some literacy skills. After twenty hours training both these students answered more questions correctly by typing with facilitation with their facilitators screened from the question than they had previously answered correctly by typing independently. One increased his total correct typed responses from 15 to 24 (out of 25 possible), and the other from 8 to 15. Nonetheless, the

researchers still stated that “no student demonstrated emerging literacy skills ... that exceeded their already established communicative abilities” and said that these students “could type as well without physical assistance as they could with FC.” (Eberlin et al., 1993: 526) This study has since been cited repeatedly as evidence that facilitation has nothing to offer students with severe communication impairments (Green & Shane, 1994).

Such negative studies have stimulated further research into the factors that affect test success for people using facilitation, and more recent studies have examined the effect of the nature of the tasks set, the training of the facilitators and the aid users, and their experience in undertaking tests (Biklen & Cardinal, 1997). The first results of this research showed that test outcomes were in fact predictable. Studies in which students were allowed to develop competency in taking tests and to practise the skills required produced a high proportion of successes: studies which did not allow any practice produced almost one hundred percent failures (Cardinal et al., 1996). Almost regardless of the research results, however, the extent and virulence of the controversy has been extraordinary (see Cardinal, 1994 and 10.3 below).

Facilitated communication was a topic at the research symposium of ISAAC held at Maastricht in 1994. The session chair, Professor Steven Calculator, commented that no other communication strategy, or its users, had ever been subjected to a similar scrutiny. Calculator wondered what would have happened to other augmentative communication strategies if they and their users had been tested to such an extent in the early days of AAC (Calculator, personal communication, 1994). This intense scrutiny may be the justified response of academia to the emergence of yet another questionable strategy, or it may be related to what one critic of FCT

referred to as “inappropriate challenges to professional belief systems” (Shane, 1993c: x). The issue of professional belief systems is discussed in more detail in the following section, which examines the beliefs of major societal institutions about people with severe communication impairments, and the impact of those beliefs on the achievement of citizen status by individuals with such impairments.

Section 3. Institutional responses to atypical communication strategies and their users

Today we are at the point where at least some members of each of the three major classes of people with SCI, people with primary diagnoses of sensory, physical or intellectual impairments, have been offered communication interventions that would, in an accepting and accommodating world, allow them to take control of their lives and to participate in the life of the community, at least in so far as their other impairments permit.

For an adult living in a democracy it would be reasonable to say that for this to occur the minimum requirement would be a communication strategy which would allow the user to vote in elections. Individuals with SCI associated with primary diagnoses of sensory, physical and intellectual impairment have all voted in elections, confirming that the communication strategies used by each group do allow exercise of the basic rights of citizenship and that at least some countries make provision for people who use atypical communication strategies to vote. What differentiates the groups at this time is the percentage of their members who have access to that level of communication power. No published figures on this point exist. My personal experience would suggest that 80-90% of the deaf, perhaps 40-50% of the physically handicapped who are potential or actual AAC users, and less than 10% of those currently labelled intellectually impaired who are potential or actual users of augmentative communication strategies (including facilitated communication), would have both the means and the assertiveness to vote.

This section covers the position of people with disability, and specifically people with communication disability, in the world of today, the world whose responses are the outcome of the history covered above. It must be remembered, however, that people with disabilities are marginalised minorities whose images are largely under the control of the dominant culture. Because of this, attitudes to people with disabilities are vital and central for those people but make up only a small and unimportant part of the lives of the vast majority of people in the mainstream. Few people, and few groups, have gone to the trouble of forming or articulating their attitudes to disability deliberately: such attitudes must rather be deduced from reactions to particular instances. The United Nations Declaration on the Rights of Disabled Persons (see Appendix #1) and Declaration on the Rights of Mentally Retarded Persons (see Appendix #2) represent honourable intentions, although it is doubtful that the governments who signed these protocols consult them often. Governments are generally driven by more immediately pragmatic considerations, and the next chapter examines the nature of the state's interactions with people with communication disability. The other chapters in this section consider how the law deals with people who use atypical communication and how they fare at the hands of professionals, particularly in the fields of education and medicine.

Chapter 7. Counting people, counting cost—state responses to people with severe communication impairments

While the structures established by a democratic state are to some extent a reflection of the beliefs of its citizens, they also reflect, among other things, perceived economic reality, the pressures applied by minority groups, and the beliefs of the subgroup who draw up laws and regulations. These laws and regulations may reflect well-articulated and generally accepted policy, but frequently they grow without reference to any framework and form a crazy quilt—covering some areas twice, others not at all, and still others inconsistently. This is certainly the case in the area of disability. In Victoria, for example, wheelchairs are available for children but not for people in nursing homes, while communication aids are available for people in nursing homes but not for children (Crossley, 1996). It seems unlikely that these differing systems of provision reflect community attitudes: they reflect, rather, the often arbitrary manner in which bureaucracies divide responsibilities, service provision being determined on the grounds of factors such as age or place of residence rather than the individual citizen's need for a wheelchair or a voice.

Whatever their initial rationale, these bureaucratic decisions eventually impact on community attitudes. Teachers dread the prospect of having children with unremediated communication impairments integrated into their classroom (Bloomberg & Johnson, 1990b). Equally, a student who has no effective means of communication is being set up to fail, reinforcing negative stereotypes about people who cannot talk.

Because the state sets up the constraints and structures within which we all live, it is important to examine the basis for the applicable ground

rules and the specific impact of state actions on people with communication impairments. Accordingly, this chapter outlines the factors that influence state provision for people with communication disabilities.

7.1. Conceptualisation, definition, enumeration

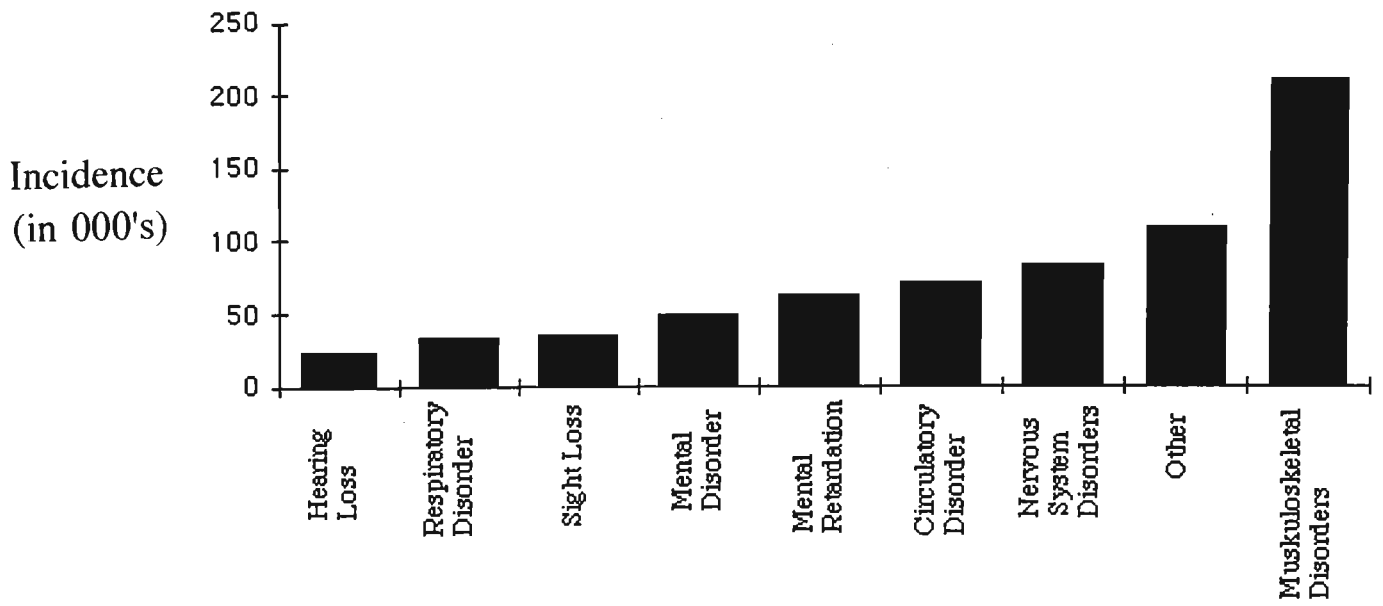
The first requirement of the state in its dealings with disablement is that its definitions are as far as possible certain—that it is possible to say without doubt or argument that a particular person has or does not have a particular disability. As disablement is a loose and largely socially constructed term (see 1.1 above) which denotes not simply the existence of a specific impairment but also the effects of that impairment, this first requirement is difficult to fulfil.

The Australian Bureau of Statistics (ABS) defines a “disabled person” as “a person who has had one or more ... disabilities or impairments ... for six months or more²⁶” and gives a list of specific dysfunctions, including “loss of hearing” and “speech difficulties in native language” (Australian Bureau of Statistics, 1990: 3). A disabled person is thus defined as a person with a disability, a formulation that underlines the difficulties faced by governments in this area. The ABS classifies disabilities as ‘primary’ and ‘other’. There are 1.6 disabilities for every ‘disabled person’—3,982,300 disabilities, on ABS 1988 figures, to go round 2,543,100 people.

In the area of severe impairment multiple impairments are very common. Of all developmentally disabled children, approximately one third have

26 The ABS relies on respondents to its surveys nominating themselves as disabled and choosing their own labels and degrees of severity. This and other aspects of ABS disability statistics have been criticised (Borthwick, 1994: 8-12 and Fulcher, G., *Problems with ABS figures on sight loss, mental disorder and mental retardation*, unpublished manuscript).

Figure 4—Severe Disability ('000) 1988 ABS Figures



one handicap, another third have two handicaps, and the remaining third have three or more handicaps. (Accardo & Capute, 1979: 176)

This raises a number of problems for data collection.

Many children ... will not be included in studies because they are receiving services from agencies concerned with disabilities other than those under study and hence may not be known to the data sources being used (eg. a blind retarded child in an institution for the retarded may be missed in a study of blind children). (Graves, 1991: 29)

In relation to people with severe expressive communication impairments, which are typically 'secondary' impairments associated with primary diagnoses such as cerebral palsy or stroke, Borthwick has noted that it is common for an individual "to be treated as if he or she was allowed only one impairment at a time—intellectual impairment *or* psychological illness, for example, but not both. We must deal with the needs of the person without asking them to adopt one identifying impairment." (Borthwick, 1994: 10)

The ABS definitions of severity are

- (a) Severe handicap—personal help or supervision required or the person is unable to perform one or more of the tasks
- (b) moderate handicap—no personal help or supervision required, but the person has difficulty performing one or more of the tasks
- (c) mild handicap—no personal help or supervision required and no difficulty in performing any of the tasks, but the person uses an aid, or has difficulty walking 200 metres or up or down stairs. (Australian Bureau of Statistics, 1990: 5)

Severe communication impairments, both receptive and expressive, come under category (a)—severe handicap. The ABS figures on the incidence of severe disability are broken down into categories which ABS considers 'primary', and while 'Hearing loss' is considered a primary disability, inability to speak is not.

See Figure 4

wheelchairs and communication aids are not. As Alison Davis remarked, "If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses ... my disability would be an inconvenience and not much more than that." (Davis quoted in Newell, 1991: 48)

The general attitude to aid use is demonstrated by the fact that if you do a defined activity with the use of any aid other than spectacles then that automatically brings you, however easily you can then do that activity, under the ABS definition of handicap.

7.2. Accommodating SCI: Sensory disability

A considerable infrastructure of state provided or mandated support for people who are deaf has developed in Australia. These supports include the Deaf Interpreter Service, the obligatory provision of Hearing Loops in public lecture halls, the availability of free hearing tests and aids to children, hearing dogs and captioned television. In terms of educational provision, there are signing and oralist schools, both state-funded, and in Victoria a deaf student who wishes to attend a regular school or tertiary class can have the assistance of a note-taker or sign interpreter. A recent innovation has been the establishment of a fully-subsidised telephone relay service. As the result of an action taken in the Human Rights and Equal Opportunity Commission under the Disability Discrimination Act which was decided in 1996, Telstra has been obliged to provide funds for the purchase of telephone typewriters or modems by individual deaf people to allow them to access the relay service and the telecommunications network (Link, 1995b: 35).

More important than all of the above, however, is the emphasis put on the early detection and remediation of deafness. Deaf infants are seen

as having the potential for significantly addressing or overcoming their handicap, and developing into contributing members of society, and every effort is made to capitalise on that potential. The provision of free cochlear implants, at least in Australia, is debated by many in the deaf community who find the reporting of the implant as a miracle cure “false and misleading and offensive” (Link, 1995a: 19) but may nonetheless be seen as further evidence of general recognition of the underlying competence of deaf children.

7.3. Accommodating SCI: Physical disability

There is no program of early detection for speechlessness, and no program to provide consistent early remediation for children with SCI. Such state-provided accommodations as have been made specifically for this group have been related to the provision of electronic communication aids.

After *Annie's Coming Out* was published in 1980, a number of projects which claimed to be able to assist individuals like Anne McDonald to communicate received government support. One such device was Cedric—a computer operated by eye gaze. The user sat in front of a screen, looked at what he or she wanted to type, and the computer printed it or said it through a speech synthesiser. Cedric was a very clever invention. It was fun, it was invented in Australia, and it looked good on television. None of the journalists who featured it were so churlish or so well informed as to ask if it were of any use.

Cedric cost about \$18,000 for a basic unit and \$25,000 with peripherals (in 1986 dollars). It was a typing device, but it was not portable enough to be a general-purpose communication device. It could be used by people, such as spinal quadriplegics, who could control their head movements but not their body, but these people could also use any

number of simpler and cheaper devices for typing, ranging from a mouthstick (\$10) to an eyeblink switch linked to a microcomputer (\$4,000). More importantly, most of this group could talk. Many people—for example, people with cerebral palsy—cannot control their head movements enough to use either mouthsticks or eyeblink switches, but these people could not use Cedric, either. When Anne McDonald went to try Cedric the inventors took one look at her and said it was pointless to make the attempt, as her involuntary eye and head movements would make it impossible even to calibrate the device. The only people who really had a use for Cedric—who could not get by with anything less—were people with rare degenerative conditions such as motor neurone disease (ALS), who could only move their eyes (Borthwick et al., 1993: 24-25).

In late 1987, four years after it had become available, **one** Cedric had been sold in Australia. About the same time, a less glamorous but quite functional device, the Eyetalker, was developed in the U.S. to fill the same needs as Cedric for about half the cost. In 1990 the company gave up. Its chairman said that although it was altruistic to help people with disabilities, there was no money in it. “Disabled people don’t have the money to purchase this equipment, the technology is just too expensive. The main market was in hospital intensive care wards, but public hospitals simply did not have the resources to buy them.” (quoted in Borthwick et al., 1993: 25) Ironically, the company went on to try and sell the eye-gaze calibration system as a marketing research tool that would enable advertising executives to determine which part of an advertisement people looked at most closely, so they would know the best place to put a trademark. The research and development that went into producing Cedric cost about \$400,000 of public money, money which could have been spent on buying currently available communication aids and distributing them to

non-speakers. At that time no government funding was available for individual communication aids.

A similar situation arose more recently with a so-called 'Mind Switch' being developed at the University of Newcastle in NSW. This was promoted as allowing quadriplegics to control electronic devices such as televisions and door openers. The fact that there are already environmental control systems allowing quadriplegics to do just that was overlooked by the media, who were certainly not informed of this fact by the inventors (who, when I spoke to them in 1996 after they had received Australia-wide publicity, had not met even one person with a disability).

Another communication aid whose development was funded in 1980 was the Vocriss. A purpose-built speech synthesiser, it would have been very valuable had it been available in quantity in the early 80s. But when at last it came into production in 1986 after years on the drawing board, it was already faced with competing devices that did the job better—that were lighter, more easily reprogrammed, and had better quality speech. Vocriss sales were helped by a minor price advantage and a connection with the Victorian Spastic Society, which helped to develop it. Ironically, that very connection was the origin of one of its problems. The Vocriss was developed for people with a specific diagnosis, rather than to remedy a more general disability: it was made for people with cerebral palsy, rather than for people who could not talk. It was designed to be carried on the tray of a wheelchair, and was too large and too heavy to be used by people who could walk.

The development of at least three other devices aimed at helping people in wheelchairs to communicate was being financed by different arms of government at the same time as the Vocriss (Borthwick et al, 1993:

27). Meanwhile, nobody was producing anything to assist the largest group of people without speech, those who could walk who were diagnosed as having intellectual impairments. When the other inventors working on speech synthesisers found that the Vocriiss was being developed to meet the communication needs of wheelchair users who could not talk, they did not hand back their grants or look for another project. They went right on and 're-invented the wheel', making it slightly oval so that people would know it was different. Survival of the fittest appears to have resulted in all their inventions sinking without trace or, like Cedric, being used for other purposes. Unfortunately, the combined government contribution to their efforts, at least \$600,000 in the early 1980s, would have paid for 200 Vocriisses or 1200 Canon Communicators.

What the whole enterprise showed was a lot of unfocussed good will on the part of individual politicians or bureaucrats who had control of research funds, a considerable lack of good information about the nature and needs of people with severe communication impairment and a willingness of university technology departments to take advantage of this situation to obtain funds to allow them access to the newest technology.

In both Australia and the U.S., in fact, the extension of the use of communication devices owed more to governmental action designed to promote the integration into regular schools of people with disabilities in the 1970s and 1980s than it did to government funds specifically directed towards communication aid development:

In the United States, the different areas of effort [in AAC] came together and began to receive serious attention with the passage of P.L. 94-142 (Education for All Handicapped Children Act) in 1975, which guaranteed all handicapped children equal educational opportunities ... P.L. 94-142 makes it mandatory to devise plans tailored to the intellectual capacities of severely disabled individuals. This requires new techniques and

strategies that enable severely speech-impaired individuals to benefit from all educational opportunities. (Vanderheiden & Yoder, 1986: 28)

In the aftermath of the disorganised research funding described above, a move started in Australia to fund centres from which people with SCI could obtain assistance with non-speech communication and information about the available aids, on the model of similar centres already operating in England, the United States and Canada. The first to open was DEAL Communication Centre in Melbourne, which was funded by the federal government in 1985. It was followed by state funded centres, and by the end of 1996 every state had at least one such centre, however small. While funding for individual communication aids still tends to be arbitrary, varying throughout Australia depending on geographical location, age of person with SCI, and the time of year, it is still the major area in which people with SCI receive support. Telephone access has recently become available as a spin-off from the program established for the deaf (see 7.2 above).

7.4. Accommodating SCI: Intellectual disability

In the 1980s people diagnosed with intellectual impairment were left to pick up the technologies developed for other groups such as manual signing and wheelchair-sized communication aids. In the nineties communication aid manufacturers have released numerous small communication aids suitable for people who can walk. In Australia, people diagnosed as intellectually impaired have similar access to communication aid funding and the telecommunications system as do people with severe physical impairments.

Infants with Down syndrome, though not infants with diagnoses of intellectual impairment unrelated to Trisomy 21, may have access to

government supported early intervention programs focusing on communication development, but this is far from universal. The major problem faced by people with communication impairments associated with diagnoses of intellectual impairment is not inequity in state provisions, but rather the effect of professional attitudes which make it difficult for them to access those resources which are available (see 9.3.7 below).

7.5. Accommodating SCI: Conclusion

To the extent that the state makes better provision for the deaf than it does for other people with SCI, this chapter supports the original hypothesis of this thesis that the deaf have made more progress towards social acceptance than the other groups. Given the paucity and dubious quality of the statistics on communication impairment, however, it may be that the deaf do better not because they are more favoured but because they have a higher public profile. While deafness is sometimes referred to as ‘the hidden disability’, because it is associated with no obvious identifier such as a guide dog or a wheelchair (mildly deaf people might occasionally be identified by their hearing aids, but profoundly deaf people cannot use such aids and so do not offer even that cue), the existence of a group of people who cannot hear is nonetheless well understood. Every bureaucrat and politician has some concept of deafness and what can be done about it. In the absence of specific data on speechlessness unassociated with deafness, politicians and bureaucrats can be forgiven for not knowing that this population exists and can certainly be forgiven for having few ideas as to how they can be helped.

The situation is rendered more difficult by the absence of a community of the mute. Muteness is generally seen as secondary to another, primary, condition, and there are many of these conditions. Our

current taxonomy of human variation is based on diagnosis rather than impairment or disability, and people who are mute are consequently split into separate enclaves which may never meet. Indeed, one of the unintended gains from the integration of people with disabilities into regular school classes is that children with varying diagnoses may actually meet one another, although it remains to be seen whether this will lead to the school recognising the common features between a non-speaking child with Down syndrome, say, and a non-speaking child with cerebral palsy. Even professionals in non-speech communication are likely to have worked with only one diagnostic group and be familiar with the strategies appropriate for that group—single-switch computer access, say, or Paget-Gorman sign, but not both.

While the state's approach to communication impairment may be arbitrary and *ad hoc*, at least one branch of its operations—the law—hypothetically applies to all citizens equally. Legal records often enshrine virtually the only evidence of the contact through the centuries between the state and people who use atypical communication strategies. Deaf citizens indubitably receive more recognition and systematic service provision from the state than do other groups with communication impairments. The next chapter will examine the past and present attitudes of the law to people who cannot talk with the aim of establishing whether or not the deaf preserve their relatively privileged status in court.

Chapter 8. Silent witnesses—non-speech communication and the law

The laws of a country may be thought of as enshrining the attitudes of a society or its rulers, over a period of time. The experiences of specific groups under the law give an indication as to how they were viewed in a given society at a given period. This chapter will look briefly at historical references to communication impairment in law and in court cases, but it will concentrate on modern court cases involving people who use atypical communication strategies, to discover how a system based on the right of those involved (the victim, the accused, and the witnesses) to be heard, copes with individuals who cannot speak.

Almost the only window on to the lives of people with communication disability living before the Enlightenment is provided by the occasions on which they became engaged with the machinery of the law. Law reports are the one of the best sources of information to have survived about earlier societal attitudes, and where communication impairment is concerned one of the very few sources. The law existed before the press or the learned journal, and because English law depended on precedent it kept voluminous records. Cases which were in any way legally exceptional were documented, and court reports provide snapshots of people with communication impairment and the strategies they used. As will be seen, people who are deaf and people using 'idiosyncratic communication' have often (though by no means universally) been treated as competent witnesses in individual proceedings, despite a legal presumption of idiocy that has persisted in English law almost to this day. This suggests that in the field of law the decisions of individual judges can potentially override systemic deficiencies.

8.1. Early history

Legal records show that people without speech were seen as almost inhuman in earlier times. Roman law divided the deaf into two groups, the speaking and the mute. The speaking were regarded as persons at law—they had been born hearing, and acquired speech before becoming deaf. “In short, they belonged to society, though they had a disability.” (Lane, 1984: 93) On the other hand, deaf-mutes were considered “ineducable, and outside the privileges and obligations of the law” (Code of Justinian, iii, 20, 7 & vi, 22,10, given in Lane, 1984: 93) and were given a curator. Deaf-mutes were not allowed to marry until the 12th century, when Pope Innocent III decreed that they could do so if they could demonstrate understanding of the ceremony in sign. The first recorded attempts to teach deaf children to speak were undertaken by a Spanish monk, Ponce de Leon, in the sixteenth century (Valles, 1587, cited in Lane, 1984: 78). He was engaged by noble families to teach their deaf sons to speak, because if an estate and title passed by primogeniture to a mute heir it would be lost to the family because mutes were still not considered persons at law.

8.2. English law: deaf-muteness in court

English inheritance law, in contrast to Spanish, discriminated only against monsters, who could not inherit²⁷ (Taylor & Smith, 1910: 188). Mere muteness, however, did not constitute monstrosity. Many other discriminations remained. The standard presumption, for example, was that a person who was mute was incompetent either to give evidence or stand trial. Lord Chief Justice Hale ruled in 1736 that

27 “The law of England has given no precise definition of what is intended by a monster. According to Lord Coke, it is a being ‘which hath not the shape of mankind’.” (Taylor & Smith, 1910: 289)

A man, that is *fundus & mutus a nativitate*, is in prefumption of law an ideot, and the rather, because he hath no poffibility to understand, what is forbidden by law to be done, or under what penalties: but if it can appear, that he hath the ufe of understanding, which many of that condition difcover by figns to a great meafure, then he may be tried, and fuffer judgement and execution, tho great caution is to be ufed therein. (1 Hale PC, 1736)

Hale's formulation does make clear that the presumption was rebuttable, though mute witnesses may not have been relieved to find that his main purpose in discovering their understanding was to render them subject to the penalties of the law.

At the Old Bailey January session in 1786 one William Bartlett was tried for grand larceny. John Ruston, a man deaf and dumb from birth—*mutus et surdus à nativitate*—was produced as a witness on the part of the Crown. While no standard deaf sign systems were then in use, deaf people had, as discussed above in Chapter 2.1., developed individual systems to allow them to communicate with their family and close acquaintances. Martha Ruston, John's sister, was given a preliminary *voir dire* examination by the judge. She told the judge

that she and her brother had been for a series of years enabled to understand each other by means of certain arbitrary signs and motions, which time and necessity had invented between them. She acknowledged that these signs and motions were not significant of letters, syllables, words or sentences, but were expressive of general propositions, and intire conceptions of the mind: and that the subjects of their conversation had in general been confined to the domestic concerns and familiar occurrences of life. She believed, however, that her brother had a perfect knowledge of the tenets of Christianity, and was certain that she could communicate to him true notions of the moral and religious nature of an oath, and of the temporal dangers of perjury.

The relations of speech and language, and the inherent capacity of sign language, were directly at issue:

It was objected by the prisoner's Counsel, that although these modes of conveying intelligence might be capable of impressing the mind with some simple ideas of the existence of a God, and of a future state of rewards and punishments, yet they were utterly incapable of

communicating any perfect notions of the vast and complicated system of the Christian religion: and therefore the witness could not with propriety be sworn upon the Holy Gospels. The difficulty of arraigning a man for perjury whom the law presumes to be an idiot, and who is consequently incapable of being instructed in the nature of the proceedings against him, was also urged against the admissibility of the witness. (John Ruston's Case (1786) [1 Leach 408]²⁸)

The Court overruled the objection, and swore in the witness. Martha Ruston was sworn in as an interpreter, "well and truly to interpret to John Ruston ... the questions and demands made by the court to the said John Ruston, and his answers made to them." Bartlett was found guilty and transported for seven years.

Another objection to admitting the evidence, of course, might have been that the proceedings were unlike ordinary instances of interpretation in that the defendant would have no opportunity to check whether Martha Ruston's account of what John Ruston purportedly said was accurate. John Ruston's communication was idiosyncratic: only one person spoke it, and only one person understood it, and no other interpreter could be brought in to monitor it. The judicial climate of Bartlett's day did not, however, encourage arguments based on the rights of the prisoner, and the defendant's counsel apparently did not raise the point.

As these cases show, it was not, despite the legal presumption of idiocy, invariably believed that people who were mute were stupid. Nonetheless, when the issue of deaf-mute witnesses was discussed one hundred and forty years later in *Best on Evidence* (1922), the underlying legal presumption of idiocy remained unchanged:

although a person deaf and dumb from birth is presumed to be an idiot (1 Hale PC34) yet if he can be communicated with either by signs or tokens (R v. Ruston) or by writing (Morrison v. Lennard) and it appears that he

28 Incorrectly cited in Halsbury, Jowitt and Phipson as R v Ruston.

is possessed of intelligence and understands the nature of an oath he may be examined as a witness. (Phipson, 1922: 134)

Because English law depends on precedent rather than reason or human rights, the 1977 edition of *Jowitt's Dictionary of English Law* (Burke, 1977) again reiterated the presumption of idiocy. It included the first legal reference to 'dumbness' not accompanied by deafness, but only to state that it did not exist:

Deaf and dumb

A person born deaf and dumb is presumed by the law to be an idiot, but this presumption can be, and generally is, rebutted (Co. Litt., 42b).

There is, in general, no separate affliction of dumbness, apart from deafness of which dumbness is the necessary result.

A deaf and dumb person can, like any other person, enter into a contract which he understands, or marry, and he is a competent witness if he can converse by signs and understands the nature of an oath (*Harrod v. Harrod* (1854) 1 K. & J. 4; *R v. Ruston* (1786) Leach C.C. 408). (Burke, 1977: 555)

Since the introduction of standardised sign language systems it has been possible to monitor the performance of a sign language interpreter in the same manner as any other interpreter, and the possibility of disadvantaging the defendant has been lessened. In other fields of communication impairment the old problems remain.

8.3. Severe communication impairment in court

Despite Burke's statement that there is "no separate affliction of dumbness", there are some 35,000 people in Australia and 600,000 in the United States with communication impairments not connected with deafness, and a need has from time to time emerged to make decisions about their testimony. Though few jurisdictions have had experience of witnesses using non-speech communication techniques, courts in Australia, the United Kingdom, and the United States have been prepared to admit

evidence gained through idiosyncratic communication—communication, that is, where a witness could be understood by only a limited number of people. In *U.S. v. Addonizio*, in which a person with a severe communication impairment used a speech interpreter, the Court of Appeals for the 3rd circuit found

Kantor was unable to speak above a loud whisper and apparently had difficulty making himself understood at times. According to [Kantor's physician], however, Mrs. Kantor's constant attendance at her husband's bedside during the period of his deterioration instilled in her the ability to understand his words almost without hesitation....We find this procedure to have been a sound exercise of the court's discretion in "appointing an interpreter of its own selection."²⁹

Neither the defendant nor the court was able to crosscheck Mrs. Kantor's version of what her husband wished to say. If it was equivalent to interpretation³⁰, it was, as in John Ruston's case, interpretation of a unique language spoken by only one person and understood by only one other person.³¹ Kantor's dysfunctional speech was the equivalent of the pre-Enlightenment person-by-person sign language.

Some general evidential problems apply to all non-speech people, regardless of the mode of non-speech communication used. Firstly, non-speech communication other than deaf sign is very slow and laborious compared with speech. A speaker may easily talk at a rate of 150 words per minute. The fastest non-speaker is unlikely to achieve 30 words per minute and few would achieve more than 10—in a videotape presentation

²⁹ *U.S. v. Addonizio*, 1971, CA3 NJ, 451 F2d 49, at 68 -cert den 405 U.S. 936, reh den 405 U.S. 1048

³⁰ The analogy is by no means exact: a facilitator does not translate, but rather transmits, changing modality rather than language.

³¹ See also *People of the State of New York v. Dorothy Miller*, 140 Misc 2d 247: 530 NYS 2d 490: 1988, to the same effect.

at the ISAAC conference in Maastricht in 1994 Stephen Hawking complained that he could not produce more than 15 words a minute. The physical effort and concentration involved in generating those words is many times greater than that involved in speech, and consequently non-speech communication can generally not be sustained for lengthy periods.

Secondly, if the communication is typed it can be exact but will suffer from lack of intonation—the added meaning speakers give by tone of voice and facial expression, and which signers emulate with vivid hand movements. It may also suffer from being taken too seriously and “over-interpreted”: in our culture written communication is always given heavier weight than spoken, and what in speech would be a throw-away line or a slip of the tongue may be subject to detailed analysis if typed.

Thirdly, if the communication is not spelt—if, for instance, a communication board is used which is based on symbols—then a skilled translator is required to question the aid user in order to clarify his meaning. A symbol board, for example, is likely to have one symbol for all the tenses of a verb. If a user points to RUN does he mean “I ran”, “I was running”, or “I wanted to run”?

Finally, if non-speaking people require facilitation in order to use a communication aid the question arises as to whether the words are theirs. The problem of verification is obviously reduced if the non-speaking person can hear or read and can unambiguously signal yes and no, in that then they can be asked whether the utterance produced with facilitation is indeed what they wanted to say. Unfortunately, while most people using facilitated communication can read or hear, many do not have clear and unambiguous ways of indicating yes and no without using their communication aids.

8.4. Testimony with augmentative communication

As communication techniques for people with severe expressive communication impairments only came into common use in the late nineteen seventies there are relatively few accounts of their use in court. Until recently most accounts involve communication by people who had lost speech late in life. These people could perhaps be seen as the equivalent of the speaking deaf, in that they had used language and been accepted into society prior to becoming disabled. Two possible reasons come to mind for the paucity of cases involving people with developmental disabilities. First, many of the users of the new communication strategies were young children. Second, until the advent of facilitated communication, relatively few of those with developmental disabilities had access to a communication strategy which allowed them to initiate any communication likely to end up in court. Further explanations may be found in the nature of the other impairments typically associated with developmental communication impairments and the living situations of this group, but exploration of these issues is outside the scope of this thesis.

One account by a speech pathologist includes some examples of the assumptions customarily made about people who cannot speak (the italics are mine).

A 47-year-old woman who has been nonspeaking and quadriplegic for the past 18 years due to bilateral CVA's witnessed an incident and was called upon to testify as to what she had seen. *Because she is so severely handicapped, people often assume Jane has no way to communicate, so events occur in front of her which ordinarily would not be done with a witness in view.* After witnessing a particular incident, Jane used an electronic row-column scanning device to slowly but diligently print what she had seen. As a result, a hearing was held.

...we decided that she would testify at the hearing using a letter board arranged by frequency of occurrence, as this was the faster method. I indicated the letters for her in a row-column pattern. As she slowly chose

each character by looking up, I called out each letter as well as her yes's and no's, so that the court reporter could record them. As the hearing progressed, we added phrases to the board which were frequently used during testimony, such as 'I don't remember.' We also arranged that by rotating her fist Jane could tell us whether she wanted to spell out a reply rather than merely answer 'yes' or 'no'. Also, by closing her eyes she could indicate that she did not understand a particular question.

For four hours both attorneys asked Jane detailed exacting questions. At first, the defence attorney even tried to discredit her....Much to the attorney's dismay, her memory was fine.

I am sure that before this hearing, no one in the room had ever actually seen a nonspeaking person. *I am also sure that none of them thought Jane capable of communicating as well as she did. After all, how could this quadriplegic woman with severe upper extremity contractures and drool running down her chin ever have an intact mind?* . (Fishman, 1983: 23)

8.5. Testimony with facilitated communication

While isolated instances of facilitated communication are recorded from the 1960s (see Oppenheim, 1974 and 6.3 above), this augmentative communication technique did not come into widespread use until the late 1980s. Users of facilitated communication have nonetheless been involved with the courts since the seventies, apparently to a considerably greater extent than users of other augmentative communication strategies. As was suggested above, this may be in part because some other commonly-used augmentative communication strategies such as Makaton and Blissymbols have restricted vocabularies, which reduce the possibility of users initiating complaints or contesting their treatment—to date, the most common reasons for court appearances by communication aid users.

The first court case to involve facilitated communication took place in Victoria in 1979 and involved Anne McDonald (see 6.3 above). On reaching the age of 18, the age of majority in Australia, McDonald sought to leave St. Nicholas Hospital, the state government institution in which she lived: the institution opposed her departure on the grounds that while

they claimed no authority to detain her if she wished to leave they were not convinced that she was in fact the author of the request she was purported to have made. McDonald took an action of Habeas Corpus in the Supreme Court of Victoria seeking her release, and won (Crossley & McDonald, 1980: 229). In his judgement Mr. Justice Jenkinson commented:

Communication by her is achieved, it is claimed by counsel on her behalf, by assisted, voluntary movements of her arm, by her voluntarily closing her eyes tightly, by her voluntarily protruding and retracting her tongue, and by unassisted, voluntary turning of the head towards right or left. With her arm she indicates letters of the alphabet successfully to indicate her communication of words and sentences, it is claimed.

On a consideration of the whole of the evidence ... I am persuaded that it is the applicant who makes these communications.³²

Anne McDonald left the hospital. Her financial affairs were, however, placed under trusteeship. When this later became inconvenient she approached the Supreme Court again seeking control of her own affairs. The onus of proof in guardianship cases differs from those involving liberty of the person, and a higher standard of proof was therefore required than had been called for in *Re McDonald*. The court arranged a test of McDonald's communication by the Senior Master of the court. The judge in that case found that

Senior Master Jacobs was convinced of the ability of Miss McDonald to communicate ... it is in my view surely better for Miss McDonald—indeed surely her right as a human being—that ... she should be and remain as free of restraint as any other person in our society.³³

Both McDonald cases were, however, apparently regarded as an individual instance of idiosyncratic communication, and no suggestion was

32 R. v. Health Commission of Victoria, ex parte Anne McDonald, Supreme Court of Victoria, 17 May 1979, unreported case.

33 In the Matter of Anne Therese McDonald and In the Matter of the Public Trustee Act 1958, Supreme Court of Victoria, 25 September 1979, unreported case: see report to the Court by Senior Master Jacobs, 20 September 1979.

made in either judgement that any general theory was involved that itself required evaluation.

During the next decade the use of facilitated communication was extended to people with diagnoses other than cerebral palsy, and to countries outside Australia (see 6.4 above). Some of the questions raised were legal in nature, some of which involved the criteria a means of communication must meet to be acceptable in a court of law. In 1992 the New York State Family Court of Onandaga County heard a case of purported child abuse (*In the Matter of M.Z., et al.*, 14 September, 1992, unpublished case). It was suggested by the petitioner that the child, who had Down syndrome and severe communication impairment (being described in the judgement as ‘partially verbal’), had with the assistance of another person spelt out complaints of abuse. Judge Buck ruled that the evidence could not be admitted unless (a) the use of the method of facilitated communication was supported by expert testimony, and (b) that testimony met the requirements set by *Frye v. U.S.*³⁴ for the admissibility of expert testimony—the *Frye* test. After hearing witnesses on this preliminary point, the court ruled that those requirements had not been met, and the case was dismissed.³⁵ Judge Buck commented that

It should be pointed out that these findings do not constitute any judgement on the utility or reliability of facilitated communication....Given the potential for breakthrough to understanding and possible remediating some of the tragic and mysterious conditions affecting some children, professionals and non-professionals alike would eagerly welcome definitive findings about facilitated communication. (*In the Matter of M.Z. et al.*)

34 *Frye v. U.S.*, 293 F.1013, D.C. Cir, 1923.

35 A similar case with an identical result was heard in the same year in Ulster County: *S v. S* (unpublished case).

The requirement for a *Frye* hearing was added to the requirements for the *Addonizio* acceptance of idiosyncratic communication because 'facilitated communication' was taken to be a method capable of generalisation rather than a series of individual instances of idiosyncratic communication. The *Frye* test requires that a procedure is generally accepted as reliable by the scientific community before the results of its use can be introduced into evidence. It has been used to evaluate recall under hypnosis, DNA testing, and polygraph evidence (Crossley, 1993b: 9). It had never previously been applied to a communication technique.

As facilitated communication required no equipment and could be employed by persons without any professional training, it was very difficult to draw conclusions about one claimed instance of its use on the basis of other instances of its use. In the words of Judge Buck,

the experts testified ... that there was no prescribed method of testing facilitators...What worked with one child did not necessarily work with another, even one with the same diagnosis, and a child might be able to engage in 'open' communication (i.e. self-initiated, unstructured communications) with one person, but not at all with another. Nor are there any requirements imposed by law or practice to certify the skill level of facilitators. (*In the Matter of M.Z. et al.*)

These factors complicated the ascertainment of scientific consensus. The basic texts on facilitated communication then available (Biklen et al., 1992, and Crossley & Remington-Gurney, 1992) did not provide a technology capable of automatic application to all cases. They suggested that, in cases of communication impairment, hand function be assessed and remedial measures attempted if necessary. They also suggested that some people may be unable to use language without physical support. The procedures suggested to implement these ideas are drawn from clinical experience, and were not put forward as unalterable or inevitable.

The Frye test would seem to demand that, in order to attain legal status, communication techniques in general, and facilitated communication in particular, must attain the status of a procedure in the physical sciences, where a particular operation will inevitably lead to a predictable result. *Frye's* general acceptance, or scientific consensus, provides in theory an atheoretical method of assessing new procedures, requiring only a finding of fact as to the existence of such a consensus. The difficulties encountered in altering professional beliefs that have been demonstrated in the context of inquiries into facilitated communication (see 10.3 below) demonstrate, however, the improbability of attaining such a consensus.

The dispute in this area reproduces the form of the previous arguments (going back at least to Blackstone and Bentham) over the evidence of such groups as children and people diagnosed as having intellectual disability: is the court, faced in an individual case with evidence that may be valid, to refuse to hear it because, it is thought, the general adoption of such evidence as admissible will produce in the future more harm than good? While Bentham's reasoning on this point deals with exclusion of the evidence of people diagnosed as having intellectual impairment, its general principles seem applicable to the circumstances of people with severe communication impairments:

From whichever source it be derived, the propriety of regarding imbecility, upon occasion, as a cause of *suspicion*, is obvious and indisputable. From whatever source derived, the taking of it for a cause of *exclusion* will be found equally indefensible.

Mental or corporeal: imbecility, a term of relation, admits of degrees *ad infinitum*. Imbecility, in a variety of respects, is the lot of all created beings. Supposing that, in any degree, imbecility were capable of constituting a proper ground of exclusion, by what mark could that degree be distinguished from any other? From the impossibility of finding an answer to that question, results the impropriety of taking it for a ground of exclusion in any case. In the absence of any universal mark of such a

degree of imbecility ... there is but one rational course, which is, the examining of the proposed witness: which only rational course is the very course that, upon the supposition of the exclusion, is not to be taken.

Infancy, superannuation, insanity: whatever be the modification,—connected or unconnected with the circumstance of age,—the answer will be still the same. (Bentham, 1827: 143)

The New York State court initially decided, through *Frye*, in favour of the principle of exclusion (*In the Matter of Luz P.*). Evidence in a particular case would be considered on its individual merits only if other evidence of the same general nature could be regarded as reliable in other hypothesised future cases.

This exclusion provided protection against the court receiving illegitimate testimony. The question was, however, whether this justified the refusal to hear possibly legitimate testimony—and this question does have human rights implications. The International Covenant on Civil and Political Rights provides, in part:

Art. 14.(3) In the determination of any criminal charge against him, everyone shall be entitled to the following minimum guarantees, in full equality:

(f) to have the free assistance of an interpreter if he cannot understand or speak the language used in court.

If someone cannot speak they plainly, cannot speak the language used in court and would thus appear to be entitled to an interpreter.

On appeal the New York Supreme Court Appellate Division reversed the lower courts on the relevance of *Frye* (*In the Matter of Luz P.*).

The court said, at pp 544-545:

While the particular technique of facilitated communication using keyboards, etc., is a relatively recent phenomenon, the more general problem of the means by which a speech-impaired witness can communicate at a trial has been before the courts in the past ...

The test for the court in cases such as these is a pragmatic one. Can the interpreter, or in this case the facilitator, effectively communicate with

the witness and reliably convey the witness's answers to the court? A determination of these questions does not require expert testimony. To the contrary, the proffered facilitated communication lends itself to empirical rather than scientific proof. **Thus, the test proposed by the County Attorney, whereby the court could question Luz outside the presence of the facilitator and then hear her responses through facilitated communication, should adequately establish whether this is a reliable and accurate means of communication by Luz. Fact-specific questions can be devised which should demonstrate whether the answers are subject to the influence, however subtle, of the facilitator.** If the court is satisfied from this demonstration that the facilitator is 'qualified' to transmit communications from Luz to the court, then the facilitator may be appointed as an interpreter. (Emphasis added)

The Court explained that a *Frye* test was inappropriate, "since the ability of an interpreter, translator, 'signer' or anyone else who transmits the testimony of a witness is not based on a scientific theory." Pointing out that a Spanish interpreter had been provided for Luz's parents without any such test being called for, the Court stated, at 545, that "It was enough that the interpreter and the respondents could understand each other and that the interpreter swore to translate accurately." The Court approved the preliminary test proposed by the County Attorney (which was the same as that used by Senior Master Jacobs in *McDonald*), namely that Luz P be questioned by the Court outside the presence of the facilitator and then convey her answers through facilitation. The Court said that that test "should enable the court to come to a reasoned conclusion as to the reliability of the facilitator without the necessity of expert testimony." The Court continued, at 546:

If the court is not convinced that the facilitator is reliable, then that facilitator may not serve as the interpreter. However, such a finding should not foreclose Luz from testifying if a reliable facilitator can be found elsewhere. The DSS will of course have the burden of establishing the reliability of the facilitator at the preliminary proceeding.

When *The matter of Luz P* was referred back to the Family Court for the testing proposed by the County Attorney, Luz P passed the first tests

given her in court very well. However, the opposing attorney persuaded the judge to impose new conditions on the method of giving evidence. The *Times Herald Record* of January 12, 1994 described that hearing:

The morning hearing started with county attorney Lewis A. Borofsky questioning the girl.

Conditions for questioning had been agreed upon by the court and opposing attorneys. The teacher would be temporarily deaf by wearing headphones that played static-like white noise.

The idea was that if the teacher could not hear the questions, she could not answer them, assuring that the answers would truly be the child's.

Borofsky prepared the child for court by practising the method with her in about 20 one-hour sessions since September.

First, yesterday, he asked simple questions and the child was able to type several answers correctly, some with no support from the teacher.

Second, he asked more pointed questions leading up to the alleged abuse. The child grabbed her teacher's hand to answer them. Sometimes she stumbled, but mostly she answered rationally.

But then attorney Alan Zwiebel, representing the parents along with attorney John Burke, objected.

Zwiebel stopped the hearing, insisting that the teacher was reading the questioner's lips. He demanded that the teacher not look at the questioner or at the keyboard while further questions were being asked and answered.

Without the teacher able to see the keyboard, the child's answers turned into gibberish."

The County Attorney said:

"The court changed the goalposts on me. The child did great until they changed the rules. Now they want to change them again. Nothing that happened today proves that facilitated communication doesn't work. All they proved is that if you isolate the child from the facilitator, she can't communicate."

He refused to continue testimony under the new conditions.

A number of other court cases involving testimony by people using facilitated communication also involve allegations of abuse. In some cases the abuse is said to have been conceded. An American newspaper report, for example, stated

Autistic Girl Spells Out Details Of Abuse

The girl, who is autistic and cannot speak, slowly spelled out her story of sexual abuse at the hands of a teacher's assistant.

"She was hitting herself in the chin....I took my left hand and held her hand down on her upper thigh. This is when my finger tips actually touched her genital area. I know what I did was wrong," [the accused] said in a sworn affidavit.³⁶

If any cases exist where facilitated communication would be effective, and if statements made through facilitated communication are to continue to be inadmissible in their nature, then some evidence will be denied the court, some abusers may go unpunished, and some abused people may go unprotected. In some cases other evidence may be available, but while physical evidence (such as wounds or sexually transmitted diseases) may suffice to prove abuse, it is unlikely, in the absence of the testimony of the victim, to identify incontrovertibly a particular abuser. It is also the case that in many jurisdictions, including that of the New York Family Court, other evidence is only admissible to support a statement: if the statement is disallowed, none of the other evidence can be led. As has been mentioned, some reports of abuse have been supported by confessions: if it is widely known that the victim's only possible mode of giving evidence is legally null, fewer confessions (and no plea-bargains) can be expected.

No case involving allegations of abuse made either by people using traditional AAC methods or by people using facilitated communication has yet proceeded to judgement through the Australian court system. In 1990 a rape case was partially heard by a magistrate's court³⁷ in Moe, a Victorian

36 *Syracuse Herald-Journal* 1 May, 1990.

37 *Police v. Williams*, Moe Magistrate's Court, 21 May, 1990, unreported case.

country town. The main witnesses were the three women claiming to be the victims of the assault. They were all under the care of the State Office of Intellectual Disability Services. They were all severely communication-impaired: they had no speech, or no intelligible speech, and no sign. It was claimed by the prosecution that the women could communicate through facilitated communication, though they could not do this with all people, and they could not necessarily do it at all times—as the magistrate said, the stress of the courtroom made communication difficult (see below).

Two days were spent taking evidence about the difficulties of taking evidence. One of the complainants was sworn in and interrogated through facilitated communication about her understanding of an oath. Before any evidence as to the charge was led, however, the difficulties of the case became apparent. Several of the people with whom it was claimed that the women could communicate were ruled out as ‘facilitators’ because they were themselves witnesses in the case and should therefore not be in court while the women were giving evidence. Another facilitator (myself) was objected to by the defence on the grounds of bias. The prosecution asked for an adjournment to train an independent facilitator and to give the women an opportunity to become more used to adversarial questioning. The magistrate, while sympathetic, refused an adjournment.

The magistrate said in closing that he had discussed the issue with his colleagues,

and I can certainly say that we magistrates were aware of a significant evidentiary problem....Firstly, [several facilitators having been objected to] we are left with no facilitator in whom apparently these ladies have confidence and therefore their capacity to communicate is no longer what it would have been previously. [Secondly] these ladies have lived a very sheltered life and ... it is just totally overwhelming for them to find themselves in a courtroom with the various pomp, ceremony and perhaps pageantry that goes with it...[Thirdly, in their facilitated communication training] they have always had a positive response with full

encouragement and yet here [opposing counsel will] vigorously pursue the witnesses and no doubt cause them stress and frustration ... because they are virtually being called, put simply, liars. (Pilgrim, 1990: 6)

The magistrate did not reject the communication of the witnesses, but neither did he feel that the women would be able to give evidence under the conditions necessarily prevailing in his court. Consequently he terminated the hearing.

In an Australian guardianship hearing (known as the 'Carla case') before the Victorian Guardianship Board³⁸, a lay tribunal, the Board rejected evidence that the subject of the application had used facilitated communication to make allegations of sexual abuse. The Board ruled that the woman could not communicate and that the accusations had in fact been made by her facilitators. The Board's ruling has been criticised, in part because of the Board's refusal either to allow 'Carla' to appear or to observe her use of a communication aid (Crossley, 1993a: 19).

Today, despite the unaltered legal presumption that people born 'deaf and dumb' are idiots, people who are deaf are more likely to be able to give testimony in court than people with other communication impairments, and much more likely than people who use facilitated communication. In virtually all jurisdictions the deaf person has the right to a court-appointed interpreter, and in some jurisdictions to the interpreter of his or her choice³⁹. Injustices may still occur, especially if the witness has both language and hearing impairments, but the deaf still have a better chance of being heard than people who use other communication strategies.

38 Victorian Guardianship & Administration Board, 1992, GAB 7349, Judgement, Melbourne, Author.

39 Highly desirable, there being personal or regional variations in signing.

In the courts, people who use communication aids without facilitation are notable for their rarity. I know of only two cases other than those already cited—a successful Habeas Corpus action taken by a Canadian with cerebral palsy, and a successful prosecution for the rape of a non-speech teenager with cerebral palsy in South Africa (McNaughton, 1983; Toefy, 1994). Both gave evidence by using communication boards displaying a selection of Bliss symbols.

In the first case, which took place in 1982, Justin Clark, then 18, went to a Canadian court to fight for the right to make his own decisions and leave the institution to which he had been admitted at the age of two. He answered questions by pointing to symbols on a communication board, and his answers were relayed to the court by two ‘interpreters’. Giving judgement in favour of Justin, Judge Matheson of the Lanark County Court in Ontario commented “We have recognised a gentle, trusting, believing spirit and very much a thinking human being who has a unique part to play in our compassionate interdependent society.” (McNaughton, 1983: 3)

The second case took place in South Africa in 1993 and involved a 15-year-old girl who alleged that she had been raped. “The first problem encountered was that the legal teams handling the case assumed that her inability to speak could be equated to mental insanity [sic].” (Toefy, 1994: 19) The court was unfamiliar with the notion of any non-speech communication apart from deaf sign, but insisted that a neutral ‘mediator’ or interpreter be used, and the court social worker hence had to undertake a rapid course in the use of a Bliss board. Despite the problems, the girl gave her evidence and was believed, with the result that the accused received a custodial sentence (ibid.: 19).

Whatever the outcomes, the paucity of cases involving AAC raises some issues. Given the number of adults using AAC, and the likelihood of some of these adults having been subject to abuse⁴⁰ (abuse rates of up to 25% have been suggested in some research—cf. Sobsey, 1994), this would suggest either that communication aid users are not generally in a position to make complaints and have them taken seriously or that their communication systems do not allow them to complain in the first place. People who cannot spell, in particular, will always have difficulty saying anything which is not represented on their communication boards, and very few communication boards contain symbols for ‘rape’ or ‘assault’.

Nonetheless, it would appear that the law and the legal professions have in general been able at least to consider impartially the problems of non-speech communication. Indeed, as the next chapter will show, they may have shown more willingness to accept people with communication impairments as being competent than have some professionals who work with such people on a daily basis.

40 The severe physical impairments suffered by many AAC users mean that it is more likely that they will be victims of abuse than abusers.

Chapter 9. Medical, academic, and professional attitudes to people with severe communication impairments

Take, on the one hand, a massively retarded, physically disabled human being, unable to maintain itself alone in life ... incapable of language, unable to communicate its needs and wants intelligibly. Take, on the other hand, a fully-grown ape, alert, apparently intelligent, very well able to communicate and manage its needs and wants....Why would you use the alert, aware, communicative, responsive, ape as a subject for medical research rather than using the unalert, unaware, uncommunicative, unresponsive disabled human? (Daws, 1982: 30-31)

This extract comes from materials prepared at Deakin University for the undergraduate course HUW209 Nature and Human Nature. It was brought to my attention by Anne McDonald, a student in the course, who had found herself characterised earlier in the same text as a “profound mental retardate. Someone so mentally retarded that they cannot walk or talk, and have to be fed like a newborn baby.” (Daws, 1982: 13)

This chapter examines the behaviour of those whose professional lives bring them in contact with people with communication handicaps, professionals including doctors, therapists, teachers and psychologists, and some of the attitudes which underpin this behaviour. It does not include an examination of the theoretical literature on professional behaviour or the achievement of professional status, but concentrates rather on the experiences of people with disabilities, especially people with communication impairment, at the hands of professionals.

The two quotations above from the Deakin course materials raise many of the issues which will be discussed further: the dependence of judgements about worth on intelligence and communication, and the

related presumption that one's speech (or lack of it) reflects one's comprehension, the use of depersonalising terms such as 'retardate', and the association of people with disabilities with other species. Daws wrote in the assurance that his words would not—could not—be read by anyone who could not “walk or talk”, who was “fed like a newborn baby”, and who had been labelled profoundly mentally retarded. Such an assumption—that they will not be party to the discussion, being “unalert, unaware, uncommunicative, unresponsive”—underlies many discussions of people without speech, whether in their presence or in their absence, and distinguishes these discussions from those about other devalued groups, including other disability groups.

9.1. Professional relationships

A central issue for people with disabilities is the relationship between disability and the medical profession. Many disability self-help and advocacy groups would now suggest that the role of medicine (and professionalism in general) in disability is to a large extent iatrogenic and disempowering:

In many ways, demedicalization is simply an extension of the self-help movement to the fields of health and medical care....At issue also is the extent to which the management of disability should remain under the aegis of the medical care system....Today, most public policies respecting disability require some type or professional medical presence, whether in the acute stages of disability, in the determination of eligibility for income maintenance benefits, or in long-term institutional care. The Independent Living movement asserts that much of this medical presence is both unnecessary and counterproductive.

Central to the IL movement is the belief that the management of medically stabilised disabilities is primarily a personal matter and only secondarily a medical matter. A constant medical presence in the life of a disabled person gives rise to behaviour on the part of both practitioner and patient that induces dependency and thus hinders achievement of rehabilitation and IL goals. (DeJong, 1983: 153)

The 'medical model' is a loose theoretical construct that is often used to help understand the general relationship between clients and professionals. The medical model is centred around the acceptance by the client of the 'sick' role, the role of patient. A sick person receives certain social privileges: he or she is exempted from normal social activities and responsibilities, is exempted from responsibility for his or her illness, and is not generally thought of as morally culpable for the condition. On the other hand, the sick person is in return expected to accept the sick state as aberrant and undesirable and to work towards 'recovery', and towards this end is expected to co-operate with the doctor and comply with his or her instructions (Silvers, 1996).

This expectation of compliance may extend to all associated paramedical professions. However it may be phrased, the job description for any professional involves telling other people what to do—'Eat less fat', 'Do ten stretches', 'Read chapter 5'—on the grounds that it will be good for them. The baseline for any discussion of professional attitudes to a particular group is the traditional relationship of the professional and the layperson involving mutual acceptance of roles of superior/inferior, and agent/patient. The investigation of professional attitudes to atypical communicators must not only ascertain whether they differ from traditional professional relationships but also include an examination of professional attitudes to people with severe disabilities in general to ascertain whether there is any difference. Given that many people experience communication impairment as a symptom of a global diagnosis such as cerebral palsy or autism, it may be difficult to tease out which attitudes are responses to the communication impairment and which to the underlying disability.

Typically much health care for people with severe disabilities has been provided by specialised agencies or clinics. Because the population with disability has been removed from general practice areas, most people working in health fields have seen a filtered clientele that has contained a smaller proportion of people with disabilities than the ratio to the population as a whole, while a relatively small group of specialist practitioners has seen far more than the average (Borthwick, 1994:20). Even without these systemic pressures, some specialisation would be inevitable due to consumer preference. A man I interviewed recalled that his father's medical practice included an unusual number of people with communication impairment: "My father used to have a lot of deaf and dumb patients without speech. He grew up with some deaf kids and he learned sign language and they used to come to him for that reason." (Interview, 22/3/1994)

From medical education to wheelchair access, generalist health provision has not only been designed to meet the needs of the majority but has incorporated barriers that deter minority groups—the Queen Victoria Medical Centre, a major teaching hospital in the centre of Melbourne, became wheelchair accessible only just before its closure in the mid-1980s (personal experience). Health care professionals have been socialised in the medical model, and unless corrected assume automatically that the problems of disablement lie within the individual affected, in their diagnosed physical or mental limitations. They therefore assume that treatment should be organised to reduce or eliminate these identified undesirable characteristics—to make the blind see and the deaf hear and the lame walk. Modern disability rights activists ask, rather, whether it is more reasonable to approach the problem from the alternative standpoint that the current system has been unjustifiably imposing penalties on a

group rendered vulnerable to disadvantage by their disabilities (Newell, 1991).

Within the general category of the professions, of course, different professions have different interests, different relationships at different times to each other and to people with disabilities, and different perceptions. Trent (1994) documents the transfer of the lead role in the field of mental retardation from medicine to psychology in the 1960s: more recently, the disputes over facilitated communication have tended to pit educationalists and members of the therapy professions against psychologists (see below, 10.3). Nonetheless, in general it would be wrong to expect educationalists and therapists to be rebels. Burton Blatt, for example, a leader of the American deinstitutionalisation movement, wrote from experience that

education is a monolith no more capable of dealing with revisionism than any other monolith. Education is a monolith as medicine is a monolith ... it should come as no surprise that a field such as mental retardation, powered by professionals, is monolithic ... the ways our professionals are trained, the ways they are rewarded, the way they protect themselves, the ways they perceive themselves, [produce] ... the beliefs that

1. There is a right way and a wrong way: there is established practice and quackery.
2. There are rules, regulations, customs and values, from which there should be no significant deviation.
3. In unity there is strength. (Blatt, 1987: 198)

Professions may be said to exist to standardise, regulate, or, to put it more pejoratively, ossify practice: "to extend technically-based authority to a broad social control of practice." (Johnson, 1972: 31)

9.2. Professional perceptions of disability

Professionals are not immune from popular prejudices about people with disabilities. While professionals working in this area are likely to

have more favourable attitudes than the general public (Eberhart & Mayberry, 1995)—after all, having chosen to work in an area that brings them in contact with these people, they are thus self-selected to minimise revulsion—this does not mean that they are uninfluenced by stereotyping and stigmatising. A 1992 study which sampled 636 health professionals found that when presented with a person with a visible disability they tended to devalue the disabled person's competence, capacity, and social and psychological adjustment (Gething, 1992). Even more strikingly, a survey taken of those professionals attending the International Conference of the Association of Children with Learning Disabilities still found extensive negative stereotypes about learning-disabled children (Parish et al., 1979). The general attitudes of a particular generation, moreover, may override the current ideology of a profession: studies have found that nursing academics hold less positive views of people with disabilities than do beginning nursing students (Brillhart et al., 1990). Faculty attitudes may account for the additional observation that graduating medical students hold less positive views of disability than do entering students. Similarly, two studies of occupational therapy students (Lee et al., 1994; Lyons & Hayes, 1993) have found that there appears to be no gain in positive attitudes over the time of their course.

Policymakers in this area, similarly, are likely to be from an older generation and thus conspicuously more prejudiced, even when themselves disabled. A newspaper interview with Dr Bruce Ford just after he had been appointed chairman of the State Committee for the International Year of Disabled People (IYDP) made his position clear, quoting him as saying, "I'm just as embarrassed by a drooling, mentally retarded adolescent as you are. It's normal. It's natural ... not to want to be associated with the inarticulate." (Dunstan, 1980: 9). Dr. Ford has mild cerebral palsy, which

has not impaired either his speech or his ability to obtain professional qualifications.

As well as embarrassment, professionals may share common misconceptions about people with disabilities. Even if negative attitudes to disability are not inculcated by professional training, positive attitudes may not be either. The emphasis on 'book learning' in most professional courses means that most recent medical graduates, for example, know the genetic basis for Down syndrome, but have never met a person with Down syndrome. What they believe about the potential of people with Down syndrome will depend on the beliefs and background of their lecturers and the texts they are given. A recent text on language development stated that the language and academic development of people with Down syndrome plateaus at the level achieved by non-disabled 4-5 year olds (Rondal, 1995: 5): this despite the many accounts of people with Down syndrome reading, completing secondary school, working in open employment, living independently, driving cars and marrying. A doctor who has read only the former information is likely to give very different advice to the parents of a new-born with Down syndrome than is a doctor who knows about these achievements.

Perceptions of disabled people held by health science students have been found to be narrow and pessimistic, which may relate to the fact that much research on disability is "based on a limited view of persons with disabilities and their families, one that unduly emphasises the 'pathology'" (Turnbull et al., 1986: 122) because "researchers are part of the rest of the world in which disability is viewed as a terrible thing. Their focus, like everyone else's, is to find out what's wrong" (ibid.: 123). Weinberg has pointed out that researchers generally ignore the possibility of satisfactory

adjustment and high quality of life when this population is studied, and Wright has suggested that most measures in disability studies are designed from the framework of negative attitudes rather than coping frameworks and thus contribute to perpetrating myths about disability (both quoted in Friedland & McColl, 1992: 396).

These myths may have a pervasive effect, because many people with disabilities use health services not just when they are ill, but to monitor their conditions or medication and receive ameliorative treatment. If, as Shanley and Guest (1995) suggest, hospital nurses possess negative attitudes to people with learning disabilities, this is likely to affect the quality of care provided. American data suggest that rehabilitation medicine is seen as a low status area of medicine (it has, for example, a higher proportion of foreign medical graduates). It has also been suggested (Office of Technology Assessment, 1983) that this may be due to the greater involvement in the area of such other professions as therapists and counsellors and a correspondingly lessened area of medical authority and control. It may also be because patients with chronic impairments confound medical expectations—they neither get better nor die, though they may require long-term specialist intervention.

To add to the difficulties in obtaining quality care, some health professionals may feel threatened by the very existence of the severely disabled patient, who may be seen as a personification of medical failure, particularly if the origin of the disability was associated with medical intervention:

health professionals, especially doctors, may feel threatened by the very existence of the severely disabled patient, who may be seen as a personification of medical failure, particularly if the origin of the disability was associated with medical intervention....Much of the grossly inappropriate behaviour which severely disabled people suffer from health professionals stems from the difficulty that many professionals

have in really looking at their disabled patients, and from their lack of knowledge about the meaning of what they see when they do look. The result of this 'blindness' is that health professionals often do not know in what ways the severely disabled patient they are about to treat differs from their normal patients, and in what ways he is the same. Mismanagement, ranging from minor misdiagnosis to appalling cruelty, often follows. (Crossley, 1982:5)

This 'blindness' was described by a woman with cerebral palsy and communication impairment:

Medical competence often disintegrates when faced with a person with a severe disability. When I developed pneumonia and ended up in hospital the doctor wanted to put in a tracheostomy so I could breathe and a drip so I didn't suffer from dehydration. At least he wanted to save me: the only problem was that I was fully conscious, breathing perfectly well, and drinking from a cup. He simply could not observe me in the same way he would have observed a normal patient. Again, this reflects the views of the dominant group in society—people, that is, without disabilities, who learn that it is not nice to look at people with disabilities. (McDonald, 1991: 3)

The doctor had been so nonplussed by the disastrous picture McDonald had presented that he had assumed the worst in all areas, without making the basic observations he would have made automatically with a normal patient.

The same problem is sometimes termed 'diagnostic overshadowing' (Reiss & Szysko, 1983)—the tendency for clinicians to ascribe all abnormalities to the one diagnosis of disability, such as mental retardation, ignoring other possible explanations. Robert McNamara, who had muscular dystrophy, refers to the same condition under another name:

In my experience, doctors and health professionals are as ignorant as the general community when it comes to dealing with people with a disability and the political dimensions of disability. They focus obsessively on the impairment and disability. They are curious about it, inquisitive and a little afraid of it. It tests their knowledge base and many of them become absorbed by the oddity before them. The characteristic that makes me different, my disability, dominates nearly everyone's perceptions of whom I am and what I am about. I call it, "disability myopia".

I believe that most doctors and other health professionals find it very difficult to deal with people with a disability as whole persons. They focus on the disability and respond to the same stereotypes as the rest of the community. Seeing people with a disability as part of a family or the community is even more difficult for them.

That experience is not unique. I go to the optometrist to check on my short sightedness and he ends up looking up a text on the aetiology of muscular dystrophy. A couple of years ago I went into hospital with food poisoning and while they were pushing in the nasal-gastric tube the resident was asking me,

Resident: 'When was it first diagnosed?'

Me: 'Two hours ago.'

Resident 'What?'

Me: 'It must have been the chicken.'

Resident 'No, I mean your condition.'

Me: 'My condition? I told you! Two hours ago! Nausea, sweating, and a temperature. Probably caused by food poisoning don't you think?' (McNamara, 1994: 3)

The doctor's first and most basic assumption was that any health problem McNamara had must have been associated with his disability.

9.3. Professional reactions to disability

While there may be as many professional reactions to disability as there are professionals, it may be assumed that if a particular treatment is provided by the members of a professional association, and this association finds nothing to criticise in this treatment, it meets with the general approval of the members of that association. Some of the forms of treatment which reveal professional attitudes are outlined briefly below.

9.3.1. Segregation

People with severe disabilities are at risk of exclusion from society through being placed in institutions and nursing homes for which professionals are the gatekeepers. The care provided in these institutions has varied from state to state and decade to decade. In the nineteen fifties

there was straw on the floors of some wards at Kew Cottages, a large Melbourne institution for people designated mentally retarded (Matron Dizais, 1975, personal communication). In 1996 nine men, all of whom had severe communication impairments, burnt to death in a locked ward in the Cottages (*The Age*, 1996:1). All institutions restrict liberty, most restrict potential, and many offer a quality of life which would not be tolerated by people who could complain. People with communication impairments are more likely to be institutionalised than other people in their class. Most of institutional residents have severe communication impairments: some 80% of residents in Kew Cottages (Bloomberg & Johnson, 1990a), and as many as 90% of nursing home residents (Kato et al., 1993: 2).

The results of institutional maltreatment may be ascribed to the severe disabilities of the residents, rather than evaluated by reference to ordinary medical measures. Anne McDonald was grossly malnourished after 14 years in a state hospital. When she sought to leave, the psychiatrists responsible for the institution told the Supreme Court that as McDonald was eighteen years old and the size of a five-year-old she must therefore be severely retarded.

I couldn't feed myself ... and thus it was clear I must have no more IQ than a child who couldn't feed itself. This was validated by weighing me. As I was the weight of a one-year-old this must be my mental age. This would all be very humorous if the measurers had not believed their results and used them as evidence for why I should be locked up. (McDonald, quoted in Crossley, 1997: 21)

Only one doctor, a paediatrician, Philip Graves, disobeyed his superiors' instructions and told the court that intellectual assessment of people like McDonald depends on "their capability of communicating and expressing their ability," not size, and that her stunted growth was due to malnutrition

rather than retardation (transcript, *ex parte Anne McDonald*, 1979). His judgement was borne out by McDonald's accelerated growth on leaving the hospital (Crossley, 1997: 267). The senior psychiatrist to give evidence, George Lipton, who was responsible for institutional care in Victoria at that time, has since been elected President of the Australian College of Psychiatry.

9.3.2. Neglect

The need for active intervention may be ignored in people whose disabilities (or abilities) are not valued. People with Down syndrome have a high incidence of heart defects. Most of these are comparable in severity to defects in children without Down syndrome, where it is virtually automatic to correct them by surgery. As late as the 1980s it was proposed that a different attitude should be taken to medical care for children with Down syndrome, and that remediable life-threatening defects should be allowed to remain (Bull et al., 1985). These unremediated defects not only shortened the lives of these people but also produced an immense and painful handicap for the survivors through breathlessness and cyanosis (Wilson et al., 1985). The resultant fatigue and susceptibility to infection also significantly affected educational and physical outcomes for this group. Hayden and DePaepe suggested that a conscious effort would be needed to reduce the underlying prejudice:

To create a more responsive system, the barriers to the provision of community medical care and services need to be addressed. The perceptions that medical personnel have about people with mental retardation can be influenced by including additional education and training in the field of developmental disabilities within the curriculum of medical schools. The provision of generic workshops and seminars that provide current information about persons with mental retardation to persons who are currently in practice can assist in reducing stereotypes and fears. (Hayden & DePaepe, 1991: 190)

One aspect of professional neglect of people with disabilities which has special relevance for people with communication impairments is an observed tendency of health care professionals to overlook or disregard obvious signs of pain or distress when the sufferer cannot call for attention and say what is wrong. What responses there are may be directed more to reducing the impact of the distress on other people than treating its cause. The case of 'Ms. B', a quadriplegic without speech who lives in a large government nursing home, is instructive. She laughs at jokes, but the only means of expression she has available is crying or screaming. During 1996 I repeatedly found Ms. B in a distressed condition and screaming, stricken with frequent attacks of acute cramping or colicky pain. While nursing staff agreed she was in severe pain, their only response was to fill the other bed in her cubicle with a resident who was deaf. The ward's medical officer did nothing. Only threats of legal action eventually convinced staff to refer Ms. B. to the palliative care team based at the same facility.

Another horrifying but illustrative example of professional cruelty occurred in 1980, when a profoundly retarded child was admitted to the Royal Children's Hospital from Kew Cottages. The child was seriously ill and was unable to take food by mouth, so it was decided that a naso-gastric tube should be inserted. A tutor sister thought this was too good an opportunity for her students to miss, so the tube was inserted, and removed, inserted, and removed until each of the 20 students had a turn. The child died the next day. What is especially horrifying about this incident is that only one of the students refused to carry out the procedure, despite the child's obvious distress. A group delusion seemed to operate: "they can't feel pain" (Crossley, 1982: 6). The only other explanations for this situation and that reported by McDonald (below) are deliberate cruelty or negligence verging on the criminal.

There were [in my hospital] children in constant pain, children whose pain was ignored because doctors somehow managed to convince themselves that a screaming child vomiting blood was not in pain. If we had been animals we would have been put out of our misery. (McDonald, 1984: 60)

There is no doubt that it is easier to handle people who cannot express an opinion or complain. At a geriatric nursing home the Director of Nursing said, "It's easier to work with the ones who can't talk. You don't have to stand there and ask would you like to do this or would you like to do that. You just do it." Another Director of Nursing, speaking of a previously outspoken resident who had had a stroke, said, "Thank God she's aphasic [and thus mute]." (DEAL, 1996: 25)

In some nursing homes containing many residents with severe communication impairments staff had become habituated to acting without consulting residents or indeed without addressing residents in any way. We observed staff approach residents and carry out quite intimate procedures, such as disconnecting a gastrostomy tube, without uttering a word. Sometimes residents who were half asleep or looking in the other direction were startled to feel an unannounced hand in their clothing.

Staff who had so lost touch with ordinary courtesies and habits of interaction ... had become accustomed to disregarding residents' communication, regardless of the source or the message. As one elderly lady whose repeated efforts to attract attention were being ignored said "I'm only trying to save the time they'll need to change me." (DEAL, 1996: 25-6)

9.3.3. Death-wishing

Negative reactions to disability sometimes go beyond segregation and neglect to death wishing, that is, wishing that people with disabilities would cease to exist either because life for individuals with disabilities is perceived as unbearable (see below, 11. 4) or because individuals with disabilities are seen as harming society. In relation to death wishing it is important to recognise that community attitudes have often been led by professional opinion, and more particularly by the most 'liberal' (least religious) elements of professional opinion. In 1901 Alexander Johnson,

past president of the National Conference on Charities and Correction, and of what is now the American Association on Mental Retardation (AAMR), an association of professionals working with people diagnosed as mentally retarded, stated, "I do not think that in order to prevent the propagation of this class it is necessary to kill them off or to resort to the knife: but, if it is necessary, it should be done." (Quoted in Wolfensberger, 1975: 37) In 1902 Barr, another past president of AAMR, delivered a paper called "The Imbecile and Epileptic versus the Taxpayer and the Community" (ibid.: 36). It is clear that at this time the professional association not only shared popular prejudices but fed them and augmented them with dubious beliefs on inheritance.

Similar views continued to be expressed through the eugenics movement of the twenties which was given impetus by Oliver Wendell Holmes Jr's notorious statement made when delivering a 1927 Supreme Court decision upholding the Virginia sterilisation law, "Three generations of imbeciles are enough". That decision resonated for 45 years: the Virginia law was finally repealed in 1972, after 7,500 people had been sterilised (Gould, 1981: 333).

Sterilisation was only the beginning. *Selling Murder* (1991) is an assemblage of footage from a series of films made in Germany between 1935 and 1945 which denigrated and dehumanised people with disabilities. The earliest film which has survived was made in 1935. In chilling images it shows 'doctors' wearing white coats and jackboots and recommends compulsory sterilisation. *Selling Murder* states that between 1933 and 1939 350,000 people were sterilised in Germany, either because they were diagnosed as disabled or because they were believed to carry hereditary weaknesses. Teams of doctors and nurses carried out the operations. A

later Nazi film shows 'professors' describing people with disabilities as "life unworthy of life" and saying that a "conversation with these wretched people, in so far as they are capable of talking," would indicate the extent of their disabilities and make it clear that they could only "find deliverance through death." That film was scripted by psychiatrists and the selection of people for death was portrayed as being carried out by professionals, based on medical records and IQ tests given specifically for the purpose, presumably by more professionals. Some ninety thousand were killed, including people who were deaf or epileptic or who had Down syndrome, by lethal injection, poison gas or starvation.

While overt killing of people with disabilities has not been officially sanctioned in the U.S., Britain or Australia, covert killing has probably always occurred, and has been supported by leading members of the relevant professions. In 1981 (ironically, the U.N. International Year of Disabled Persons) *The Lancet* published an article by a group of senior physicians which questioned whether doctors treating the "mentally subnormal ... lack judgement and the courage to withhold antibiotics and life-saving procedures." It stated, without citing any evidence, that "Rejection of such children is rare" and that "often parents develop such an obsessional devotion to, and affection for, their afflicted offspring, that even when nature offers a peaceful end to a useless and hopeless existence ... they seem blind to the fact that a swift and painless natural death would be the happiest thing for the child and for them." (Medical Services Study Group of the Royal College of Physicians, 1981: 887) The doctors involved seem confident that they know what is best for all parties.

9.3.4. Use as research material

People with communication impairments have often been used as research material, testing hypotheses involving either actual harm or at least no discernible benefit to the experimentee. Researchers have, for instance, used people with intellectual difficulties as guinea-pigs to study:

- the effects of radioactivity, where the subjects (institutionalised American children) were fed radioactive substances (President's Advisory Committee, 1996):
- dental caries, where the subjects, institutionalised Swedish adults, were fed toffees (Pettersson, 1994): and
- hepatitis, where the subjects (institutionalised American children) were deliberately infected with hepatitis (Willey & Pasamanick, 1971).

The obvious comparison is with the Tuskegee experiments, where southern American blacks were deliberately given placebo treatment for syphilis to observe the effects of the disease in its untreated state (Curran, 1973). The obvious conclusion is that powerless groups regarded as outside the inner circle of humanity are regarded by medical professionals as expendable.

Even the story of Itard's Victor (see 3.2 above) provides one example of this tendency. While Victor may have benefited from his education, that benefit was not the reason that Itard was funded to carry out his study. The story of 'Genie', a young girl discovered in 1971 closeted away from the world and without language, provides an updated variant.⁴¹

⁴¹ Interestingly, Victor's story had a profound influence on Genie's life. Truffaut's film *L'Enfant Sauvage (The Wild Child)* was released in America at the same time as Genie's case

Victor had provided a test of Condillac's Enlightenment ideas of language: Genie was seen as possibly providing a test of Chomsky's new theories of language, in which "the inner rules of language—what Chomsky calls 'universal grammar'—are ... ingrained on a level more basic than thought." (Rymer, 1993: 29) This interest, it should be noted, depended specifically on Genie not being classified as retarded, as belonging to the sphere where, it seemed, even rules more basic than thought did not apply: researchers "declared an interest in the cognitive area, but if Genie turned out to be a mentally retarded child ... she wouldn't be a good case for the study of cognitive development. The potential for cognitive development would not be there, there would not be a flowering." (Rymer, 1993: 47)

Some researchers argued that the primary consideration must be Genie's therapy: others "said that this was too great a scientific opportunity—that research had to be primary." (Rymer, 1993: 61) Still others regarded both these positions as in their different ways arguing for the primacy of research, though in more or less ethically sensitive language. One of the propositions of the researchers who claimed to be acting in Genie's best interests, for example, was to return her to her deprived conditions in order to establish a baseline and then withdraw her from those conditions gradually as part of a properly controlled experiment, a proposition that is difficult to square with many conceptions of ethics (Rymer, 1993: 48).

Genie was initially absorbed wholly into the research environment: she was assigned to live with the researchers who were funded to observe her, which did not stop them simultaneously charging her for 'naturalistic

and therefore Genie's life were being discussed by the researchers who had taken charge of her.

psychotherapy' during which she would be "taken into the backyard and worked with there in the context of a natural living situation." (Rymer, 1993: 186) When formal and informal modes of assessment were included, Genie was on a testing regimen of sixty or seventy hours a week. Even more than with Victor, all Genie's language studies were conducted only through speech: there was no equivalent to Victor's LAIT. Perhaps as a result, her spoken grammatical expression stalled at the stage of the five-word sentence, which was not regarded as sufficient to establish the theoretical issues at stake. Funding was terminated. When the research funds ended, the researchers handed Genie back, just as Itard had left Victor (Rymer, 1993: 148).

Jeffrey Braden, a psychologist, recently described deafness as "an unfortunate accident but potentially valuable natural experiment." (Braden, 1994: 1) The same idea was put more crudely by another researcher: "So we ripped the ears off kids—[that is] we tested deaf kids." (Rymer, 1993: 85) Braden claimed to be following in the footsteps of Descartes, "the first person to recognise and apply the natural experiment created by deafness for the purpose of examining the relationship between thought and language" who "concluded that deaf people's spontaneous development and use of a sign system showed their innate ability to think, reason, and develop abstract thoughts even though they could not hear or use spoken language." (Braden, 1994: 3) Braden himself used deaf people as a foil to blacks in a discussion of the relationship between race and intelligence. "Studies of deaf children as a natural experiment in intelligence may shed light on some of the possible causes and explanations of black-white differences in IQ" because "deaf people score well above blacks, and very close to whites, on nonverbal IQ tests". Analysis of the validity of Braden's argument is outside the scope of this

thesis: what is relevant is his use of deaf people as “a proving ground to sharpen and refine” his account (Braden, 1994: 201).

Braden’s approach conflicts with the belief of professionals associated with the disability rights movement, that disability studies should involve people with disabilities not simply as subjects but in setting the goals and directions of research:.

If disability research is to be emancipatory research then it must be part of disabled peoples’ struggle to take over ownership of the definition of oppression ... able-bodied researchers should ... ask ‘where are the disabled researchers and academics? (French, 1992: 188)

While early research into non-speech communication certainly had impact on its human subjects, their benefit did not appear to be the primary aim of the research. Reports of attempts to develop communication with non-speaking ‘retarded’ human infants based on attempts to develop communication with animals indicate that far more effort was directed to the animal communication programs than to the human. Some experimenters seemed more interested in a comparison of human/chimpanzee learning styles than in the provision of useful communication to their ‘profoundly retarded subjects’ whose value apparently was that they presented ‘interesting case studies’ (Deich & Hodges, 1977: 129).

As has been described in chapter 5.2 above, intervention with non-speakers is often based on the irrational assumption by professionals that one can assess the cognitive skills of a person without expressive language and use this assessment to determine which (if any) communication strategy should be offered to the person. Deich and Hodges (1977: 145) separate ‘the handicapped child’ who lacks ‘the motor skills to produce either verbal or sign language’, who may have been ‘erroneously labelled

as retarded due to their limited capacity to handle language', from 'the severely to profoundly retarded child who has no language skills and who fails at signing'. Given that the latter children are not born stamped 'profoundly retarded', they are presumably just as likely to have been erroneously labelled due to 'their limited capacity to handle language' and their impaired hand skills. As it is suggested that the communication needs of the latter group will be met by fewer than 40 of the symbols devised for use with chimpanzees by David Premack, while the first group should get access either to up to 500 of the symbols Charles Bliss devised for international communication or to alphabet boards, we are unlikely ever to know.

It is true, nonetheless, that experiments using primate language with people with language impairments came at a time when the status of chimpanzees had been raised by the suggestion that they understood language. Earlier comparisons between apes and morons had been made simply to establish a common lack of humanity.

9.3.5. Characterisation as animals (or vegetables)

An early direct comparison between children and chimpanzees came from Germany during the years covered by *Selling Murder*. It was described by Jensen as follows:

both normal children and children with varying degrees of mental retardation have been given the battery of tests that Kohler used with chimpanzees. Exactly the same rank order of difficulty of these problems emerged for human children as for chimpanzees and lower primates (Viaud, 1960, pp. 44-5). The complexity factor common to these experimental animal problems, that differentiates species of primates, rank-orders human children the same as do standard IQ tests. (Jensen, 1978: 120)

In fact Viaud does not refer to IQ, saying rather that

In 1935 Gottschaldt studied a group of one hundred hospitalised children between the ages of two and ten. He divided them into four groups in descending order of intelligence: normal, feeble-minded, imbecilic, and idiotic [presumably on the basis of speech and motor skills], and set them the same, or nearly the same, problems Kohler had set his chimpanzees. The results were comparable, and so was the order of difficulty which emerged. (Viaud, 1960: 44-5)

Gottschaldt's results are unsurprising, given that chimpanzees and children with motor impairments are equally disadvantaged on tests which require fine motor skills and a pincer grip. What is interesting is that postwar psychologists such as Jensen had no qualms in making use of test results that had been obtained in Germany at a time when the Nazis were working to establish the intrinsic inferiority of people with disabilities preparatory to exterminating them (see 9.3.1 above).

Post-war America had officially discarded eugenics but adopted behaviourism. The results for people with severe disabilities were little different. In a 1949 experiment Fuller sought to have an 18-year-old 'vegetative human organism' raise his right hand by denying him food except when reinforcing suitable movements.

While of normal human parentage, this organism was, behaviourally speaking, considerably lower in the scale than the majority of infra-human organisms used in conditioning experiments—dogs, rats, cats....Perhaps by beginning at the bottom of the human scale the transfer from rat to man can be effected. (Fuller, 1949: 590)

It is impossible to be certain without more information, but from the account given it seems likely that the teenager concerned had cerebral palsy.

As well as people with communication impairments having their performance compared with animals in research, they are in numerous professional accounts described as animals. This may reflect a general tendency to brutalise and dehumanise people with disabilities in societies

that place high value on intelligence and achievement. Wines (1889, quoted in Wolfensberger, 1975: 37) remarked about retarded workers: “Many of them are capable of being made useful to a large extent even though they may be unable to talk. I have seen idiots who were useful on a farm, for instance, who could not speak a word. Is not a mule valuable on a farm? Yet he cannot talk.” As Wolfensberger continued, “One might have considered such an analogy merely unfortunate, had he not abrogated the human capacity for suffering from a retarded person in a second comparison with animals. In describing a retarded [mute] woman chained by the neck to a dog’s running-wire in the yard, he denied that she was suffering because ‘she was a mere animal, well cared-for as an animal.’” (Wolfensberger, 1975: 39)

Being described as an animal may, in some circumstances, be a step up. ““These children are cabbages, mere cabbages’ the official visitor said, watching Sally paint with the only material available, her own tears, which had formed a pool on the table in front of her. She had overlooked the fact that cabbages don’t cry.” (Oswin, 1974, flap copy)

9.3.6. Viewed as irremediable

Because severe disability is permanent there is a tendency to think that nothing can be done. After all, the essential nature of mules and cabbages does not change—they do not benefit from schooling or therapy. When taken to extremes, this results in a failure to provide simple ameliorative treatment. A four-year-old child disabled by maternal rubella was admitted to an institution for profoundly retarded children. The hospital staff refused to accept her glasses and hearing aids because “If she’s profoundly retarded, they won’t help her.” (Personal experience, 1975)

Similarly, when Anne McDonald had an eye test, the ophthalmologist, having made his own eyeball assessment of her cognitive skills, said that as her long sight was fine and only her near sight was impaired she would not need glasses: "After all, it's not as if she's reading." This was despite McDonald having undertaken the standard eye test using the Snellen chart, which she had done by pointing to letters on her own alphabet board to indicate what letter she thought the examiner was indicating. When it was explained that Anne was in the final year of secondary school, the ophthalmologist was astounded, but immediately prescribed glasses. Obviously if McDonald had not been literate failure to prescribe glasses for close work could have prevented her from ever learning to read (personal experience, 1981).

Not only may impairments go uncorrected, they may go undetected. Studies that have shown a high prevalence of hearing loss in people with learning disabilities have also shown that this population goes largely untested.

Unrecognised hearing loss affects behaviour and may underlay much of the difficult behaviour that upsets family, staff and other residents of houses in the community with support staff. The high frequency hearing loss found so commonly in early middle age in people with Down's syndrome may account for the apparent deterioration in previously normal cooperation. Presbycusis may make people with learning disabilities seem difficult or even senile if it is not detected....As people with learning difficulties are progressively entering the community this aspect of their care is justifiably arousing concern. (Yeates, 1991: 428)

Several recent American court cases have resulted in damages awards to people with hearing impairments who had been incorrectly assessed as mentally retarded and placed in institutions without having their hearing checked. I know of no cases where people with severe expressive communication impairments who have been similarly misdiagnosed have received similar awards.

Even eating may be compromised by the presumption that intervention is unwarranted. Anne McDonald had had her lower front incisors extracted in the institution and needed a dental plate to replace them, but met with considerable opposition from the Royal Dental Hospital specialists. “People like her can’t wear dentures”, they said. “She has tongue thrust which will push the plate out”—as usual addressing their comments to her companion rather than Anne herself. McDonald persevered, and eventually it was agreed that she could try wearing a dental plate. There are two types of plate available—the cheaper plastic type and the more expensive metal model. The metal plate fits better and is harder to dislodge. She was given the plastic: “She’s going to have so much trouble keeping a plate in that it’s not worth giving her a metal one. If she’s able to use a plastic plate [the hard one] we’ll give her a metal plate [the easy one]”. The professionals were not only certain that the plate would fail, but, probably unconsciously, were taking steps to make it fail. In fact McDonald adapted to the plastic plate by controlling her tongue thrust—much easier when she had teeth to rest her tongue against (Crossley, 1982: 6).

9.3.7. Viewed as ineducable

Many educators have seen and developed the potential of non-speaking children since Eleanor Schonell wrote *Educating Spastic Children* in 1956. Rosalind Oppenheim stated her views very clearly:

The immaturities and/or deficiencies in the [disabled] child’s general functioning including the fact that the child may be nonverbal or noncommunicative should never be used as an index of the likelihood of his being able to absorb and benefit from teaching at higher cognitive levels—specifically, his ability to learn reading, writing, and mathematics. (Oppenheim, 1974: 90)

Nonetheless, many students with severe communication impairments are still dehumanised today by teachers who have no expectation that they can learn, no idea of how to teach them, and no sense of them as people deserving to be treated with dignity.

In mid-1996 I made a pre-announced visit to a so-called Special Developmental School in metropolitan Melbourne. Most of the school's students have multiple impairments, and all are diagnosed as having IQs of less than 50. The school has modern classrooms, a good staff/student ratio, and physiotherapy and occupational therapy services. The class in which I spent the afternoon consisted of five teenagers and young adults, none of whom could speak and four of whom used wheelchairs. The classroom was decorated like a kindergarten with cut-out flowers obviously made by the staff. It contained no books or educational materials other than a radio and a television. Instead, it had five large posters on the wall detailing each student's impairments and assistance needs. Despite the students' communication impairments there was no communication equipment in evidence. A sophisticated government-funded communication aid belonging to one student had been shut away for so long that its battery was completely flat.

No staff member—teacher, physiotherapist, teaching assistant, physio assistant—was observed to have any positive interaction with any student during the afternoon, and no teaching took place. The teaching assistant discouraged any attempts at interaction on the part of the students, taking the few (age-inappropriate) toys away from the one student who could reach them and moving a student who was quietly listening to me read a story around a corner so he could not see anyone. The teacher carried a teenage girl with severe cerebral palsy into the classroom from

the neighbouring toilet naked from waist to knees and put her on a bench in full view to wipe her bottom. Later she tried to feed the same student a piece of toast. Not surprisingly, the girl choked and appeared in some danger of suffocating before, fortunately, she vomited and dislodged the obstruction. At this point the teaching assistant abused her roundly for vomiting on purpose. Meanwhile the physiotherapist and therapy aide had changed the incontinence pad of a 24-year-old male student, who being a quadriplegic without speech had no way to object, in full view of the rest of the class and of anyone who happened to be walking along the path outside the large, uncurtained, windows.

The staff showed no embarrassment and made no attempt to explain any of these events, presumably regarding them as no more than accepted common practice. How common became evident when I sent a detailed account of the visit to the Education Department without naming the school concerned. The account was distributed at a Special School principals' conference then in progress. Eleven of the principals present said they thought it could refer to their schools (Peter Tarr, Sept. 1996: personal communication).

9.4. Professional assessment of disability

Doctors and psychologists tend to employ all diagnoses in the same fashion, as though all have the same degree of certainty—that a person has cerebral palsy or Down syndrome or autism or profound mental retardation in the same way as they have a broken leg. When a diagnosis is quantified—MA 4 years and 3 months, IQ 36, cholesterol 6.4—the appearance of certainty and accuracy is heightened. While a diagnosis of cerebral palsy or Down syndrome designates verifiable physical differences (brain damage affecting movement and an extra chromosome,

respectively), a diagnosis of autism is based on subjective ratings of behaviour, and a diagnosis of profound mental retardation is typically based on an eyeball 'assessment' of a person who is unable or unwilling to undertake IQ tests requiring speech and hand skills. Such judgements are given the appearance of objective reality by the manner in which they are used in professional reports, journal articles and institutional listings (for example, "profoundly retarded white female aged 15 years").

A study of the process whereby people are labelled as mentally retarded reported by Gething noted that physical disability had a major influence on diagnosis (and speech impairment was the most common single physical disability, occurring in 30% of the group labelled as retarded):

The presence of physical disability appears to influence the clinician's perceptions of the person so that he may diagnose a physically disabled person with relatively high intellectual ability as a mental retardate. The presence of physical disabilities also increases the likelihood that a diagnosis will be made without an intelligence test. (Gething, 1992: 812)

A survey in Victoria, Australia listed two-thirds of non-speakers as intellectually impaired (Bloomberg & Johnson, 1986) indicating that most professionals did not perceive a problem in assessing the intellectual skills of people who could not speak and who in the large majority of cases had been given no alternative means of communication. Jane Mercer, a sociologist highly critical of IQ tests and their application to cultural minorities, believed that "it is not possible to conceptualise intelligence apart from the sociocultural matrix which creates that intelligence." Nonetheless, even she qualified that statement by adding, "except for physical, motor and perceptual disabilities so gross as to be labelled abnormal in any human society" concluding that "the pathological-medical model ... is appropriate" for such people (Mercer, 1973: 70).

In computer jargon 'wysiwyg' (pronounced 'wizzywig') is an acronym for 'what you see is what you get', used when what is shown on a computer screen matches what appears on the printed copy. What has been described here may be termed the wysiwyg approach to intellectual assessment. Even when formal tests are used, wysiwyg is nonetheless the central presumption underpinning all psychological assessment. John Jacobson, a senior member of the U.S. psychological 'establishment', has stated that "a strong presumptive relationship, in general, between overt production and actual ability is a cornerstone of psychological assessment methodology, statistics, and psychometrics." (Jacobson et al., 1995: 754) People without speech who are not deaf are consequently very likely to be assessed as mentally retarded, either by visual assessment or on the basis of IQ tests requiring spoken answers. The reason that many psychologists and many speech pathologists do not uncover the communication abilities of these people may be because the doctrine of mental retardation has given them good reason not to expect them. These non-speakers have, by definition, sub-average general intellectual functioning, a central and all-encompassing problem with cognitive processing which can be used to explain any dysfunction.

The tendency for one group of professionals to take a particular diagnosis and its associated dysfunctions under their umbrella makes it more likely that all dysfunctions observed will be put down to that diagnosis. Other professionals may rarely see children with that diagnosis, reducing the possibility of differential diagnosis of those dysfunctions. In Australia, my experience is that teachers and audiologists effectively 'own' deafness, doctors and therapists 'own' cerebral palsy, and psychologists and psychiatrists 'own' autism. Professionals from other disciplines will obviously from time to time see individuals with these diagnoses for one

reason or another, but these professionals will typically have little impact on the overall assessments made by the dominant disciplines—assessments which will be derived from those particular disciplines' skills and beliefs. When psychologists noted, for example, that children with autism could not point properly, they decided a priori that this could not be a problem with hand function. Because the children had autism, and because autism was a cognitive problem, their problem with pointing had to be a cognitive problem too—a difficulty in understanding language.

The [autistic] child's understanding of social language is usually markedly reduced, and a lack of symbolic gesture or mime is equally characteristic....Even very simple gestures, such as pointing, are affected, and if autistic children do indicate their needs in this way it is usually with the hand rather than with the extended index finger. (Howlin & Rutter, 1987: 2)

Neurologists and occupational therapists could certainly suggest different explanations for a lack of gestures or pointing (Crossley, 1994: 19), but under existing disciplinary divisions they were unlikely to be asked for their opinions.

The boundary-setting which follows from the segregation of professional groups presumably has as one of its functions the protection of the group. For example, as Australian psychologists have successfully implemented a rule that certain tests may only be administered by psychologists, this ensures that any agency wanting to use these tests will have to employ psychologists. There are, however, risks attendant on this setting of boundaries. Firstly, the group inside the boundary can find itself out of step with other groups, including its own client group, or with the wider society. Secondly, the group inside the boundary can become obsessed with the protection and maintenance of the boundary for its own sake. Examples of such boundary defences may be found throughout the history of non-speech communication, and are particularly well-

documented in the case of the most recent non-speech communication strategy, facilitated communication training, which will be examined in detail in the next chapter.

Chapter 10 Protecting the boundaries—professionalism under challenge

Each human services profession is based on a corpus of knowledge, often somewhat out-of-date, or at least not at the cutting edge of current research, because it is handed down by the profession's elders, either in university lectures or the pages of academic journals. All human services professionals obviously need to believe that they know something worth knowing that distinguishes them from the rest of the population; they could not otherwise practise as professionals. The issue which will be examined in this chapter is the attachment of some professionals to their knowledge base, their belief system, the strategies they used in defending it, and the impact of these defences on people with severe communication impairments.

10.1. Professional belief systems

Belief systems are part of the uniform that denotes a professional as well as being an essential element in an operating system that provides guidance and sets limits to thought and perception (Johnson, 1972: 55). Development of new technologies or techniques may challenge professional beliefs and lead to adjustments in the 'ownership' of specific diagnoses or services. When deafness was first seen as a diagnosis warranting professional input it was 'owned' by the doctors. With the expansion of deaf education, teachers became the pre-eminent professionals. Now, with the advent of the cochlear implant, the balance may swing back to the medical profession.

Facilitated communication, for example, was described by one of its critics as "an inappropriate challenge to professional belief systems."

(Shane, 1993c: x) Parties to the debate surrounding facilitated communication (see 6.4 above) recognise that if its use by people diagnosed as autistic and/or intellectually impaired survives the current controversy then currently accepted conceptualisations of autism and intellectual impairment will change radically. Most would agree that in such an event psychologists may well lose their present primacy in both these fields to neurologists, therapists and teachers.

The initial response to facilitated communication from the professionals engaged in the field of autism was to ignore it:

Ironically, for well over a year [after publication of his widely-read 1990 article in the Harvard Educational Review] most experts in autism did not initiate talking with me or any of our research group about the matter....Descriptions of students with autism writing normal sentences just did not fit the prevailing conception of autism. (Biklen, 1993: 116)

Some years earlier, when I sought advice from a psychologist with a reputation as a researcher in autism about the unexpected language and literacy skills being elicited via facilitation, her response was “I view with concern your intrusion on the field of autism.” (Prior, 1987, quoted in Crossley, 1997: 129) As it happens, she had an article in press at that time which both encapsulated her beliefs about autism and made it clear why she viewed my letter as an intrusion:

Most autistic children are in fact retarded: at least half of them severely or profoundly so....IQ is a good predictor of adjustment in the majority of cases....Children who are untestable on intelligence or adaptive behaviour tests have a poor prognosis....Only a minority of children acquire functional language and even then this is usually immature, deviant, inflexible, concrete, and lacking in communicative competence....Behavioural methods ... permit the learning of basic self-help skills, eye contact, and some co-operative behaviour. (Prior, 1987: 3)

Both advocates and critics of the method agree on the importance of facilitated communication: advocates have suggested that

We now need to begin the task of restructuring our own view of people with autism and other developmental disorders, as well as the low-track education system into which they have been placed. A complete paradigm shift is underway. (Berger, 1992b: 5)

Critics have complained that

If the rhetoric and media hype promoting "Facilitated Communication" continues, it may well succeed in setting autism services back 40 years. (Schopler, 1992: 337)

10.2. Professionalism under challenge

The manner in which professionals conduct such debates and in which they respond to challenges provides some insights into their attitudes to their clients. Earlier examples of controversies in the disability area, such as the debates over Sister Kenny's unconventional treatment for polio, show many of the same characteristics. Martyr's coverage of the role played by physiotherapy's professional associations in the Kenny affair brings out the importance of economic reinforcers for theoretical positions:

Kenny's war with orthodox medical practitioners may have had its ideological roots in the undermining of medical authority by a member of the subordinate group of nursing, but her actual practice was dangerously close to the means by which members of the Australasian Massage Association [forerunner of the Physiotherapy Association] earned their living....The Association's branches therefore went out of their way to discredit Kenny and to align themselves securely with the orthodox medical profession, keeping up a steady pressure on their respective medical connections which contributed to the eventual rejection of Kenny and her methods in Australia. (Martyr, 1994:100)

Other motivations to query closely any radical new practice might be an unwillingness to retrain, an unwillingness to confess to error, or an unwillingness to weaken the position of the profession by admitting its imperfections. This is not to say, of course, that all radical new practices are automatically right, or that all should be adopted with or without question, only that such innovations have higher bars to clear than do more

conservative measures. In cases where paradigm shifts are proposed, the requirements may be set impossibly high, and the contributing motivations for such restrictions will not necessarily be publicly acknowledged. For example, if the primary motivation of disability professionals was in fact to help people with disabilities, every professional working with people with severe communication impairments should have at least wished facilitated communication to be true, because if true it would have offered many who were previously mute the chance of a voice. This is not to suggest that the professionals should have allowed this wish to overrule the evidence, but if the interests of their clients were dominant they would have given the evidence a very extensive and unbiased hearing. An examination of how they have in fact conducted themselves in the controversy suggests different priorities, and may show something of the reaction of a profession to the prospect of a 'paradigm shift' such as that referred to above by Berger.

Controversy about facilitated communication did not start in the U.S. in the nineties: it began twenty years previously in Victoria. In 1977 the Victorian Mental Health Authority (MHA) had asked Dr. Leo Murphy, Dean of Special Education at Burwood State College, and Jean Vant, former Senior Psychologist for the MHA, to ascertain whether Anne McDonald, then a 16 year-old non-speaker labelled profoundly retarded and a resident of an MHA institution, could read and spell. Mrs. Vant wrote that Anne "was given a passage to read whose contents were known only to Dr. Murphy and myself, then three typed questions relating to it" to answer with facilitation, stating that she herself had supported Anne's arm while Anne spelled answers to other questions. She concluded, "I have observed her [Anne] working with the magnetic letter board both as the person supporting her and the person who was asking the questions. I am

satisfied in both instances that she did indeed answer the questions and in each case had read the material and the questions.” Her final report, endorsed by Dr. Murphy, was provided to the MHA in September 1977 (Crossley, 1997: 17).

When in 1979 Anne McDonald sought to leave the institution and filed an application for Habeas Corpus in the Supreme Court of Victoria (see 8.5 above) her ability to communicate by spelling was a central issue in the case. The MHA’s position was that there was no evidence that Anne could read or spell. The affidavits of the MHA’s doctors—affidavits which were said to include all the comments on Anne McDonald’s intellectual functioning contained in her file—made no mention of the Vant/Murphy investigation. Fortunately for Anne, her lawyers also had access to Dr. Murphy’s correspondence with the Health Commission. Under cross-examination the Superintendent of St. Nicholas first said that there was no such report. After Anne’s lawyer had read the report’s findings to the court the Superintendent said he had never heard of or seen such a report before. Confronted with a letter from his Director which said that he had been sent a copy of the report, he finally admitted receiving a copy and placing it on Anne’s file. So why, he was asked, had he not included the report in his affidavit? “Because I don’t believe Mrs. Vant ... I don’t believe her any more than I would Miss Crossley!” (Ex parte Anne McDonald, Supreme Court of Victoria, 1979) Vant had previously been a senior professional employee of the MHA and no complaints had been made against her expertise during that time. Any person, however respectable previously, claiming results inconsistent with professional belief systems was by that action, it would seem, automatically designated as deviant and unworthy of credence. Any results, however well attested, that were inconsistent with

professional belief systems tended to be automatically designated as fraudulent and lacking credibility.

What followed illustrated that this reaction was not simply an aberration in an otherwise satisfactory system of professional self-regulation. The court's inquiry into McDonald's competence was followed by an inquiry appointed by the Health Commission of Victoria into the competence of eleven of McDonald's fellow residents about whom similar claims had been made. The Inquiry was under the chairmanship of Professor Peter Eisen, a psychiatrist. The major findings of the committee were that there was no valid evidence to support claims that the children, as they were described, could communicate by the use of an alphabet board, and that any claims that the children were capable of understanding and communicating highly sophisticated concepts were, in the opinion of the committee, false. It was further stated that "no child showed any evidence of even the most elementary level of literacy or numeracy." (Committee of Inquiry to Investigate Claims about Children at St. Nicholas Hospital: 6). Such findings do not of themselves indicate either bias or maintenance of professional belief systems.

In this case, however, the Minutes of the Committee and supporting notes were obtained under the *Freedom of Information Act*, permitting a comparison between the findings and the evidence purportedly supporting them. The details that follow are from Joan Dwyer's extensive analysis in *The Australian Journal of Administrative Law* (Dwyer, 1996).

The Secretary's notes of a Committee Meeting on 6 July 1979 refer to a testing session on 6 July 1979. They state:

"[Committee member A] told story—Isaac Newton and dog destroyed notes—while [facilitator] out of room.

[Facilitator] returned ... [Subject A] spelt out NEW. Then spelt out DIA for name of dog.

[Facilitator] had no clue about story.” (Dwyer, 1996: 80)

Those notes refer to a session which two Committee members had with one of the subjects of the investigation. While the facilitator was out of the room the young woman was told a story about Isaac Newton and how his dog, Diamond, tore up some important papers. Later, with the facilitator’s assistance, she was asked to spell out the name of the person the story had been about. After she had spelt out NEW a Committee member told the facilitator that the name was Newton. The second Committee member then asked the subject to spell out the name of Newton’s dog. She spelt DIA and the Committee Member told the facilitator that the name was Diamond (Dwyer, 1996: 80).

The Minutes of 13 July 1979 contain the following passages:

[Two Committee members] tested a number of the children [sic] last Friday.

[Leonie] answered some questions quite successfully without arm support but was not so successful with simple mathematics.

They saw [Phillip] work with Rosemary Crossley. [Phillip] competent with fractions: [Noelene] can handle sums and doesn’t need her arm supported all the time.

The Committee spoke to Mrs. Margaret Batt, and [two Committee members] watched a demonstration of her communication with [Mark] One answer took half an hour to finish but he apparently touched the letters without mistake.

[Committee member 1] wasn’t convinced as his arm could have been influenced by the way it was held. [Committee member 2] considered that his eye moved to the letter before his hand did and if his body and head were in a more rigid position he may have done better. [“done better” has been crossed out and instead the sentence now ends “achieved a more authentic result” in handwriting.]

Her opinion is that all the children will now have to be assessed. (Quoted in Dwyer, 1996: 80)

The Minutes and notes thus contained clear experimental evidence supporting the views of those saying that the people in question could

communicate and inconsistent with the findings of the Committee that they were severely retarded, that they functioned in no case “beyond [the level] to be expected of two and a half to three years of age”, and that they had no demonstrable literacy skills. Similarly, the Secretary’s notes of a Committee Meeting on 6 July 1979 refer to a testing session on 4 July 1979. The notes stated:

[Committee member 1] chose 4 numbers 4 38 17 26

[Committee member 2] wrote 4 nos in order questions to be asked (mathematical)

RC asked questions.

Maths

Gen Knowledge

[Angela] chose

India Iron Oxygen Violin

[Angela] got a number right and some wrong.

comm board—spell mineral—pointed to IRO. (Quoted in Dwyer, 1996: 81)

The evidence obtained under freedom of information legislation thus supports Dwyer’s conclusion that

The Minutes and Secretary’s notes show that the report misrepresented what was actually found by the Eisen Committee in its sessions working with the “children”. (Dwyer, 1996: 81: emphasis in the original)

Dwyer does not speculate about what motivation would induce leading professionals to falsify data. It is difficult to provide any explanation that does not draw on the principle already enunciated in the McDonald case: where professional rigidities are strong, any results, however well attested, that are inconsistent with professional belief systems are seen to be, virtually by definition, misleading and irrelevant.

The next inquiry into facilitated communication was the Victorian Intellectual Disability Review Panel, in 1988-89. The Panel’s report did

not on this occasion reject the experimental evidence it had arranged to seek, concluding in the event that the validity of communication while using the assisted communication technique was demonstrated in four of the six clients who participated in its two studies (controlled laboratory format and message-passing), but that in all three cases of the controlled study, client responses were influenced by the assistant. Significantly, however, the Panel (headed, again, by a psychologist) did demonstrate one of the most basic professional defence mechanisms. Having called for submissions from interested parties, and having received 87 such submissions, both oral and written, it made reference to none of them and drew on none of the information presented in any (IDRP, 1989). None of that information had been officially certified by publication in refereed journals, and it was therefore considered to be unusable.

Beliefs about people with severe communication impairments held by professionals affect both their behaviour to their clients and the way they approach evidence which challenges these beliefs. The Superintendent's concealment of Anne McDonald's positive test result has been mirrored by similar deliberate suppression in the current controversy. For example, both Shane (1993a: 13) and Palfreyman (1994) have said that there is no evidence that Anne McDonald can spell. Both cite among their references *Annie's Coming Out* (Crossley & McDonald, 1980), in which Ms Vant's validation test, the resultant report, and the concealment of the report from the court are described in some detail. It may be therefore assumed that their repeated statements that no evidence exists are not made in ignorance of these events. Like the Superintendent before them, and like the Eisen Committee, they are presumably so sure the test report cannot be true that they feel no qualms about ignoring it and, having defined it as irrelevant, concealing it.

It is sometimes difficult to distinguish the rejection of evidence challenging professional beliefs from the rejection of people with SCI themselves. In an article in *Communicating Together*, an American professional (in this instance, a speech pathologist) put forward as an important prop of his disbelief in the validity of facilitated communication that “Not one alleged competent user of the technique has come forward to prove the technique is genuine.” (Shane, 1993a: 13) The next issue of the journal contained an article by Anne McDonald, giving details of validation tests she had passed (McDonald, 1993b: 21-22). Shane’s response did not comment on the material McDonald had adduced as evidence of valid communication, and rested instead on a more basic exclusionary principle: “In light of my conclusions [as given above] in the paper *FC: Facilitated or ‘Factitious’ Communication*, it would be illogical to direct a response to Anne McDonald.” (Shane, 1993b: 10) This would seem a particularly effective Catch-22: the method cannot be validated unless users come forward to give evidence, and evidence presented by users cannot be entertained because the method has not yet been validated.

If those committed to present paradigms prevail it may well be that facilitation will never be able to attain the status of a ‘validated’ technique, regardless of the evidence that validation does in fact occur. Early in 1996 two U.S. government instrumentalities set up a joint inquiry into facilitated communication which called for submissions from all interested parties. Users and parents submitted accounts of their experiences with FC, and the committee was also sent *Annie’s Coming Out*, the *IDRP Report*, and a large quantity of journal articles and court reports. In what might be regarded as an effective piece of professional gate-keeping the committee, which included only one non-academic, declared after receiving public submissions that all evidence apart from that accepted for publication by

peer-reviewed journals would be disregarded. This permitted the committee to disregard not only personal accounts (which it describes as 'phenomenological') but also government reports and court findings (ADD/OSERS, 1997: 18).

The committee was, however, still obliged to consider a number of studies published in peer-reviewed journals. While the majority of the journal articles reported negative findings on the validity of facilitated communication, some—including the most recent, three experimental studies published in the August 1996 issue of *Mental Retardation*, a major refereed journal in this field—reported positive findings. Like the Superintendent of St. Nicholas, however, the committee apparently did not believe, or even see, these reports. The conflict between what they knew to be true and what they read would appear to be too great to be reconciled, and the evidence must evidently be dismissed. The committee's draft report thus stated categorically that:

There are no experimental studies documenting unanticipated communicative competence via facilitated communication when facilitator bias is controlled. (ADD/OSERS, 1997: 14)

The committee also recommended that

Given the absence of experimental documentation of facilitated communication user authorship, and several clear demonstrations of facilitator control of communication content, priority [research] funding targeting facilitated communication is not indicated at this time. (ADD/OSERS, 1997: 23)

This recommendation, if accepted, would of course go some way to ensuring that no further experimental studies that might document unanticipated communication competence would be carried out.

The conduct of this committee, added to that from the previous inquiries described above, contributes to some doubt as to whether beliefs

and attitudes held by professionals in these areas, beliefs on which they may have based their professional development, self-image, and performance, are in practice susceptible to change.

The common thread linking community and school inclusion and facilitated communication is that they represent a direct challenge to the technical rational science of segregation on which the control professions have been built. The science of segregation, originating with eugenics, supports the notion that difference must be stigmatized, contained, and eliminated from the community. Technical rationalism suggests that better and better professionally designed techniques will develop for the control of difference. Challenges to this manner of control are considered anti-professional, and because professions are purportedly based on science, anti-empirical. (Kliewer & Drake, in press: 15)

It may yet happen, of course, that the professions involved find a way to alter their practices to edge in new cases towards the new approaches while continuing to protest their opposition, as with the Kenny affair:

Kenny herself had not been 'legitimised' but her methods of treatment had—something that went largely unnoticed because of her confrontation with the medical and ancillary professions. The manipulation of poliomyelitis treatment's history in Australia allowed for the provision of a 'pedigree' for the Kenny treatment which omitted her altogether. (Martyr, 1994: 102)

10.3. Professional rivalries

It is necessary to carry analysis of the debate to a level below that of the undifferentiated professional. There are differences in the attitudes taken by different professions. These differences involve, *inter alia*, the theoretical investment of each profession, their power in the system, and their position in regard to the disability liberation movements characteristic of the last several decades. Psychologists, for example, have considerable power within the present system and a heavy investment in its governing theories. If true, the claims of the proponents of FCT would imply that the almost the entire psychological profession had been for its entire history

radically mistaken about the nature of human intelligence, a basic element of its intellectual cosmology.

Some reputable psychologists⁴², working for the most part in the field of autism, defend FCT (Donellan, 1992: Maurer, 1992), and some of its most active critics, such as Howard Shane, are not psychologists (Shane, 1993c). However, the bulk of professional critics appear to be psychologists, and the bulk of professional adherents appear to be therapists and educationalists: taking the 90 authors of 89 academic or professional journal articles⁴³ on FCT; in the 24 articles expressing negative conclusions about FCT 13 of the authors are psychologists, 11 are not, and the affiliations of 4 are unknown: of the authors of the 45 articles expressing more positive conclusions the proportions are 3 psychologists to 37 others and 2 unknown: and of the 20 inconclusive articles 4, 15, and 1. One psychologist has expressed the view that psychologists are leading the ranks of critics because they have the scientific training—the understanding of statistics and experimental methodology—that others in the field of developmental disabilities lack (Cummins, 1991), and most critics are united in seeing the roots of the popularity of FCT in this lack of scientific rigor among non-psychologists.

Western societies, including the United States, have a relatively low level of scientific literacy ... much of the scientific literature on topics such as autism ... is fairly inaccessible to most people, including some educators and other professionals. (Jacobson, 1993: 17)

From the point of view of critics of FCT, the enthusiasm for FCT among different groups requires a number of different explanations.

42 Psychologists, that is, whose work has been cited as authoritative in previous publications by psychologists now critics of FCT.

43 Excluding, that is, newspapers, news magazines, and newsletters, but including unrefereed journals on professional topics. For details see Borthwick, 1994.

Statements made by people with disability speaking for themselves can amount at best to 'self-report' or 'case studies', both traditionally suspect methodologies when not confirmed by experimental psychological studies. Similarly, enthusiasm by parents of people with developmental disabilities for the technique is not a serious source of theoretical concern. The opinions and observations of parents are not usually regarded highly by professionals, and explanations that would justify setting them aside are readily available. Prior and Cummins point out that "Parents of children with a handicap as severe as autism can be particularly vulnerable to promises of a breakthrough to normality." (Prior and Cummins, 1992: 332) More specifically, Mulick et al. note that denial, as "a form of avoidant coping, is recognized as a common reaction to the diagnosis of ... a disability in ... a loved one." (Mulick et al., 1993: 271) It is thus claimed that a therapy that suggests the possibility of unimpaired intelligence has a direct appeal to parents who are in denial regarding the reality of their child's disability. The testimony of parents is in consequence seen as having little independent weight and can be regarded as reliable only where confirmed, replicated, and published by professionals.

The problem for critics of facilitated communication training, however, is that the professions did not at first seem to be united in their opposition. In the United States, at least, many speech-language pathologists and special educators took FCT up with enthusiasm. While the errors of parents are predictable, different explanatory techniques are required to account for the concurrence in error of other professional groups. Schopler has complained that "the ideologues promoting 'Facilitated Communication' use an especially pernicious form of sales technique ... even at some of our university education departments." (Schopler, 1992: 337) Jacobson et al. state that "The growing

deprofessionalisation of direct service provision in ‘communitized’ and ‘integrated’ settings has resulted in few voices at the level of program planning and direct service delivery who can evaluate treatment alternatives according to scientific criteria.” (Jacobson et al., 1992: 27) They suggest, therefore, that there is a “growing vulnerability of consumers and paraprofessionals to pseudoscientific intervention strategies” (Jacobson et al., 1992: 27), and claim that

acceptance of new therapies seems to be more rapid among students and agency-based non-licensed clinicians than among academics and licensed clinicians ... students are more likely to be credulous ... students can expect to be more effective clinicians than their mentors....Direct service clinicians can expect to have a visible effect on the people they serve and get more respect from their peers....Administrators and managers can rest assured that their philosophy is new and improved. (Jacobson & Mulick, 1992: 3)

Jacobson et al. (1995) go into even greater detail about the shortcomings of their fellow-workers:

These developments [normalisation and deinstitutionalisation] have been paralleled by transformations in the credentialing of relevant service professions....Criteria for QMRPs [Qualified Mental Retardation Professionals] varied, but generally required far less training and experience than did community standards for most recognized professions. For example, the QMRP in psychology required completion of a bachelor’s degree in psychology or a related field and a year of experience in developmental services. Furthermore, direct care workers, who were typically responsible for the implementation of professionally designed habilitation plans, were those with the least training and most vulnerable to job instability and turnover.

As time went on, lax QMRP qualifications and the expansion of the interdisciplinary team to include members not typically recognized under noninstitutional professional regulation as professionals in any other sense led to marked variation in the quality of service planning and implementation....We believe that these trends made the developmental disabilities service system ripe for early adoption of a technique like FC. (Jacobson et al., 1995)

The fact that explanations of this sort are required emphasises that a significant number of professionals and paraprofessionals are, on this

matter at least, resisting the direction of psychologists. Another article complains that “Speech pathologists are prominent in the clinical promotion of FC, especially via fee-for-service introduction of the basic procedures”⁴⁴ and condemns “philosophically inclined therapists and teachers with Master’s degrees”. He goes on to complain that, “Very little criticism has been voiced within developmental disability services [where]....Many seem to view FC as the greatest breakthrough of all time ... [and] there has not been an aggressive and visible reaction by professional and scientific societies in medicine ... and neuroscience.” (Mulick et al., 1993: 274-278)

Mulick and his co-authors ascribe this to timidity on the part of the human services and apathy on the part of the neurosciences, but the isolation of psychologists on this matter does draw attention to the potential in FCT for a major shift of professional turf. If autism is, as suggested by the advocates for FCT, in large measure a communication disorder, and if that communication disorder arises out of a neurological disorder, then one of the obvious consequences of this would be that primary expertise in the field would cease to lie with the psychological profession and would move elsewhere. If intellectual disability, too, was reclassified as a communication disorder the effect would be even more extreme. If this approach was adopted, the professions of speech-language pathology and neurology might have first claim on the area. Jacobson notes some of the difficulties such a contest between psychology and neurology would involve:

44 This keen appreciation of the evils of fee-for-service may stem from the fact that Mulick, Jacobson and Schwartz are involved in congregate care and therefore on salary.

In Western society there is also a bias to consider neurological or biological explanations of human behaviour to be superior or more fundamental explanations than those arising from the behavioural or social sciences. (Jacobson, 1993: 17)

A further complication is that, as the quotations from Jacobson & Mulick (1992) on 'communitization' and Mulick et al. (1993) on 'philosophically inclined therapists' suggest, some of the tensions between advocates and critics of FCT have been carried over from previous disputes within the professions over such things as the value of community living. Advocates are drawn disproportionately from the deinstitutionalization movement, critics from its opponents. Rimland attacks Biklen both for his support of facilitated communication training (Rimland, 1993b) and for his advocacy of inclusive education (Rimland, 1993c) and deinstitutionalization:

The people who wrought such harm on the institutionalized mentally ill are still at work. Now they are destroying the institutions needed for the most severely retarded and autistic people....The PC people are trying to brainwash us into believing, as they seem to, that there is no real difference between the mentally handicapped and the rest of us, but there is....Biklen's ideas are specious....How do we combat these seductive but pernicious ideas? (Rimland, 1993a: 2)

The popularity of Biklen's theories on community integration for people with disabilities is linked with his advocacy of FCT, which is seen by some psychologists as a morbid symptom of deprofessionalization:

More recently ... articles have appeared that have positioned particular current challenges to segregation in the disability-related fields as anti-scientific. Most prominently criticized by the authors of these articles have been efforts towards community and school inclusion and research into facilitated communication. Certain of these authors link the three constructs together in an apparent effort to expose an unholy trinity of anti-empiricism eroding the disability disciplines.

For instance, a group described by the American Psychological Association as the Science Working Group on Facilitated Communication (Jacobson, Mulick & Schwartz, 1995) stated that facilitated communication developed because of deprofessionalization that began with the "movement of people from institutions to the community" (p.

751). This resulted in, the Science Working Group claims, “increasingly unpredictable or disappointing outcomes” (p. 752) ultimately allowing for the emergence of the “pseudoscientific” (p. 750) facilitated communication. (Kliewer & Drake, in press: 5)

The various explanations advanced to account for the popularity of FCT are also applicable to the perceived vogue for changes in the community’s management of intellectual disability. The attack on FCT is in fact seen by both sides as a lever that may possibly throw into reverse the trends towards community integration, and the attacks on FCT have been criticised for this reason by disability advocates associated with groups such as the Centre for Human Policy at Syracuse that are not yet prepared to endorse the method itself (Taylor, 1995).

The unsettled status of the AAC area, and its internal professional conflicts, may perhaps have contributed to the vigour of the debate over facilitated communication. Johnson suggests that

Charlatanism and quackery are ... a creature of professionalism and not the cause of it. That is to say that periods in which it is claimed that charlatanism is rife and needs to be stamped out are just those periods when an occupation is attempting to establish or struggling to maintain a monopolistic position. (Johnson, 1979: 57)

10.4. Disability creation

Where positive attributes are discovered in a population characterised as inferior, one method of realigning the evidence with the dominant paradigm is to reconceptualise these positive attitudes into a new disability. In *The Mismeasure of Man* Gould records the fashion in which, when evolutionary ideas changed, the physical characteristics attributed to Negroes were reconceptualised from being regarded as undeveloped and persistently childlike (and therefore inferior), to being regarded as prematurely adult and evolutionally rigid (and therefore inferior) (Gould, 1981: 119).

For seventy years, under the sway of recapitulation, scientists had collected reams of objective data all loudly proclaiming the same message; adult blacks, women, and lower-class whites are like white upper-class children. With neoteny now in vogue, these hard data could mean only one thing; upper-class adult males are inferior because they lose, while other groups retain, the superior traits of childhood. There is no escaping it ... with respect to racial differences, supporters of human neoteny adopted another, more common, tactic: they simply abandoned their seventy years of hard data and sought new and opposite information to confirm the inferiority of blacks. (Gould, 1981: 120)

Children, and particularly autistic children, with notably low IQ scores have in the past been regarded as unable to master reading skills (see 5.2 above). Some autistic children with low IQs have been found who are able to read fluently. The field of autism was therefore faced with a choice between admitting that the IQ scores were mistaken (and that IQ scores may be in general unreliable) or explaining the discrepancy by reference to a deficiency model. The outcome has in fact been the creation of a new disability.

Anyone diagnosed as autistic has, by definition, difficulties with language learning. Those with the least speech apparently have most difficulty and are generally considered to be low-functioning and severely mentally retarded (Prior, 1987). Any demonstration of literacy skills by such children is consequently unexpected, and has implications for the diagnoses of both autism and mental retardation. Even before the controversy attendant on the production of sophisticated typed language by some people diagnosed as autistic using facilitated communication, it had been known that some children diagnosed as autistic had reading skills well above those expected for children of their mental age (Goldberg, 1987; Silberberg & Silberberg, 1967; Whitehouse & Harris, 1984). These skills were described as 'hermetic,' or isolated, and therefore did not necessitate any revision of the children's intellectual status. A guiding principle appeared to be that anything done by children like this must be

abnormal. A new term, 'hyperlexic', was thus coined to cover overachievement in reading. The term was used pejoratively, in the same way as the term dyslexic (Goldberg, 1987; Silberberg & Silberberg, 1967; Whitehouse & Harris, 1984). Similarly, when some children with autism demonstrated unexpected writing abilities these were termed 'hypergraphia', and were said to exceed intellectual ability (Whitehouse & Harris, 1984).

The hyperlexics often showed reading skills before starting school. "Their decoding ability was often taken as a sign of unrecognised intelligence....On school entry the word-calling ability sometimes led to inappropriate classroom placement." (Whitehouse & Harris, 1984: 286) As Douglas Biklen has commented, "Labelling such skills as 'decoding' and 'word calling' seems little more than an elaborate and not so subtle way of denying the students' competence, saying in effect: 'They are not reading.'" (Biklen, 1993: 59) Biklen has also noted that for facilitated communication to be successful it was essential that "instances of communication were not discredited by the facilitators as islands of ability or as noncomprehending use of language", and that "the facilitators did not allow prevailing theories of autism to invalidate the evidence of literacy and competence that they observed." (Biklen, 1993: 45) It may not be coincidence that this behaviour is the direct opposite of that shown by autism professionals to 'hyperlexia'.

The contrary procedure, of removing a disability, is almost unheard-of. The only example known to me occurred in the case of Joubert's syndrome. First reported by Joubert et al. in 1969, this syndrome is a rare genetic condition where "severe mental retardation has been generally accepted as an integral part of the syndrome." (Zeigler et al., 1990) Ziegler

and his co-authors asked whether the mental retardation reported by Joubert and others was the result of a motor disorder masking the potential of the children, preventing a correct evaluation of their cognitive level, describing a case where unexpected and exceptional mental capacities were detected at the age of eight. Such a possibility, Zeigler et al. suggested, “justifies all attempts at fostering communication and bypassing the motor difficulties before conclusions about the existence and frequency of mental retardation in this syndrome can be reached.” (Zeigler et al., 1990: 265) Judging from the absence of dissent on this point, Zeigler’s reformulation of the condition seems to have been accepted. While the syndrome had been known for only two decades, and only forty cases recorded, this re-evaluation nonetheless represents an outstanding and exceptional example of clear thinking overcoming professional (medical) prejudice.

10.5. The professions and disability: power relations

Whatever the attitude of the professional to the person with disability under the preceding headings, it is the nature of professionalism that there is a power imbalance in the professional’s relation with his or her client. With most professions this power imbalance is temporary and partial: a patient’s inferiority to his doctor is operational only in the surgery, to his lawyer only in the court. As mental retardation is an all-encompassing label, seen as expressing information about its subjects in every aspect their lives, the extent of the professional’s power over the life of the client approaches the total:

The ‘difference’ of being labelled mentally retarded tends to *engulf* the person’s whole identity. By definition, mental retardation is not a temporary interruption of an ordinary life: it is characteristic of a total life. And to the extent that only a specialist can understand the ‘difference’, only a specialist can understand *anything* about a mentally retarded person. (Blatt, 1989: 8)

The possession of this power, and the reluctance to place it at risk, may underly some of the attitudes of professionals to paradigm change in this area. Undoubtedly there are professionals in the disability field who do excellent work with the best interests of their students, clients or patients at heart. That said, the material in this chapter provides justification for scepticism about the practices, prejudices and probity of some professionals.

The material presented in this section suggests that there appear to be two primary causes underlying inappropriate behaviour by professionals. The first is an inability to see in which ways people with disabilities are the same as themselves—combined with secondary prejudices and stereotypes this produces some of the cruellest behaviours. The second primary cause is self preservation—preservation in its widest sense, including preservation of power, employment, and professional reputation, including protecting a reputation for infallibility—manifesting itself in a resistance to change and a reluctance to accept correction. The evidence cited above would suggest that reluctance to accept correction, to accept that one is wrong, is behind some instances of professionals concealing or ignoring evidence which conflicts with their publicly-expressed opinions.

In the world of physics it is true to say that to each and every action there is an equal and opposite reaction. This is not true of human affairs: rather, actions and reactions intertwine and impinge on each other. To complete this study of the treatment of people who use atypical communication strategies, the next section will examine their reactions to the treatment they have received.

Section 4. Accounts by those who use atypical communication strategies

The first accounts of what it is like to be deaf were written by deaf people two hundred years ago, but the first accounts of what it like to be mute from birth have just been written, by the first non-speakers to have access to communication and education. As Birger Sellin wrote, they are,

...a new generation of mute people
a whole crowd of us singing new songs
songs such as speaking people have never heard (Sellin, 1995: i)

In this section we hear their voices.

Chapter 11. In their own words—experiences and perceptions of people who use atypical communication strategies.

No disadvantaged group in man's history has improved their lot without being heard. Our situation is no different. (Matthew, 'a voice of Autism, no longer silent', quoted in Reed, 1996: 147)

This thesis has to this point concentrated on the behaviour of society towards people who use atypical communication strategies. Despite their impairments, these people are not voiceless, and their own reactions to their treatment provide an important perspective on their situation. This chapter concentrates on the experiences of people with communication impairments who have lived in the second half of the twentieth century, people whose lives have overlapped those of today's power-brokers and professionals. These accounts fall into two categories—descriptions of systemic treatment, such as that provided by educational or residential services, and descriptions of interactions between individuals. The chapter contains information from published accounts together with information from my own correspondence, interviews, and personal experience. In particular, given my secondary hypothesis that the deaf have come closer to achieving societal acceptance than other groups who use atypical communication strategies, published recollections by people who are deaf are compared with reports by people with expressive communication impairments. The material contained in individual accounts also led me to investigate whether people with expressive communication impairments have organised into groups to work for change, as the deaf did in the 1980s (see 2.4 above), or whether their “peculiarity” still “discourages any group formation whatsoever”, as Goffman found in 1963 (Goffman, 1963: 33-4).

While the accounts given in this chapter provide important insights, they are not the whole picture. Apart from the subjective nature of personal accounts, memories and reactions, it is difficult to know whether an individual's experiences reflect those of a group, and what proportion of a given individual's experiences is represented by specific instances of good or bad treatment. In the nature of things, events which are written down or recounted to interviewers will tend to be more dramatic, and typically more negative, than those which are forgotten or not thought worth retelling, in the same way as a person who drives to work every day does not talk about all the uneventful journeys, but only the traffic jams, punctures and accidents.

Given the varied disabilities and circumstances of people with communication impairments—able-bodied deaf shoemakers, quadriplegic non-speaking lawyers, institutionalised people with autism—it might be expected that their accounts would have little in common. In fact, they are remarkably similar, not just because they have shared similar experiences, but because they also share common perceptions and explanations of the behaviour of people with unimpaired speech and hearing. People with varying diagnoses saw their communication handicaps as being responsible, directly or indirectly, for any mistreatment they received. Those who had multiple impairments, no matter how severe their other physical or behavioural impairments may have been, saw their inability to talk normally as the determining factor in the way they were treated by society. Typically these people expressed a desire to talk rather than a desire to be non-disabled.

11.1. Disempowerment

An over-riding theme in the accounts is the disempowerment which many people with communication impairments, regardless of diagnosis or age, have experienced—often at the hands (or on the recommendations) of professionals, but also in their families and the community at large. The disempowerment was typically associated with an absence of communication, either because a means of communication had not been provided, or because an individual's communication strategy was for some reason unacceptable. As one deaf man observed, "It takes a long time to achieve communication between the deaf and the hearing. It doesn't matter as much to them as to me if they fail to communicate with me." (Sainsbury, 1986: 97)

An associated issue was the relative importance given to the convenience of non-disabled people and the convenience of communication-impaired persons. Hearing parents and teachers wanted to be told that that every deaf child could learn to talk, and sign language was unnecessary (or even harmful), partly because that meant that they did not have to learn it. They overlooked the fact that deaf children could not learn to hear and that regardless of what speech was acquired, two-way communication would still be restricted by the child's deafness. While the invention of the cochlear implant now presents the possibility that at least some pre-lingually deaf children can be enabled to hear and understand speech (Cohen, quoted in Link, 1995: 16), it is also the case that part of the appeal of the implant is its promise finally to absolve the hearing of any obligation to learn sign.

The issue of convenience also arose with communication boards, which are inconvenient for speakers because they have to look at the board

for relatively long periods of time while the user is putting together his or her message. People who use them may have their attempts to communicate ignored or may find, as I have observed, that speakers, even family members, cannot be bothered to use the board and shut it away. Part of the appeal of electronic communication aids is that they reduce the effort and time required of non-disabled communication partners. My experience at Deal Communication Centre has been that while some non-speakers have been able to change from using communication boards to voice-output communication aids and thus escape from dependency, non-speakers who continue to require skilled communication partners have not. In particular, people who require facilitation to use a communication aid may find that their communication is restricted to suit the convenience of speakers.

11.2. Segregation and isolation

Segregation from the community and separation from family is perhaps the most extreme way in which people with communication handicaps are forced to fit the convenience of the non-disabled. While segregation was not unexpected in the accounts of those such as Ruth Sienkiewicz-Mercer who had been considered mentally retarded, it was somewhat surprising to find it featuring in the published accounts of deaf people, even those who grew up after the Second World War.

Of course, children with disabilities were not the only children to be removed from their families. The so-called 'Stolen Generation' of Australia are indigenous Australians who as children were taken away from their families to be reared in 'white' environments, in the form of children's homes or foster families. This practice continued into the 1960s, and while the motives driving the whites who established and

implemented the policy were undoubtedly various—"a murky mixture of racism, ignorance and misguided humanitarianism"—an underlying rationale (however ill-founded) was that the children and society at large would benefit, and that this benefit justified the suffering inflicted on the children and their parents (McRae et al., 1997: 407-13).

A similar rationale may have operated in the case of deaf children who were sent away to residential schools, but the treatment meted out to them, both in terms of the length of the separation from their families and in the discipline imposed on them, resembled that experienced by juvenile offenders rather than that of non-disabled children attending boarding schools. A Mr. Johnstone, educated in England in the forties, reported running away from school twice: "I was picked up by soldiers once on the Lewes road and once on the London road. When I got back I was whipped and given one week on bread and water. I never saw my mother and father for six years."(Sainsbury, 1986: 243)

The recollections of many deaf adults are comparable with the accounts of the Stolen Generation⁴⁵, and of non-speakers who were diagnosed as mentally retarded in childhood. Regarding her time in a retardation institution where all the residents were in nappies, Anne McDonald spelt, "You used to hold off shitting until you just about burst rather than suffer the abuse." (Crossley & McDonald, 1980:17) At the same institution it was common practice for the pudding to be stirred into the main course, and a fellow-resident, Dennis Morris, complained, "Up

45 The Aboriginal Legal Service in Western Australia recorded the recollections of Aboriginal people who were separated from their families as children: "We slept in dormitories with about 20 girls in each of them. If you wet the bed you were flogged and your nose was rubbed into the wet sheet. The food was bad. We had maggots in the meat." (McRae et al., 1997: 407-8)

the nurses. Give mine a taste of mixture [the food]." (Crossley & McDonald, 1980: 167-8)

While Aboriginal and retarded children were devalued by society at large, with the former compulsorily removed from their parents and the latter rejected by their parents, the situation of deaf children was different, in that there was no policy of permanent separation and most were loved by their parents. What the three groups shared was their lack of communicative power, their difficulty in complaining. Some of the Aboriginal children did not speak English and all had been isolated from those who loved them; the non-speaking children diagnosed as retarded were believed to have neither understanding nor communicative capacity; and the deaf children could not communicate with anyone who did not understand sign, often including their own parents (Mason, 1991).

People who cannot complain are more vulnerable to mistreatment, in that potential abusers see them as safe targets, but that alone does not explain the systematic mistreatment suffered by these children. While it is beyond the scope of this thesis to explore the psychological underpinnings of maltreatment, two characteristics the children shared may have predisposed them to abuse. First, they could all be perceived as 'other', as essentially different from their new caregivers by reason of their colour or their disabilities. Second, their atypical communication meant that they did not respond to adult overtures as expected. The deaf children did not respond to speech. Many of those institutionalised as retarded could not speak. Even those Aboriginal children who did know English may have been taught that it was polite to avoid eye contact and not ask or answer direct questions, communication behaviours directly opposite to those valued by their white caregivers (McRae et al., 1997: 369). Distress and

disorientation would have been common to all the children, even if their caregivers did not recognise or acknowledge it. “We cried because we felt abandoned,” Anne Mc Donald recollected. “The nurses didn’t know what to do; they didn’t know we could feel anguish.” (Crossley and McDonald, 1980: 16)

Sainsbury has noted how deaf children suffered similar anguish in their forced separation from family and friends. With only minor rewording, her outline of the reasoning behind the use of residential schools in *Deaf Worlds*, her detailed account of the experiences of pre-lingually deaf adults in England based on interviews collected in the early nineteen eighties, could have been used to justify the removal of Aboriginal children:

Traditionally, much of the specialist educational provision for deaf children has taken the form of residential schooling, away from the influence of parents whose commitment to speech may be doubtful, to ensure socialization of deaf children into the customs and habits of hearing society. (Sainsbury, 1986: 244)

The deaf were to become like the hearing, in the same way as the black were to become like the white. Miss Gratton, whose education took place in the forties and fifties, said⁴⁶, “I went to a residential school for the deaf in the West Country. I never saw my mother for five years. I didn’t like going on the boat from Jersey--I cry, cry, cry. But there were very few other deaf on the island.” (Sainsbury, 1986: 243)

Most of the schools had timetables resembling those of ordinary boarding schools, with short holidays of a few weeks at Christmas and in the summer rather than total separation from the parental home. Even so,

46 Sainsbury uses ‘said’ although most of her informants communicated at least partially in sign, and I do likewise in reporting communication produced with communication aids.

many of those who had attended the residential schools appear to have been educated in an atmosphere of considerable violence (Sainsbury, 1986: 243). Mr Wilcox, who was educated in the fifties, recalled how staff “were very strict at school—we were sent to bed with no supper. I believe it’s much better now but then there was a lot of cruelty—flogging. Some of the mental children had very bad punishing.” (Sainsbury, 1986: 244) Mr. Murdoch, also educated in the fifties, reported, “They were very cruel at Blankton’s. There were violent beatings”. Miss Britton, from the same generation, said of her residential school, “The staff were bad. They threw things at us and beat us. They hit us in the face with things. They were cruel ... I was often sick.” (Sainsbury, 1986: 243)

It did not seem as if much had changed since the twenties, when an elderly woman remembered that her teachers’ “favourite punishment was to lock us up. I will never forget it. And I was treated as stupid by my parents. We only had one holiday a year. I was frightened and miserable.” (Sainsbury, 1986: 244) A Mrs. Owen reported similar experiences in the thirties: “Some [teachers] were cruel. For the slightest thing you were sent to bed with no dinner. We were up at five in the morning doing the cooking and the cleaning.” (Sainsbury, 1986: 244)

Only a tiny minority of those interviewed by Sainsbury reported that they had enjoyed themselves at their residential schools and most felt deeply antagonistic towards their schools. By contrast, one woman had both good and bad memories of her school experiences in the fifties and sixties. Taken to the Derby School for the Deaf at the age of five, Christine Monery was kept at school for a month before being allowed any contact with her family. “I think it was cruel; I was terribly frightened and unhappy. I couldn’t understand why my parents had deserted me. I cried

all the time.” (Monery, 1991: 82) The school, like virtually all deaf schools in England at this time, was oralist. “There were no deaf teachers and signing was forbidden.” (Monery, 1991: 83) Later Monery became head girl, and as an adult she advised parents to send their children to a deaf school, ironically because “the school community builds strength and confidence, especially through the shared communication of sign language.”(Monery, 1991: 83) So, despite the fact that signing was forbidden and her teachers did not sign, it was access to sign language which defined her schooldays and made them a positive experience.

Monery’s is one of a number of accounts in *Being Deaf: The Experience of Deafness* (Taylor and Bishop, 1991) which describe similar experiences: attendance at schools where sign was forbidden, enormous stress placed on the acquisition of speech and lip-reading, and, frequently, failure in the classroom. *Being Deaf* opens with a poem written in 1974 by William Madsen, who later became Associate Professor of English at Gallaudet:

What is it like in a corner to stand,
 Though there’s nothing you’ve done really wrong,
 Other than try to make use of your hands
 To a silent peer to communicate
 A thought that comes to your mind all at once?

Madsen concluded, “You have to be deaf to understand.” (Madsen, 1991: xiii)

Riki Kittel, in a passionate defence of her use of total communication (sign and speech) with her profoundly deaf young son, makes the obvious point that choosing not to use sign language “saves the parents the necessity of learning some sign” and means that “teachers need not learn to sign”. She contends that, as until recently most English teachers of the deaf were trained at Manchester University, which espoused

oralist techniques, and were not encouraged to learn sign, this affected the advice they gave to parents of newly-diagnosed deaf babies (Kittel, 1991: 60).

Certainly many hearing parents, having been told that signing was inferior, did not sign and were hence cut off from communication with their profoundly deaf children. Clive Mason wrote that his parents “told me off for signing” and “told me I was not allowed to sign”. When he went home he wanted to get back to his residential school because “at the school I had full access to communication” though the teachers “didn’t sign to me in the classroom and I didn’t absorb much in the teaching situation” (Mason, 1991: 84). Not being allowed to communicate with one’s parents does seem like the ultimate disempowerment; however the parents were doing what they had been told was best. Lorraine Fletcher, mother of Ben, was told “*too much signing will make him lazy and prevent him from learning to speak*” (Fletcher, 1991: 77, emphasis in the original), advice she later rejected⁴⁷.

From one point of view the insistence on speech could be justified, in that, as Sainsbury notes, relatives were more likely to have on-going contact with deaf people who could speak and lip-read: “the greater the reluctance or inability of deaf people to use voice the greater was the likelihood of complete loss of contact with relatives outside the home”, and the better deaf people lip-read “the more likely they were to maintain family contacts.” (Sainsbury, 1986: 211) This was a predictable result of the common tendency to place responsibility for communication solely on

47 American children suffered as much as English children from their inability to communicate with their parents. “You used to cry all the way home [from boarding school] on the train every summer”, one adult said (Becker, 1980: 32).

the deaf child. Not only parents but many siblings never learnt any sign. "My two brothers and sisters have never signed," Mrs Glending told Sally Sainsbury. "But I go for holidays to my son and daughter-in-law. They're very good to me. They sign and so does grand-daughter." Mr. Fulton reported that "My brother and sister ... don't sign--they never did. They speak and I lip-read--I understand." (Sainsbury, 1986: 205) Miss Ayers, aged 35, who lived in a half-way psychiatric hostel, said: "My mother signs a little bit, but my father doesn't know any signs, and nor do my brother and sister. I find I can talk a little bit to my mother." (Sainsbury, 1986: 187)

In these circumstances it is not surprising that many deaf people reported feeling isolated even in their families. One of Sainsbury's informants noted that her hearing friends and family "have no sympathy with the deaf. They talk, talk, talk to each other. Ask 'What?' One word to explain all that talk." (Sainsbury, 1986: 205) This isolation was exacerbated for people who were not living in their own homes. Another informant reported having "a chat twice a week when a particular care assistant comes in. I find it lonely." For Mr Wilson the problem was that the "only way I can have a chat is by writing usually, and they don't often do that." (Sainsbury, 1986: 134) A hospital resident commented "I can't talk to anyone here: the staff don't know sign....The hearing don't bother with the deaf." This sentiment was echoed by another resident who complained that "The hearing don't show any interest in us," after reporting that the only hearing person he could converse with was the occupational therapist (Sainsbury, 1986:95).

While some of the deaf interviewed by Sainsbury acknowledged that their own lip-reading or written communication skills were a problem, and

the lack of signing skills among the hearing was an obvious barrier, the “major obstacle” to communication, according to Sainsbury, was generally held to be the “impatience of the hearing.” (Sainsbury, 1986:97) This was an issue which hearing non-speakers also raised frequently: “Half of the time I go to communicate some of the staff say ‘What the hell do you want?’ or ‘Get lost’ or ‘I haven’t got the time for that damn spelling board.’ Some people have asked me questions and walked away before I point to a word to answer.” (Viggiano, 1979: 4)

Another complaint made by both the deaf and the hearing was that many people correlate speech clarity or fluency with intelligence. As Robert Rourke found:

Some hearing people voluntarily told me that my speech was very good compared with other Deafies such as “Oh, you must be very smart because you can talk very well”, “Why can’t other Deaf people speak like you?”, “I can’t understand your Deaf friend’s voice”. And I nearly VOMITED....I had to straighten them out that it is not complimentary and comparing with other deaf people’s oral skills is very unfair and sickening and it is very wrong to judge the d/Deaf’s intellectual level by how good their oral skills are. I admit that some of my hearing family members have made some of these remarks. Boy, I was tempted to jump on them and stuff their mouth with soaps! (Rourke, 1995)

Indeed the deaf could strike this prejudice twice, in relation to their speech reception as well as their expression. One woman told Sainsbury, “Because I find lip-reading difficult everyone treats me as if I’m mental.” (Sainsbury, 1986: 102)

Presumptions about intelligence may explain why a significant proportion of the deaf adults interviewed by Sainsbury were living in ‘subnormality’ hospitals. As many as half were there because families could no longer provide care for them and some had no handicaps other than deafness (Sainsbury, 1986: 111). She cites Mr. Jones, age 32, who had been admitted to hospital at the age of 12 when his mother developed

tuberculosis and could no longer care for him, and Mr Goad, age 36, who had entered hospital at the age of 16 when his mother had a new baby and considered that she would be unable to look after both of them. Both Jones and Goad were institutionalised in the mid sixties. Whether they were actually assessed as mentally retarded by psychologists who knew no sign or whether assessment was considered irrelevant is unclear.

What is clear is that their admission to long-term care to suit the convenience of others parallels the admission to similar institutions of non-speech children who were viewed as mentally retarded. Whatever the rationale for removing young deaf (or Aboriginal) children from their parents, the rationale for the residential placement of non-speaking children could scarcely have been the improvement of the children, given the lack of services in most institutions. For example, St. Nicholas Hospital in Melbourne, an institution which opened in 1964 to house 160 children with multiple disabilities, very few of whom had any intelligible speech and none of whom spoke fluently, provided no speech therapy or education for its first ten years of operation and had a death rate of almost ten percent a year (Crossley & McDonald, 1980:20-29).

McDonald, who interpreted *Frankenstein* as a pioneering study in disability, has written eloquently about her 14-year incarceration in St. Nicholas:

I went into an institution that saw its role as sheltering society from the sight of monsters. Only once in ten years did I go outside its walls, and that was because there was a strike....Never being released, I had no idea what the world outside was like; I had to learn about it as the monster did, by listening to people talk....The nurses viewed us as the villagers viewed the monster, as the work of the devil. Rules were laid down to prevent them using folk magics to exorcize us, rules that were often broken. New residents were viewed as dangerous until they had been operated on by a witch. The speaking children, who had no words to speak, were feared because they might be cursing you in the devil's language.

Sputum with human form, I heard you normal people tell each other. When I count my injuries, I say with the monster, “Was there no injustice in this? Am I to be thought the only criminal when all human kind sinned against me?...I, the miserable and the abandoned, am an abortion, to be spurned at and kicked and trampled on. Even now my blood boils at the recollection of this injustice. (McDonald, 1993:4)

Other institutionalised non-speakers who obtained a means of communication have also described their institutionalisation in terms of imprisonment. Ruth Sienkiewicz-Mercer, author of *I Raise My Eyes to Say Yes*, recollected:

In May of 1962, at the age of eleven, I began my sixteen year jail term [at Belchertown State School, a US residential institution]. Many of those eleven years were spent in virtual isolation. Even though there were many people around me, no one tried to communicate with me. Finally an attendant noticed that I laughed when she made a joke, and that my facial expressions had meaning. Her simple observation proved to be a real turning point in my life, because that day was the day that people began to speak to me and to work with me on my communication skills. (Sienkiewicz-Mercer, 1992: 1)

Sienkiewicz-Mercer adds that the increased human contact made her final five years at Belchertown a little more bearable, “although it still wasn’t a picnic”. (Sienkiewicz-Mercer, 1992: 1)

People writing about an institution which they still inhabit give different accounts. Joseph Deacon’s autobiography, *Tonguetied*, is notable for its total lack of criticism and for its repeated praise for those currently providing services at the institution. This may be due to the fact that the manuscript was reviewed by staff before publication. The austere nature of the place is revealed by some of the events Deacon describes with pleasure, such as the annual access to his best friend and sole communication partner during three years spent in the TB ward, and ‘special treats’ such as milk drinks and eggs (Deacon, 1974: 35); and it is unlikely that the residents were completely spared the mistreatment endemic in institutions. It is also possible that Deacon had largely internalised the belief of the society

around him that he was severely subnormal and that he should therefore be grateful to those who kept him alive. He certainly saw his disability as a cause for apology:

I wanted to sit in the back row [at the cinema] so that my head, which I cannot keep still all the time, would not annoy anybody, but they were all full up so I had to sit in the row at front. [My attendant] told the people behind that I was a spastic and they were very nice and did not mind a bit. (Deacon, 1974: 19-20)

A more direct explanation for this lack of complaint is found in a speech by Jim Viggiano, also an institutionalised non-speech person with cerebral palsy:

Another form of communication frustration is that I leave letters in my typewriter overnight since it takes me between 2 and 3 days to type a page with one finger. If people don't like what is being expressed it could vanish over night and Nobody knows Nothing. All they say is "We aren't responsible for your stuff," Does anybody here really know how much of a psychological impact it is to find a letter gone from your typewriter after spending days typing it then having Nobody to accuse of taking it? If you do know how psychologically frustrating it is, then tell me about it! It's a wonder that this speech hasn't vanished yet since the staff isn't fond of it. (Viggiano, 1979: 4)

It is difficult to complain about people on whom you are dependent for your next meal, and this difficulty is exacerbated if your complaints have to be channelled through those same people. Nonetheless, Viggiano's speech was frank, both about the institution and his audience of professionals:

It's a great honour to be addressing such brainy people who have Ph.D's, B.A.s, and MDs after their names. But with all your years of studying there's not a book that tells how frustrating it is to have a life or death matter to communicate and a so called 'normal' person just talks away before having a chance to tell him that one of his psychotic patients was playing with matches while there were 5 other patients in the room who can not get out of the way. I just sat by the nurse's desk until a person finally paid attention and took the matches. A good 5 minutes went by and 6 people could have been burnt. (Viggiano, 1979: 4)

“But what the hell,” concludes Viggiano, “I’m just a dumb C.P. ... who isn’t supposed to have constructive thoughts of his own.” (Viggiano, 1979: 1)

11.3. Individual misconceptions

Unsurprisingly, many non-speech people desperately want to speak. The views of some are based on experience of the power of speech. ‘Harriet’, who has Down syndrome, and was one of the adults who used facilitated communication at Deal Communication Centre in the late 1980s, spelt, “I LIKE TO TALK. YOU GET MORE RESPONSE IF YOU TALK.”⁴⁸ She has some speech and is able to use it to attract attention and make everyday requests. Others attributed all their problems to their lack of speech, and were reluctant to accept any lesser form of communication. ‘Fred’, who has Phenylketonuria (PKU), spelt, “TALKING IS WHAT I REELY WANT TO DO I WANT TO TORK [I NEED A] TORKING COMPUTER I WANT TO TORK LIKE OTHER PEEPLE I BELEVE MY PROBLEMS ARE DU TO NOT BEING ABLE TO TALK.” (Crossley, 1997: 190, original spelling) Even those who asked for augmentative communication saw it as being no substitute for speech. ‘Lou’, who had been institutionalised with a diagnosis of severe mental retardation associated with PKU, spelt, “GIVE ME A TYPEWRITOR I HATE NOT BEING ABLE TO TORK HOW MUCH IS A CANON [communicator] I’LL NEED ONE I’M SICK OF NOT BEING ABLE TO TALK I STILL GET UPSET WHEN I CANT TALK TO PEOPLE”. ‘Jill’, a teenager with autism, also placed a high value on speech. “I PUSH WORDS OUT, BUT THEY AREN’T WHAT I WANT TO SAY I LIKE TYPING BUT I WISH I COULD TALK I HAVE TO TALK LIKE OTHER PEOPLE BECAUSE I WON’T

48 The opinions in the following paragraphs are those of adults who attended DEAL Communication Centre in the late 1980s and typed with facilitation. The quotations are taken from their case notes.

HAVE ANY FRIENDS IF I DON'T TO TALK IS MY GREATEST WISH". Jill did talk, but the Deal speech pathologist observed that her speech was generally unintelligible, containing a lot of repetition and echolalia.

The communication of people who had always been viewed as mentally retarded could show low self-esteem. Fred's early verbal expression included the spelled messages, "I CANT TALK IM SAD I CANT TALK I'M SICK OF BEING A BABY I NEED HELP." Not surprisingly, at that time he believed the assessments that had been made of his capacities— "I [k]NOW IM RETARD[ed] I CANT STOP MYSELF HITTING MY HEAD I NEED TO HURT MYSELF IM GASTLY." He was, he suggested, worse off than Anne McDonald, even though she was more physically handicapped. "MY LIFE IS WORSE THAN ANNIES SHE CANT HIT HER[self] HOW DOES SHE COPE WITH NOT TALK[ing]? LAST TIME I SAW HER SHE SEEMD HAP[py]". (Crossley, 1997: 188-9)

'Anna', who was born in the fifties and has little speech, saw her communication difficulties as confirming people's view of her disability. "Having Down Syndrome puts you in a pigeon hole," she declared. "Getting out is impossible unless you are speaking and writing like a normal child." (Interview, 4 Sept. 1993) This pigeon-holing of children with Down syndrome was described by the father of the author of *The World of Nigel Hunt*:

"My wife and Nigel and I went to see this 'expert', who was to help decide our child's fate. The first thing the good lady said to us--in Nigel's hearing, of course--was "Oh, yes, a little mongoloid. Quite ineducable. Do you want him put away?" Had we been more easily impressed by experts...." (Hunt, 1967: ix)⁴⁹

49 Of course, even people who can talk fluently find it hard to leave the stereotypes associated with Down syndrome behind. Mia Peterson, a 23-year-old with Down syndrome, designed a survey on language learning, wrote the grant, got it funded, carried out 8

Speech, or the lack of it, was so defining of personhood that people with very severe physical handicaps still rated their communication difficulties as their most severe disability. Sienkiewicz-Mercer noted that:

I have found that the most difficult aspect of my disability has been my lack of speech. People in the community at large who remain ignorant of the abilities of people with disabilities, have a tendency to equate one's speaking abilities with one's intelligence. The misconceptions on the part of those around a non-speaking person can be both painful and dangerous to that person, as it usually means that he or she will be treated in a sub-human manner. (Sienkiewicz-Mercer, 1994: 3)

McDonald similarly emphasised the importance of speech:

Deceiving yourself was the hospital pastime. You imagined you talked perfectly. We had never walked: it did not look like we ever would. For busting out of confinement, speech seemed more desirable. We knew there were kids in St. Nicholas who could walk, but none who could talk properly. All our imaginings depended for their fulfilment on speech. (Crossley & McDonald, 1980: 19)

'Anna' could walk, but she still considered that "Not being able to talk is worse than not being able to walk." She thought the worst of not being able to talk fluently was having people "think you're stupid. I couldn't go to [ordinary] school because I couldn't talk." (Interview, 4 Sept., 1993)

11.4. Individual ignorance

The varying ways in which speakers underestimate or misdiagnose people with severe speech impairments have been summarised by Bob

workshops, interviewed 54 people with Down syndrome and 4 with other disabilities and wrote the final report. When she did a poster session at the American Association of Mental Retardation the professionals who had come to see what their colleagues were doing found Mia in the middle of the display, saying that she was a principal investigator on a research project to look at communication. "Some people went pale and walked away. Some were overjoyed." (Meyers, 1997, personal communication)

Counsell, who has severely dysarthric speech. He described four different responses provoked by his atypical communication:

Whenever I meet someone new ... if I don't speak to them I offend them....If I do speak to them they react in one of four ways; they look at me in horror and think that I am mad, they shout at me thinking my impeded speech means I am also deaf, they hear my voice and begin to ask those around me questions which should be asked of me, or they speak to me as they would to a baby or a beloved family pet. (Counsell, 1982: 57)

This perception of non-speakers as insentient was raised frequently. It was harder to shake off when the individual was in an environment in which incapacity was expected and it was bolstered by professional opinion:

A newly graduated psychologist at Lakeville performed "intelligence tests" on me, despite the fact that he didn't know how to communicate with me. He determined that I was an unteachable imbecile. This diagnosis proved to be disastrous for me. He and those around him were so sure that I had no mental powers, that they simply dismissed what my parents said about my communication skills. (Sienkiewicz-Mercer, 1992:1)

Writing about community attitudes to people with disabilities in 1981, Maree Ireland remarked that, "especially with non-verbal people, there is still the assumption that we are people with less intelligence than themselves....Like that saying "Innocent until proven guilty", we should adopt a saying "Intelligent till proved un-intelligent" without the need to prove it." (Ireland, 1981: 2) In 1996 Ireland, now a lawyer, had the opportunity to explore current assumptions when she and some other communication aid users attended a memorial service for nine residents of a retardation institution who had died in a fire. Being the most obviously disabled group present, Ireland and her colleagues (who were all either tertiary students or graduates) were presumed to be residents of the institution and a number of strangers came up and welcomed them with gracious condescension. Two people patted Ireland on the head. (Personal observation, May 1996)

Being patted in this way is a common experience. Viggiano recounts how perfect strangers would look at his spelling board:

and the first words out of their mouths are “How do you play games?” or they say “Can you spell cat?” or they say “Where’s the letter A?” Some people talk like I was deaf. And some people just pat me on the head and say “You are a good little boy.” I point to the sign on my board that says “I talk by spelling words.” Then I point to the sign next to it that says “DON’T PATRONIZE ME!” (Viggiano, 1979: 3)

Anne McDonald was patted so often that she started to wear a t-shirt reading “Pat me and I’ll bite your hand off!” Presumably the pater wants to show empathy, but perceives the disabled person as so significantly different that ordinary rules of social interaction no longer apply. Certainly one is put in mind of Bob Counsell’s feeling that he was a ‘beloved family pet’.

Another of the reactions that Counsell reports, the assumption that impaired speech indicates deafness, is mentioned in many accounts:

They seem to assume that if someone is non-speaking, it is because his or her mind is muddled, and that, since an individual is unable to talk, he or she must also lack the ability to hear. I wish I had a dollar for every time someone spoke to me slowly and loudly, while I sat there wishing I could stand up and tell them that English is my native language, and I have never had a hearing aid. (Sienkiewicz-Mercer, 1994: 4)

Deafness was also mentioned when ‘Anna’, an adult with Down syndrome, was asked how people talked to her. She replied, “They don’t talk to me—they talk to Mum.” When she was asked if people she saw more often spoke to her she responded, “Not much. Some people are OK. It’s hard if you can’t talk [much]. Mostly I shut up. Most people say “Hello” but nothing else. They need to realise being dumb doesn’t mean you’re deaf.” (Interview, 4 Sept., 1993)

Rick Hohn, who has cerebral palsy and lives in the United States, found that even when he went to the doctor he was either ignored or treated as deaf:

My pet peeve is going to the doctors and having them totally ignoring me. They talk to the person that brought me. My attendant, that is Spanish and knows little English, tries her best to explain to the doctor that he can talk to me and I will respond. I prepare what I want to say on my DynaVox so I don't waste his time. It does little good even if my attendant ducks her head so that the doctor will talk to me, but he either still ignores me or starts yelling at me as if I were deaf. This happens even when I don't bring anyone with me. (Hohn, 1997)

Evelyn Moseley, an Australian woman who lost her speech after an attack of encephalitis, found that more than her communication was disregarded:

Meeting new people ... was a frustrating experience....Even when they became aware of the communication board they would direct the conversation to the person with me, not to me personally, and they avoided eye contact. This was when the impact of the communication barrier really hit me. I had become invisible. (Moseley, 1995: 63)

Sometimes it was better to be ignored—virtually all non-speakers experienced people talking about them in their presence. “It is so incredible that the instant you are not able to verbally communicate, people tend to ignore you and talk over the top of you.” (Moseley, 1995: 64) It was as if non-speakers were believed to be uncomprehending or unfeeling, if not deaf. At the age of 12 Anne McDonald heard a nurse say loudly that she would die from starvation in the next six months; at age 16 she was introduced to a middle-aged woman who said “If it was a puppy you'd knock it on the head, wouldn't you?” (Crossley & McDonald, 1980: 21 & 82) At age 21, after a television program screened a story about her (*Sixty Minutes*, 21 Nov., 1982), a viewer wrote in to say her life was worthless and she should be killed. The interesting thing about this last comment was that the producer had no hesitation in putting it to air (*Sixty Minutes*, 28 Nov., 1982), an action which would be almost inconceivable if

McDonald belonged to another devalued group—was black or Jewish, say. After she objected strongly to the show's producer, McDonald was allowed to respond on air, and *inter alia* typed "After 60 Minutes correspondent said I should be killed I realised what a long way disabled people have to go before society accepts them." (*Sixty Minutes*, 12 Dec., 1982)

'Anna' also heard strangers make inappropriate remarks, but was defended by her mother. When people asked what was wrong with her and were told Down syndrome, they said things like, "Oh dear, has she got any life? How long will she live?" till her mother said, "Shut up!"; or, "Why isn't she in a home?" to which her mother replied, "She is—mine!" Anna's view was that "Heads need reading. They should learn to save their questions till I'm not there." (Interview, 4 Sept. 1993)

Unlike Anne and Anna, people who are deaf cannot hear any comments made about them, but they can certainly observe expressions and gestures and they sometimes suffer from the insensitivity of speakers in other ways. Two thirds of Sainsbury's informants reported that hearing people had made jokes at their expense when they were signing, and she found that:

The widespread need to communicate by a method so demonstrably different from that of the mainstream of society presented for a minority an enormous hurdle to communication. For a few—5 per cent—to be observed signing by the hearing caused enormous embarrassment and no more. But for another 12 per cent, that embarrassment became so acute that they stopped signing. Nevertheless, for the majority of deaf people communication was so essential that they carried on regardless of the impression they made on and the ridicule of hearing onlookers. (Sainsbury, 1986: 89)

In the light of deaf experience, Sienkiewicz-Mercer may be over-optimistic when she asserts that possession of a communication device will lead to social acceptance because "those who currently hold the opinion

that someone who can't talk can't think will have no choice but to recognize our intelligence and humanity, once we start talking to them.” (Sienkiewicz-Mercer, 1994: 5) Certainly Paul Marshall, a Canadian with cerebral palsy, discovered with disappointment that obtaining a ‘voice’ was not enough, that he was still handicapped by the relative slowness of communication aid use:

When I learned Bliss[ymbols] I thought all my problems would be solved because I was given the gift of a way to communicate. I did not know that I would still have to overcome mountains of trials that come with being a handicapped person living in a so-called normal world...Our socialisation, our problem-solving, and how we adapt, is difficult in a world that requires its population to verbalize rapidly. (Marshall, 1994: 7)

Overall, the accounts of people like Marshall indicate that people with communication impairments suffer from stereotyping, systematic disempowerment and individual ignorance. In the terms of this thesis, it is perhaps surprising that the three groups—the signers, AAC users and FC users—report such similar experiences. The fact that deafness has been recognised as a specific impairment for more than two centuries, and that numerous deaf people have been successful in education and employment, has had remarkably little impact on the behaviour of many hearing individuals. The overwhelming impression left by the accounts considered in this chapter is one of ignorance and insensitivity, associated with a presumption that speech and intelligence are inextricably connected, and an associated belief that it is acceptable to behave badly to people with less intelligence than oneself.

11.5. Talking politics

In the light of the reactions of atypical communicators to the treatment they receive and their reactions as individuals, it is important to consider whether their treatment has provoked any group or political

action, or whether they are so disempowered that no organised or effective response has been possible.

A significant social movement becomes possible when “there is a revision in the manner in which a substantial group of people, looking at some misfortune, sees it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable to society.” (Driedger, 1989: 119) In the second half of the twentieth century the deaf community has produced many representatives who advocate for deaf people in general and complain of prejudice and discrimination—who perceive their problems as stemming from injustice rather than simply being the way things are. The resultant development of deaf activism has been described in Lane (1984), and its flowering, the revolt at Gallaudet, in Sacks (1990).

Not only has action by the congenitally speech-impaired not been documented in the same way, its absence has been remarked. In *Stigma*, Erving Goffman suggests the sociological study of stigmatised persons is “usually concerned with the kind of corporate life, if any, that is sustained by those of a particular category.” He goes on to cite “speech defectives” as a group “whose peculiarity apparently discourages any group formation whatsoever” (Goffman, 1963: 33-4). In the 1960s, before the introduction of Blissymbols and the development of electronic communication aids, this may have been a fair comment, as without advances in communication techniques and technology it was impossible for non-speakers to undertake group action. Any groups of “speech defectives” would have been comprised of individuals like Joseph Deacon whose dysarthric speech was not understood by outsiders, and who were therefore not recognised as communicating.

By the 1980s enough non-speech people had obtained a means of verbal communication for it to be possible for them to form their own organisations. Anne McDonald and Evelyn Moseley, both quoted in this chapter, have been associated with the establishment and running of the Communication Aid Users Society (CAUS), an activist advocacy group for people with communication impairments based in Melbourne. When CAUS started in 1981 it was reportedly the first organization set up by and for non-speakers anywhere in the world, a milestone in the development of group identity. Interestingly, though perhaps unsurprisingly, it has remained an organization for those with severe communication impairments associated with severe physical impairments such as cerebral palsy and acquired brain damage. While there is nothing in its rules excluding people with diagnoses such as autism or Down Syndrome, the people who are most likely to use facilitated communication, this population has shown no interest in joining CAUS, despite efforts to recruit them (Crossley, 1995: 21). This appears to support the thesis that traditional AAC users are not only further along in the fight for recognition, but further along in their participation in regular political processes—forming a lobby group, holding meetings and so on. The 1995 CAUS conference in Melbourne was a landmark—the first national conference in Australia and possibly the world to be held *by* communication aid users rather than *about* or *for* communication aid users (O'Brien, 1995: iii).

During the 1980s CAUS tried to raise the profile of Australian communication aid users and to advocate on local issues, but it was not until the nineties that aid users moved to establish a right to communicate. In the United States, AAC user Bob Williams tried to make the connections necessary to create a movement for non-speakers' rights

through *Talking/Politics*, “an informal newsletter for people interested in thinking together about communication rights”, set up in 1989 by Mayer Shevin, a speaking disability activist:

In the words and deeds of Anne McDonald and others with severe disabilities worldwide, we can hear the makings of a clarion call if we choose to listen. It is a clarion call to action similar to one issued nearly a decade ago. In 1979, the Center on Human Policy helped stir many of us to action by calling for a universal community imperative. Ten years later, the typical life experiences of people labelled severely or profoundly disabled demand that we take another step closer to true community.

One way we can do this is by issuing a communication imperative which affirms and asserts that: Every person regardless of the severity of their disabilities, has the right and the ability to communicate with others, express every day preferences and exercise at least some control over his or her daily life. Each individual, therefore, should be given the chance, training, technology, respect and encouragement to do so. (Williams, 1990:8)

Williams rooted his demands in the discourse of the American civil rights movement:

December 15, 1991 will mark the bicentennial of the ratification of the Bill of Rights and its First Amendment guarantee to free speech. In the nearly two hundred years since the First Amendment’s adoption, freedom of expression has gone on to be widely recognized not only as a fundamental right but a prerequisite to the full enjoyment of all other civil and human rights. However, for far too many Americans, freedom of expression remains an unrequited right at best: an American ideal which has yet to be fully realized. (Williams, 1991:3)

He sought to build an organisational base for communication rights by mobilising “persons with severe speech disabilities to work in close alliance with our families, friends and all other supporters of the First Amendment throughout the nation to realize free expression as a real right at long last”. (Williams, 1991:4)

While *Talking/Politics* ceased publication the same year, the situation of non-speech people in the U.S. continued to move along. McDonald herself gave a presentation at the 1992 TASH conference in San

Francisco entitled *The Right to Communicate*, in which she proposed the establishment of “a right to communicate in formal situations such as courts, hospitals and schools”, because without “such legally enforceable rights, people without speech will be at the mercy of decision-makers who can arbitrarily refuse to disallow communication.” (McDonald, 1992, 3) Her words formed the basis of a resolution passed by TASH in 1993 and widely-promulgated in 1994 (TASH Newsletter, Dec. 1994: 2). In 1993 Rick Creech joined with a small group of AAC users in Pittsburgh to discuss employment options. In 1997, 87 non-speech people, many of whom have jobs, attended the fifth annual Pittsburgh employment conference (Sutton, 1997). Bob Williams is now the U.S. Commissioner for Developmental Disability and, ironically, is in the position of having to articulate government policy on facilitated communication (Williams, 1997).

Recent developments in mainstream communication technology, particularly in Internet access, have allowed non-speech people to connect to an extent which has not been possible previously. There is now an international community of articulate, active non-speakers who interact through ACOLUG, the Augmentative Communication On-Line Users Group. Compared to the deaf community, most non-institutionalised communication aid users probably have relatively limited social contact with each other because of the mobility impairments which are often associated with severe communication impairments. While every non-speech person does not have access to the Internet, more AAC users are already connecting through ACOLUG than have ever been able to meet together, and they are sharing information and discussing advocacy issues around the world (personal observation, August 1997). It will be

interesting to see whether this increased interaction fosters “group formation” during the next decade, followed by increased political activity.

11.5. Achieving inclusion

All people with communication impairments share an intense interest in developments in communication technology, which can either disempower them, as the introduction of the telephone disempowered the deaf a century ago, or empower them, as the Internet does those non-speakers who have the equipment and literacy to access it. In Australia, the relative social and political situations of deaf people, AAC users and FC users seem to be encapsulated in the development of the telephone relay service, the Australian Communication Exchange (ACE), which allows people with hearing or speech impairments who use telephone typewriters or computer modems to make phone calls to hearing, speaking people who do not have special equipment.

The telephone relay service started 3 years ago after intensive lobbying, including action under the Disability Discrimination Act, by members of the deaf community (Link, 1995b: 35). While the impetus certainly came from the deaf, who had a number of strong lobby groups, non-speakers were able to ride on their coat-tails, as it was evident that a service which would assist more than one disability group was a more saleable proposition politically (Jan Ashford, CAUS, personal communication 1995). Three years later many people with hearing impairments are on the ACE staff, but not one AAC user, although after CAUS raised its concerns in 1996 an AAC user was nominated to the ACE board (Jan Ashford, CAUS, personal communication 1996). In July 1997 the Board comprised four persons ‘with hearing impairment’, three ‘Deaf’, two persons ‘with speech impairment’ and two persons with no disability

specified (ACE, 1997: 6). While relatively few AAC users are believed to make use of ACE at this point, probably because they do not have the necessary hardware, the desire to do so is there, and AAC users do see the service as relevant to them (Melinda Smith, CAUS, personal communication 1996). I am not aware of any facilitated communication users who have contemplated being phone users in their own right rather than having others relay messages for them, although several do use e-mail (FC-List, E-mail, 1997).

The educational achievements of members of the three groups—signers, AAC and FC users—reflect their histories and affect not only their status in the community but also their activism. Broadly, the most academically advanced among sign users are professors, the most academically advanced among AAC users have university degrees and a few have postgraduate qualifications, while the most academically advanced among FC users have completed secondary school. While the first FC users are in the tertiary system and one has completed a degree, these are exceptions—progress through the ordinary school system is not yet generally accepted as possible for this group. Successful lobbying and networking, especially for non-speakers, require academic skills if not formal qualifications, so one would expect activism to follow on education.

Sue Rubin, an FC user who has graduated high school in Los Angeles and has taken as her role model farmworker organiser Cesar Chavez, may lead the way. She uses e-mail to communicate with other people with autism and writes that, “In using Chavez as a model, I must organize autistic people who are able to communicate, to advocate for our human rights, and bring abusive situations to the public light.” She is realistic in her recognition “that people will not make changes in the

condition of the disabled only because it is the right thing to do”, but asserts that “Advocates can fight a world indifferent to our needs.” (Rubin, 1995:18-19) Rubin, who was once assessed as having an IQ of 24, recently won a major university scholarship in open competition and received a letter of congratulation from the President of the United States, Bill Clinton (Clinton, 1997). Not only her words but also her achievements are agents for change.

Twenty-five years ago Bob Williams, Rick Creech and other successful AAC users and advocates were the same age as Sue Rubin is now. They blazed a trail which many other people with severe communication impairments have followed. Rubin and others like her may do the same for those who need facilitation in order to communicate. If they do so, they will enable people who use facilitation to be included in the ordinary systems of society to the same extent as people who use sign or other augmentative communication strategies.

Nonetheless, as this chapter has shown, inclusion does not necessarily equate with acceptance. After two centuries, people who are deaf may still be ridiculed for using sign, and some are too embarrassed to sign in public. Clearly, more public education is needed for their communication to be fully accepted. This was a surprising finding, and suggests that those who use even less familiar communication strategies are unlikely to attain full acceptance in the foreseeable future because, as Commissioner Williams commented in 1994, “many still find it difficult to believe people with speech disabilities like my own have anything to say or add to life.” He went on to observe, “It is this perception and the stereotypes and prejudices which fuel it that we need to challenge.” (Speech quoted in Lapos, 1996: 44) How far the different groups of

atypical communicators have progressed in demolishing these stereotypes and prejudices, and whether they have been able to find a path around those which remain, will be considered in the concluding chapter.

Conclusion

As this study shows, atypical communicators are currently seen as belonging to one of three groups: hearing impaired, physically impaired, and intellectually impaired. The study has attempted to document the manner in which, and the extent to which, the nature of each group's communication problems has been recognised and alternative communication strategies developed. It starts with the formalisation of sign languages and their use by the deaf during the past two centuries, continues with the development of non-speech communication techniques and technologies for use by people with neuro-motor impairments thirty years ago, and concludes with the introduction of facilitated communication to people diagnosed as intellectually impaired in the last decade. The account also examines any changes in status which have occurred for each diagnostic group following on the attainment of a means of communication, and the extent to which each group has succeeded in attaining full participating membership of the wider society.

In relation to deafness, my thesis began with the emergence of a favourable situation during the French Enlightenment for the development of communication between the deaf and the hearing. It proceeded to report on the manner in which the deaf community's attempt to take charge of their own language was then suppressed due to the ruling ideology of degeneracy, and concluded with the deaf community's re-assertion of their right to be in control of their own language, lives and institutions in the modern era of civil rights. In Habermas' terms, they have made use of their competence to speak and act.

This study suggests that expressive impairments associated with severe physical handicap, in particular cerebral palsy, place greater barriers than deafness in the path of political organisation. Nonetheless, while the history of communication intervention with this group is very short (scarcely three decades) and is certainly not yet complete, the start of what appears to be a sequence similar to that of the deaf can already be discerned. The first people with severe communication and physical impairments from birth are now graduating from university, writing books, marrying and attaining full-time employment in the regular workforce. They are still in the process of taking some control of their means of communication—while it is *de rigueur* for each manufacturer of communication aids to employ at least one communication aid user as a design consultant or sales representative, typically communication aids are designed and marketed by speaking people. Possibly in future there will be more firms like Churchill and Company, a large English manufacturer of communication aids established by Toby Churchill, a non-speaking engineer who designed the first aid sold by the firm for his own use (Churchill, 1994: 1).

This study also suggests that people with severe expressive impairments who have been diagnosed as intellectually impaired have not yet progressed far through the cycle. The possibility of this group attaining more than the most basic communication continues to be contested.

The initial hypothesis of this thesis was that the journey of each group would follow the ideal course for any child born with a communication impairment: that establishment of effective communication would be followed by recognition of learning capacity and provision of appropriate educational options, with citizenship rights, and inclusion and

acceptance following. As the preceding chapters have shown, the actual historical development of the three groups has deviated from this model in many respects. The differences of their actual historical development from the theoretical model suggest that the original hypothesis gave too little weight to the dimensions of power in the relationships between people with severe communication impairments and social institutions and professional structures. In particular, the comparative lack of progress experienced by people diagnosed as having intellectual impairment, and the extreme ferocity of much of the professional reaction to the challenge of facilitated communication, illustrate the tenacity of the present professional superstructure.

Repeating patterns have certainly appeared in the history of each disability group, both in the difficulties faced by attempts to change the status of each group and in the nature of professional intervention and reaction. The study documents the reaction of different professional groups—including teachers of the deaf, speech pathologists and psychologists—to each successive re-evaluation, and have shown that the ‘discovery’ of communication ability in each disability group has been followed by a dependence on professional intervention and concomitant professional control that is eventually resented by group members. In the case of the deaf and the physically handicapped, this resentment has been evinced in political action using communication methods devised and propagated by the groups’ ‘benefactors’.

My secondary hypothesis was that the deaf, the group whose abilities had been recognised longest, would have come closest to achieving social acceptance, and that individuals who are deaf would at the present time progress through this sequence more easily than people whose

communication impairments are not due to deafness. While the progress of the deaf towards full social acceptance and accommodation is still incomplete, as the experiences of the deaf individuals reported in the last chapter indicate, this study indicates both that the deaf have achieved independent and autonomous self-advocacy before the other groups, and that they are generally recognised as at least potentially competent. If we were to conceptualise social acceptance in terms of air travel and think of people who are deaf as having just taken off, then people whose communication impairments are associated with physical impairments are still clearing security, while most non-speech people diagnosed as having intellectual impairment have not yet entered the terminal.

The journey from Epée to the Gallaudet revolt took well over two centuries, included many backtrackings and defeats, and illustrates the amount of resistance that any group trying to break free from the confines of societal stereotypes and professional self-interest can expect.

This thesis has attempted to describe and contextualise the advantages and disadvantages which those people with severe expressive communication impairment, who started to break free of their confines only in the late nineteenth century, have over the deaf of two hundred years ago. Unlike the eighteenth century deaf, these people live in an age of rapid technological change and communication, an age with the capacity to provide the mute with voices and spread the news around the world within a day. Unlike the eighteenth century deaf they have a significant social role based on their disabilities—they provide employment for large numbers of professionals, professionals trained to assess, teach or nurture people with severe disabilities, particularly people who are diagnosed mentally retarded.

During a discussion at the Board meeting of a sheltered workshop in Belchertown, Massachusetts, the professionals were discussing between themselves whether to call the mentally retarded people in the service clients or consumers. A young man who was [diagnosed as] mentally retarded and who worked at the workshop and also sat on the Board interrupted the meeting. "Don't call me a consumer," he said, "You use us as commodities to be bought and sold so that you, the human service workers, can be the consumers." (Chicopee, 1983: 3)

For these people to escape from their 'presumption of idiocy' entails not just re-appraising their competencies, but redistributing resources and retraining professionals whose careers have become irrelevant. Any move in this direction may well appear to be 'an inappropriate challenge to professional belief systems'. Whether it will also be a successful challenge remains to be seen.

In 1987, shortly after she had started to type with facilitation, fourteen year old 'Lisa', who was diagnosed as having autism and an IQ of 50, wrote what she called a happy poem:

Make me another world,
A world where I can sing.
Another world where the towns
Are bright in the sun.

Does the sun shine
On rainy days in another world?
Does the road go on into another world
Where I can talk and sing?
(Deal Communication Centre case notes, 1987)

The resources to build the road exist. Lisa, who now types without facilitation, who has presented at international conferences on autism, and who is about to graduate from university, has the potential to travel it. However, my conclusion must be that, in 1997, for most people like Lisa, the road does not go on.

Glossary of Terms

Communication

Communication: Sharing of ideas and information using a mutually known system. For example, you can communicate with a deaf person who uses sign language if you also know sign language.

Aided communication: Any communication strategy requiring the use of a communication aid, that is, any tangible object used to assist a nonspeaker to communicate. Communication aids range from cards showing symbols for “yes” and “no” to laptop computers that translate typed utterances into speech. Speech, gesture, and manual sign are all unaided communication strategies.

Alternative communication: Forms of communication, such as signing, using communication boards or communication aids, used instead of speech when speech is nonexistent or unintelligible.

Assisted communication: Communication by a person in which the response of that person is expressed through the use of equipment and is dependent upon the assistance of another person. For example, a person using an eye-pointing board needs the assistance of a partner, who has to observe and translate the user’s eye movements.

Augmentative communication: Forms of communication that augment, or add to speech. For example, Jane’s speech is understood by her family but not by strangers, so when she is away from home she augments her speech by using a communication book containing useful words and phrases. The same strategies which are used as alternatives to speech are used to augment speech.

Facilitated communication: An assistive communication technique in which a partner makes physical contact with a communication aid user to help overcome motor or emotional problems, such as low muscle tone or lack of confidence. It differs from co-active movement in that the direction of the movement is determined by the aid user, who is responsible for the content of the message.

Nonverbal communication: Nonverbal means not involving words, e.g., gestural communication. It is often incorrectly used as meaning without speech, for which the appropriate terms are nonspeech or non-oral. People who type but do not talk are not nonverbal.

Neuro-Motor Impairments

Problems with producing desired movement patterns, including speech, due to neurological dysfunction..

Eye/hand coordination: The ability to coordinate eye and hand movements. In the simplest sense, the ability to keep your eyes on what you're doing. More complex aspects include the ability to correlate perception of depth and strength of movement.

Inhibition: The ability to stop unnecessary or inappropriate movements, e.g. most adults inhibit themselves from scratching their genitalia in public. To make controlled voluntary movements it is necessary to inhibit involuntary movement, and to point correctly to a picture to answer a question it is necessary to inhibit movement until the question is finished.

Disinhibition is the opposite of inhibition. Many people with poor eye/hand co-ordination are visually disinhibited—that is, they are unable to inhibit the automatic movement of their eyes to anything in their environment that moves or makes a noise.

Initiation problem: Difficulty in starting a movement, even though the person knows a movement is required and wants to move. People with initiation problems may need a spoken or physical prompt to start moving, e.g., a tap on the elbow to start typing.

Muscle tone: Tone refers to the readiness of a muscle for movement. Normal muscle tone is the state of the muscle that allows natural movement. Some people's muscle tone is too low (hypotonia); their limbs feel floppy and heavy. They have difficulty moving against gravity, and they are likely to tire quickly. Some people's muscle tone is too high (hypertonia); their

muscles feel tight, and their limbs feel stiff. Their range of movement may be restricted, and their movements may be jerky.

Perseveration: Repetition of a movement sequence more often than is necessary or appropriate. There can be perseveration in speech: “I went to the shops, shops, went to the shops to shops to buy shops.” There can be perseveration in written words: “I am in in inside in grade 6.” Sometimes perseveration of a sequence will cue another unwanted word, as in the above example of in and inside. Sometimes a typist cannot get as far as a word—they get stuck on the first letter and hit it again and again, or (in a variant form) they hit a wanted letter then every other letter along the same row.

Speech Impairments

Aphasia: Loss or impairment of the ability to use words or sounds.

Receptive (Wernicke's) **aphasia** affects the ability to decode spoken and/or written language. It is less common than expressive aphasia (which it may accompany).

Expressive (Broca's) **aphasia** affects the ability to speak and/or write. There may be problems with recall of words, confusion between words with similar sounds (e.g. saying "knife" for life"), or difficulty in repeating something just heard.

Apraxia (also referred to as **Dyspraxia**): A neurological impairment which affects the ability of a person to reproduce sequences of purposeful movements, which may include speech. A person who has this condition may be able to reproduce the same movements spontaneously or involuntarily, e.g., a woman who could not touch her nose on command despite indicating understanding of the request was observed doing so when brushing away an insect. People with oral dyspraxia may be able to greet people and swear spontaneously, but not produce considered utterances.

Dysarthria: An impairment in the functioning of the muscles involved in respiration, phonation and articulation due to a lesion in the peripheral nervous system, central nervous system, or both. Involvement of muscle groups controlling the tongue, the palate, the vocal cords, and breathing can seriously affect the intelligibility of speech.

Echolalia: The involuntary repetition of the last word of another person's sentence or a previously heard utterance. Echolalic speech is often associated with word-finding problems. Individuals with echolalia are often diagnosed as autistic.

Word finding problem: Frequent inability to find the correct word. Everyone experiences occasional word finding difficulties: “Can you bring me the whatsit from the whosis?” For some individuals the problem is very severe and causes communication difficulties similar to expressive aphasia.

Hearing Impairments

Deaf: Having a hearing loss which affects comprehension of speech. As commonly used, 'deaf' is a vague term, which does not differentiate between those who are born deaf and those who become deaf as adults, and which encompasses people who can hear if you speak loudly and clearly, people who can hear speech quite well with hearing aids, and people who cannot hear at all.

Deaf community: People who are profoundly deaf, typically pre-lingually deaf (see below), who use sign to augment or replace speech and who come together for social and/or political purposes.

Manual alphabets: Codes for representing the letters of the alphabet by hand shapes. These vary between countries and ethnic groups.

Pre-lingual deafness: Deafness existing from birth or acquired early in life, before speech and language are fully established. The term indicates the timing but not the severity of the hearing loss.

Post-lingual deafness: Deafness acquired after speech and language are fully established. People who are post-lingually deaf, regardless of the severity of the deafness, do not usually learn sign or consider themselves members of the deaf community, though they may belong to societies for people with hearing impairments.

Sign languages: Languages in which meaning is conveyed through formalised hand shapes and movements. These vary between countries and ethnic groups.

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Appendices

Appendix #1—Declaration on the Rights of Disabled Persons

Appendix #2—Declaration on the Rights of Mentally Retarded Persons

Appendix #1—Declaration on the Rights of Disabled Persons

G.A. res. 3447 (XXX), 30 U.N. GAOR Supp. (No. 34) at 88

The General Assembly,

Mindful of the pledge made by Member States, under the Charter of the United Nations to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming its faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, the Declaration of the Rights of the Child and the Declaration on the Rights of Mentally Retarded Persons, as well as the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned,

Recalling also Economic and Social Council resolution 1921 (LVIII) of 6 May 1975 on the prevention of disability and the rehabilitation of disabled persons,

Emphasizing that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of preventing physical and mental disabilities and of assisting disabled persons to develop their abilities in the most varied fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,

Proclaims this Declaration on the Rights of Disabled Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The term “disabled person” means any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities.

2. Disabled persons shall enjoy all the rights set forth in this Declaration. These rights shall be granted to all disabled persons without any exception whatsoever and without distinction or discrimination on the basis of race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation applying either to the disabled person himself or herself or to his or her family.

3. Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.

4. Disabled persons have the same civil and political rights as other human beings: paragraph 7 of the Declaration on the Rights of Mentally

Retarded Persons applies to any possible limitation or suppression of those rights for mentally disabled persons.

5. Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.

6. Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration.

7. Disabled persons have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions.

8. Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.

9. Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.

10. Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.

11. Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property. If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account.

12. Organizations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons.

13. Disabled persons, their families and communities shall be fully informed, by all appropriate means, of the rights contained in this Declaration.

Appendix #2—Declaration on the Rights of Mentally Retarded Persons

G.A. res. 2856 (XXVI), 26 U.N. GAOR Supp. (No. 29) at 93, U.N. Doc. A/8429 (1971).

The General Assembly,

Mindful of the pledge of the States Members of the United Nations under the Charter to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, the Declaration of the Rights of the Child and the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned,

Emphasizing that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of assisting mentally retarded persons to develop their abilities in various fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,

Proclaims this Declaration on the Rights of Mentally Retarded Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.

2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.

3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.

4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.

5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.

6. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offence, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.

7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

