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Facilitated Communication Training
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TEICHERS COLLEGE PRESS

Teachers College, Columbia University
New York and London

Photographs by Helen Graham

Published by Teachers College Press, 1234 Amsterdam Avenue, New York, N.Y. 10027

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Library of Congress Cataloging-in-Publication Data

Crossley, Rosemary, 1945–
Facilitated communication training / Rosemary Crossley.
p. cm. — (Special education series; **14)**
Includes bibliographical references and index.
ISBN 0-8077-3327-X (paper)
• 1. Communicative disorders—Patients—Rehabilitation.
2. Communication devices for the disabled. 3. Handicapped—Means of communication, I. Title. H. Series: Special education series (New York, N.Y.); 14.
RC429.C76 1994
616.89'8206516—dc20 93-44306

ISBN 0-8077-3327-X

Printed on acid-free paper
Manufactured in the United States of America
01 00 99 98 97 96 95 94 93 8 7 6 5 4 3 2 1

Dedication

To Chris Borth wick, who, as ever, did all the cooking, and to Anne McDonald, who lived through it.

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Acknowledgments

The development of a systematic program of facilitated communication training from my original use of facilitation with children with cerebral palsy owes a great deal to the staff who have worked at the DEAL Communication Center since 1986, and whose names are listed in alphabetical order below. Those staff whose names are asterisked also made significant contributions to some of the working papers on which this book is based. Any errors in the text are, of course, my own.

DEAL STAFF 1986-1992

*Jim Allen
*Margaret Batt
*Anne Burke
Jenny Denning
Anne Doherty
Helen Graham
Jane Jones
Jenny Lambier
Lindsay Low
Jean Melzer
Alan Moore
Sean O'Connor
Alice Owens
Elizabeth Pearson
*Jane Remington-Gurney
*Sue Rushfirth
Rosemary Ryall
Sue Vincent

Special thanks go to Nancy O'Donnell A.M., Jane Remington-Gurney (now Advisor, Facilitated Communication, Queensland Department of Family Services), Doug Biklen and all at the Facilitated Communication Training Institute of Syracuse University, Graetne Clunies-Ross, Joan Dwyer, Carl Parsons, Michael Regos, and John Warburton.

The DEAL Committee of Management, and private and public benefactors, all gave essential support and encouragement despite

the controversies that facilitated communication produced. And a facilitated communication program could not exist without facilitators—those parents, caregivers, integration support teams, and training center staff who, despite all difficulties, gave their help ungrudgingly to people with severe communication impairments.

Lastly, but never least, are the DEAL, clients, each one of whom taught us something. These are the people we hoped to help, either through traditional nonspeech communication or through facilitated communication training. Sadly not all have been helped, either because our skills were not equal to the task, or because of unwillingness on the part of others to recognize their abilities and their right to a means of communication.

• Some of the material in this book is based on articles originally published in *American Journal of Speech Pathology* and *Topics in Language Disorders* and I thank the editors of these journals for their assistance.

Introduction

COMMUNICATING WITHOUT SPEECH

In *The Count of Monte Cristo* Dumas (1845) described a man who had lost speech and writing skills following what would now be diagnosed as a brain stem stroke 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 by a person with severe communication impairment unrelated to hearing loss. Prior to the 1970s such communication strategies were rare, and those that were used were generally, as in Dumas, devised by families and caregivers to suit one individual. Only recently have there been attempts to develop widely applicable communication techniques for people with severely impaired speech and hand function. When McNaughton began teaching children with severe physical impairments, in 1968, little provision was made for those who could not speak: "the odd lucky child received a wheelchair tray, with magazine pictures related to basic needs" (McNaughton, 1990).

Seminal work in nonspeech communication was carried out in the early 1970s when protocols for the use and design of communication boards were devised (McDonald Er Schultz, 1973; Vicker, 1974), and Blissymbols were used successfully by children with cerebral palsy in Canada from 1971 (McNaughton & Kates, 1980). The new field acquired a title, augmentative and alternative communication, and its own terminology (Appendix A). Augmentative communication is used to augment speech that is limited in vocabulary or intelligibility. Alternative communication is used instead of speech, where speech is either absent or totally unintelligible. Both

augmentative and alternative communication involve the same equipment and strategies.

Developments in technology, and in the theory of nonspeech communication, were taking place at the same time. The Canon Communicator, a minitypewriter designed in Holland for people with dual sensory impairments, was speedily taken up by people with severe communication impairments, as had been the Possum scanning typewriter, designed in England for people who could not use their hands to type. Augmentative communication, like many other fields of human endeavor, was given a tremendous boost by the sale of the first personal computers, in 1975, and since then the increasing miniaturization of electronic components and developments in voice output technology have led to the production of many new devices, catering to people with, a range of academic and physical abilities.

Most work in augmentative communication was initially directed toward assisting people with severe physical impairments such as cerebral palsy, and the aids and strategies developed reflected this. People who were unable to point with their hands directly to communication displays were accommodated by using eye pointing, headpointers, or manual or switch-controlled scanning systems. Large communication displays or eye-pointing charts were mounted on wheelchairs, to be followed in the 1980s by laptop computers and speech synthesizers.

Individuals with severe communication impairments are often falsely labeled as intellectually impaired, not surprising when one considers how the standard categorization of intellectual impairments, the Diagnostic and Statistical Manual of Mental Disorders, bases its categorizations on expressive language skills. In the 1970s relatively little was done to provide the technology or techniques to help this group, most of whom are ambulatory. Even for many professionals the image of the augmentative communication user appeared to be that of a person with an able mind trapped in a disabled body.

While generally augmentative communication catered specifically to the needs of intellectually able, literate individuals with severe physical impairments and severe communication impairments, an exception to this trend occurred in Britain. There, three speech therapists, Cornforth, Johnson, and Walker (1974), developed a communication training program using manual signing for people with hearing impairments who had been assessed as having severe learning difficulties. Sign language programs using their

Makaton vocabulary were widely implemented and have been successful in providing some functional communication for many students with a range of developmental disabilities. Communication through signing requires communication partners who know the signs, and is not functional for students who have severe hand function impairments or who have difficulty replicating the signs.

More recently, communication displays using Blissymbols and other pictorial systems have been used successfully by some people diagnosed as intellectually impaired. This has been followed by the development of smaller, cheaper voice-output aids with utterances coded by pictures or symbols. An intrinsic problem with picture or symbol-based displays is the limited vocabulary available. Aid use has also not been functional for individuals who have had problems accurately selecting items from large displays.

Despite all the developments in nonspeech communication strategies and technology over the last 20 years, there is still a substantial number of individuals who have not yet achieved fluent, functional communication with any of the available systems. Some of these people may be helped by facilitated communication training.

FACILITATED COMMUNICATION TRAINING

Facilitated communication training is a strategy for teaching individuals with severe communication impairments to use communication aids with their hands. In facilitated communication training a partner (facilitator) helps the communication aid user overcome physical problems and develop functional movement patterns. The facilitator uses his or her hand(s) to support or inhibit the aid user. The immediate aim is to allow the aid user to make choices and to communicate in a way that had been previously impossible. Practice, using a communication aid such as a picture board, speech synthesizer, or keyboard, in a functional manner, is encouraged to increase the user's physical skills and self-confidence and reduce dependency. As the student's skills and confidence increase the amount of facilitation is reduced. The ultimate goal is for students to be able to use the communication aids of their choice independently.

Facilitated communication training is a teaching strategy of particular relevance to individuals with severe speech impairments who can walk but have had difficulty acquiring handwriting and manual signing skills. Many such people are diagnosed as autistic

and/or intellectually impaired. Through facilitated communication training many of these people have achieved functional communication, often revealing unexpected understanding and academic potential.

My initial use of facilitated communication had no theoretical basis: It was a measure forced upon me by circumstances. After teaching children with cerebral palsy for 5 years, in 1977 I started to try and devise a means of communication for a socially responsive 16-year-old with athetoid cerebral palsy and no intelligible speech, who had been labeled profoundly intellectually impaired.

Anne had been living in a state institution since she was 3, and was still the size of a 3-year-old. She had no wheelchair and 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 toward her heels. When she was seated in a baby buggy (a larger version of a baby's stroller, and the only seating available) her head and shoulders retracted to the extent that she was at risk of suffocation. In order for her to look at anything placed in front of her it was necessary to flex her hips forcibly and bring her head forward. In order for her to point it was necessary to use my hand to internally rotate her arm and raise it from its retracted position behind her. With this support Anne pointed correctly to named objects, pictures, and a few Blissymbols before going on to learn to read and spell.

Anne left the institution at the age of 18, still in the baby buggy, after instructing a lawyer and winning an action for Habeas Corpus in the Supreme Court of Victoria. Now in her senior year at university, Anne still uses facilitated communication. For her it is a matter of choice:

> I communicate by spelling on an alphabet board, on which I can reach a top speed of 400 words an hour. I own a Canon Communicator... which I use with a headpointer...; a speech synthesizer...and a computer which...is the slowest to use of all my high-tech communication equipment.... I can type at 10 words an hour, provided someone else sets up the computer.... The gadgets enable me to do things I can't do without them, but they don't let me do them fast enough to make it worthwhile. If technology made me normal, it would be great;

> as it is it makes me slower and less efficient and reduces the time T would otherwise spend with non-disabled people. (Harrington, K. A letter from Annie, *Communicating Together,* 1988)

In Anne's case facilitation produced only minimal physical improvement. For her, independence could only come through alternate means of access, a headpointer or switches, that she found unsatisfactory. There will always be some people who can only communicate with facilitation or who have to choose between restricted or slow independent communication aid use, and dependent, faster, more fluent communication.

While Anne's use of facilitated communication caused considerable local controversy at the time, Anne was certainly not the first individual with such disabilities to have shown academic abilities, and therapists experienced in working with people with cerebral palsy were not surprised that a child with severe cerebral palsy and no speech could have been misassessed and have considerable, untapped potential. However, the use of facilitated communication training with individuals with other diagnoses still arouses controversy. Since the 1960s facilitated communication has been used occasionally with people with autism—Rosalind Oppenheim, in particular, in her book *Effective Teaching Methods for Autistic Children,* which was first published in 1977, articulated a rationale and a program for teaching children with autism to communicate through facilitated handwriting—but until recently it has been applied to only a few individuals.

The development of a training program based on facilitated communication was stimulated by the 1986 opening of DEAL, Australia's first center devoted solely to the needs of individuals with severe communication impairments not caused by deafness. It was expected that the clientele would be largely people with cerebral palsy or acquired brain damage. In fact, from 1986 to 1990, only 213 (32%) of DEAL's 666 clients with developmental disabilities were diagnosed as having a severe physical impairment and 636 (95%) were labeled as either intellectually impaired or autistic or both. Statistics on the incidence of severe communication impairments are limited but it appears that (1) a high proportion of those individuals labeled as severely or profoundly intellectually impaired have severe communication impairments, and (2) the majority of those with severe commu-

nication impairments are labeled as intellectually impaired (often in association with other diagnoses such as cerebral palsy or autism). In a statewide survey of all individuals with developmental or acquired severe communication impairments, 71 % of all respondents had been labeled as intellectually impaired (Bloomberg & Johnson, 1990).

Of the DEAL clients labeled as intellectually impaired or autistic, two thirds were reported as having some exposure to manual signing programs but only four 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.

During assessment of selection skills, some 90% of the 452 individuals labeled as intellectually impaired who did not have cerebral palsy showed neuromotor problems that adversely affected their ability to make accurate selections from a communication display. The most common were eye/hand coordination impairments, impulsiveness, perseveration, low muscle tone, and inability to isolate an index finger. Facilitation was used when necessary to provide temporary remedies for these problems while academic skills were assessed.

The results of academic assessment were initially surprising—some 70% of the 431 over age 5 showed useful literacy skills, defined as the ability to type a comprehensible sentence without a model, such as "it woz nice." On reflection our surprise diminished. Unlike Anne, 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, packaging, and so forth. Their speech and hand function impairments, however, had prevented them from demonstrating any of their acquired literacy skills. Initially all but two of those with previously unused spelling skills required 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. Not all users of facilitation have literacy skills; facilitation is also used when necessary to assist individuals accessing symbol and picture boards, or choosing from real objects, such as toys.

Facilitated communication training is far from problem-free. Essentially, it is an ad hoc solution to some of the communication problems of ambulatory school-age children or adults with both

severe speech and hand function impairments whose communication cannot be put on hold while they undertake a lengthy occupational therapy program. The most obvious concerns are the dependency that the use of facilitation may produce and the risk of facilitators unduly influencing communication. While some hundreds of individuals have been assisted by facilitated communication training, it is not an ideal strategy—it is the strategy you use when you don't have a better one.

Facilitated communication training has excited attention because the communication produced with facilitation is unexpected in both style and content, and challenges previous assumptions about the language skills of specific groups, especially people with autism. The most important contribution facilitated communication training could make to the field of nonspeech communication would be to bring about the reevaluation of individuals with severe communication impairments who are labeled as intellectually impaired, and a reexamination of the methods used to assess these individuals. Detailed neuromotor assessment of all infants with significant speech delays and early intervention by speech/language pathologists and physical therapists could eradicate the need for facilitated communication training within a generation. In the meantime the findings that led to facilitated communication training should add further impetus to research into the neurological links between speech and hand function.

Meanwhile, the aim of all communication intervention should be free speech. As far as is possible people with severe communication impairments should be enabled to say what they want to say, in the words thay want to use, when and where they want, without restrictions imposed by their communication partners, technology, or the enviroment.

In 1992, Anne McDonald wrote a plea for the right to communicate:

For people without speech, talking is often dependent on the generosity of others, either in providing interpretation or facilitation or in giving up time to listen. While this is inevitable, there needs to be an irreducible right to make your opinions known on issues concerning your future well-being. At the moment social conversation and medical consent are equal in the sight of the law, both depending on the accidental availability of communication partners with the necessary skills and commitment. There is no right to be heard. There is no right to an interpreter. There is no obligation to listen

While social interactions will always be dependent on the politeness and tolerance of individuals, it should be possible to legislate for a right to communicate in formal situations such as courts, hospitals and schools. Without such legally enforceable rights, people without speech will continue to be at the mercy of decision-makers who can arbitrarily decide to disallow communication.

Communication falls into the same category as food, drink and shelter it is essential for life. Without communication life becomes worthless.

The aim of this book is to enable more individuals to communicate as freely as possible.

1

Assessment for Facilitated Communication Training

Facilitated communication training is a strategy for teaching people with severe communication impairments to use communication aids with their hands. It is just one of many strategies for helping people with severe communication impairments, and this chapter aims to place it in the context of the overall field of augmentative and alternative communication and to outline the path that might lead to someone becoming involved in a facilitated communication training program.

SEVERE COMMUNICATION IMPAIRMENT

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 hearing 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.

Many people whose speech is severely impaired also have difficulty with handwriting.

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

Augmentative and alternative communication is the formal title for the nonspeech communication strategies used by people who are

not deaf. Augmentative communication includes any communication strategy needed to make an individual's speech more functional; Jan's family understands her speech but when she's away from home she augments her speech by using a communication book which includes proper names. 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 nonspeech communication. For simplicity the term augmentative communication is used throughout this book. A list of terms used and their definitions can be found in Appendix A.

Who Needs to Use Augmentative Communication?

Anyone whose speech is not clear enough, fluent enough, or reliable enough to allow them to get across everything they need to say.

What Communication Strategies Can Be Used Instead of Speech?

Speech may be replaced or augmented by:

1. gesture and body language
2. manual sign
3. handwriting
4. communication aids.

Gesture and body language are used to some extent by almost all people. While some formalized 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 all parties to the interaction share extensive sign vocabularies—that is, they can use and understand thousands of signs 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. Consequently manual signing only attains its full power when used in the deaf community.

Handwriting is as powerful as the literacy skills of writer and reader. It loses the inflexion given by speech, sign, and gesture, but it is probably the most common way of compensating for the kinds of speech incapacity caused by acute illness in older children or adults.

Communication aids are devices 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 while others cannot, and have to use alternatives such as mouth sticks, headsticks, switches, or eye-pointing. Some can read and spell and others cannot: They need communication aids on which language elements are represented by pictures or symbols. Some individuals use wheelchairs that 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 that allows the user to speak on the phone or type an essay.

What Is the Best Nonspeech Communication Strategy?

The best nonspeech communication strategy (or combination of strategies) is the one that allows the person with severe communication impairments to communicate as freely as possible in as many situations as possible to the maximum number of people.

How IS THE BEST NONSPEECH COMMUNICATION STRATEGY SELECTED?

In deciding what strategies are feasible the first thing to consider is what physical abilities the person has. Hand skills are the obvious place to start.

Body language, gesture, and sign language have the advantage that no equipment is needed—they are called unaided strategies. Handwriting needs minimal equipment. However, if communication is to be fluent and comprehensible, these strategies do need good hand skills. Manual sign and handwriting place considerable demands on motor planning and memory as well as on fine finger

and hand movements. Unfortunately, many individuals with severe communication impairments have problems in using their hands effectively, and for these people manual signing and handwriting are not realistic options.

A range of communication aid options is available for people with severe communication impairments who do not use their hands at all. Ironically, those with severe communication impairments who use wheelchairs have more communication aid access options than those who walk. Large communication aids and displays that can be mounted on wheelchair trays, access strategies using headpointers, eye-pointing boards, or switch-controlled scanners—all these are feasible for wheelchair users, but impractical for walkers.

People with severe communication impairments who can walk, but cannot sign or write, need small, easily portable communication aids that they are able to use with their hands. The aid displays a set of choices, and the user makes selections from these choices, reducing the demands on fine motor skills, motor planning, and memory.

Academic assessment will determine the items on the display which may include pictures, special symbols such as Blissymbols, written words or phrases, or the letters of the alphabet. The communication aid itself may be an electronic device, with spoken or written output, or it may be a board or a folder that the partner reads the message from as the user constructs it. Whatever the nature of the communication aid or the display used, people who are walking have to use their hands to select the items they want.

At initial assessment many of these people do not have the pointing and selection skills necessary to use communication aids effectively. As they have no other practical communication options—they cannot sign or write, they cannot carry eye-pointing displays, or enlarged keyboards or scanning setups, and they cannot wear headpointers—the only remaining option is to try and teach them the hand skills necessary to use portable communication aids. One teaching strategy that may be used with these individuals is facilitated communication training.

WHAT IS FACILITATED COMMUNICATION TRAINING?

Facilitated communication training is a teaching strategy in which a communication partner (facilitator) helps a communication aid user overcome neuromotor problems and develop functional movement patterns. The immediate aim is to allow the aid user to make choices

and to communicate in a way that has been impossible previously. When the student's skills and confidence increase, the amount of facilitation is reduced. The ultimate goal is for students to be able to use the communication aids of their choice independently.

COMMUNICATION AID USE INVOLVING FACILITATION

For facilitated communication training to be considered an option for an individual, he or she will

- have severe communication impairments
- not currently have a fluent alternative communication strategy
- not show the potential to acquire manual signing or handwriting skills easily[1]

or

- live in an environment where manual sign or writing are not going to be viable communication options
- have difficulty with the clear, unambiguous selection of nominated items from functional communication displays
- not be able to use other direct or indirect access options (usually for practical reasons, such as the unsuitability of these options for individuals who walk and have to carry their communication systems with them).

Once it has been decided that an individual is a candidate for facilitated communication training it is then necessary to

- ascertain the nature of the problem(s) that currently preclude successful communication aid access
- select appropriate remedial strategies, including facilitation strategies if needed
- ascertain what representational systems (concrete objects, pictures, pictographs, written words, letters) are currently meaningful to the potential user
- enable the individual with severe communication impairments to use the most empowering of the representational systems and selection strategies currently available to him/her by obtaining or making appropriate communication aids and teaching those in the individual's environment how the aids are used.

The individual with severe communication impairments can then practice using a communication aid with facilitation. This is just the start of the training program. Further teaching and assessment in areas such as literacy, hand function, and pragmatic interactive skills, will be required.

If the person with severe communication impairments shows the ability to spell at the initial assessment, further assessment and refinement of literacy skills is desirable. If no usable spelling skills are shown, then the person's involvement in a literacy program is desirable. Spelling is the most empowering communication strategy for people with severe communication impairments who cannot sign fluently, and every effort should be made to develop literacy skills regardless of the presenting diagnosis of the individual with severe communication impairments. Infants and individuals for whom literacy acquisition is problematic will need to be taught to use as large a vocabulary of pictures and symbols as possible.

Given that the individual is using facilitation because of problems with hand use, regular hand function assessments, which may result in the prescription of exercise routines or splints, are important.

Whatever the representational strategy, all aid users will need to be taught acceptable attention-getting strategies and other pragmatic skills, such as how to position themselves so that people they are talking to can best receive their message.

Multiple facilitators will have to be trained: It is important that the user is able to communicate with as many people as possible to avoid dependency on any one. The amount of facilitation provided requires regular review with the aim of reducing it as quickly as possible.

Up to this point I have made no mention of specific labels or of psychological or intellectual assessment. This is because the capacities of people with severe communication impairments cannot be judged until their communication impairments have been addressed. No one should be excluded from communication training because previous intellectual assessments were negative, and no ceiling should be placed on the options offered to individuals because of the labels they wear. Intellectual assessment of people with severe expressive problems is difficult and unreliable. Communication training is a prerequisite for accurate assessment.

ENDNOTE

[1] They may already have tried to sign and write and failed, or the initial assessment may reveal hand function problems that make it unlikely they will acquire fluent signing or writing skills.

2

Facilitated Communication: How and When

Students whose speech is not adequate for communication have to use other means. Also, students whose fine motor skills are not adequate for acquisition of normal pen and pencil skills need a substitute, usually a keyboard or computer interface. Speech or fine motor skill impairments rapidly become severe educational handicaps if energetic measures are not taken to remedy them. Apart from their day to day effect on the student's classroom performance, these impairments make it extremely difficult to reliably assess a student's actual abilities.

Many students find themselves caught in a downward spiral: Assessed as significantly intellectually impaired as a result of their speech and motor impairments, they are placed in a school where their speech and motor impairments are seen as being the unavoidable corollary of their intellectual impairments. They are unlikely to receive an occupational therapy assessment, and speech therapy is likely to be at a premium. The combined effect of continued failure (after all, the student does not have the basic output skills necessary for success), low expectations, and lack of therapy is likely to be deterioration or stagnation rather than the improvement in skills that is every teacher's aim. The student's behavior is often as poor as their academic performance.

Since the opening of the DEAL Communication. Centre in 1986 we have seen many students in this situation. Lyn is one of them. When she first attended DEAL she was 14, diagnosed as autistic, and assessed as having an IQ of 50. Lyn's handwriting was at a first grade level, her muscle tone was low, and she was very impulsive. She had been given training in manual signing and had acquired

approximately 100 signs (more than many students, but still much less than the expressive vocabulary of a 2-year-old signer). She used a typewriter with difficulty for simple copying tasks. She was thought to be reading at roughly a 6-year-old level. When facilitated access to a minikeyboard was provided to compensate for Lyn's fine motor problems it quickly became clear that her literacy skills had been significantly under-assessed. Lyn transferred from her special school to a high school and handled the regular syllabus successfully. She is able to type and use her communication aid independently, but had difficulty sustaining the speed and endurance necessary for her heavy academic load without facilitation. Without the initial facilitation Lyn would probably not ever have had access to a regular education.

Because of Lyn's fine motor problems neither signing nor handwriting provided her with an effective alternative to speech. Children who are not succeeding with signing or handwriting, both of which place high demands on fine motor skills, should be reassessed with a view to finding another communication strategy with which they can be more successful. The obvious alternatives all involve making a choice by pointing, either to real objects or to pictures, symbols, words, or letters. These may be used on communication displays, electronic communication aids, or typewriters. The clearest, most effective, pointing is done using the index finger of the preferred hand.

Even though pointing is far less demanding motorically than signing or writing, many students still present problems requiring remediation before accurate pointing is possible. A student's failure to point accurately is all too often seen as a reflection of intellectual impairment or ignorance, and because of this the student's perceptual-motor status is not assessed in detail. After seeing many students similar to Lyn—students who required further communication augmentation, who required intensive manual training to acquire the necessary physical skills, but who were of an age that meant that their educational program had to continue while they had this training—we devised a communication aid access and training program called facilitated communication training.

To facilitate is to make easier. In facilitated communication training the task of using a communication aid is made easier for a student with a severe communication impairment. The degree of facilitation needed varies from person to person, ranging from an encouraging hand on the shoulder to boost confidence, to full sup-

port and shaping of a student's hand to enable isolation and extension of an index finger for pointing.

Facilitation differs from other hands-on training methods such as coactive movement and graduated guidance. in coactive movements, teachers put their hands over the students' hands and lead them through a movement pattern. You might, for example, put your hands over the student's hands and help pull trousers up, or scoop with a spoon. Coactive movements are performed by both students and teachers together and it does not matter if the teachers' movements are stronger than that of the students (at least not at the start of training). In coactive movement you lead the student through the movement; in facilitated communication you are setting up a situation that will allow the student's own movement to be functional. It is vital, that the choices made be those of the aid user. The direction of the movement is controlled by the person being facilitated, not by the facilitator. The aid user's movements should be stronger than that of the facilitator, who gives the minimum assistance necessary.

Any student whose speech requires augmentation and whose hand skills are not adequate to achieve a level of expression matching his or her receptive language is a candidate for facilitated communication. Beware of putting the cart before the horse here—as assessment of students with severe expressive problems is so difficult, no student should be excluded from the training program on the basis of previous negative assessments. Often the training is a prerequisite for accurate assessment. Always give the student the benefit of the doubt. In addition to school students, many adults with developmental disabilities who can walk have very limited communication. Their hand function should be carefully assessed. Faciitation may help those whose hand use is impaired to access communication aids more successfully.

As facilitated communication requires both hand skills and the potential to improve those skills, it is not usually the method of choice for people with severe physical impairments. These people are offered scanning or coded systems instead. Facilitated communication offers most to students who are ambulatory and who need an easily portable communication system that can be accessed manually. To date, successful users of facilitated communication include children diagnosed as intellectually impaired (including children with Down syndrome), children diagnosed as autistic, and children with mild cerebral palsy. Regardless of diagnosis, all potential users present with impairments of motor skills that predude use of handwriting or

signing for more than the most basic communication, and that significantly impede their independent use of communication aids.

COMMON PROBLEMS HELPED BY FACILITATION

Poor Eye-Hand Coordination

The student makes selections without looking, or without allowing enough time between movements to scan the display and locate the target.

It is vital to ensure that the student makes eye contact with the target before making a selection. The student who points without looking is unlikely to hit the target, and someone who does not scan the available choices cannot make a meaningful selection. At first the facilitator may have to restrain the student from moving until he or she is looking at the target area. Where the student's head is actually turning away from the target the facilitator may need to physically assist in the maintenance of a midline, eyes down, position. If these restrictions are enforced consistently eye/hand coordination usually improves quite rapidly.

Low Muscle Tone

The student's arm and hand are 'floppy" or "heavy." There is difficulty raising the arm against gravity and muscles fatigue quickly.

The immediate remedy is to provide some kind of support, adjusted to the aid user. Supports used include the following:

I. The facilitator places hand under aid user's forearm.
2. The facilitator holds the user's sleeve or a wrist band.
3. The user grasps one end of a rod and the facilitator holds the other end.
4 The communication display is positioned so that the user can rest his or her forearm on the table or a typist's support—this is the optimum solution, but only suits users with no other accessing problems and only works while the user is sitting at an appropriate table.

If muscle tone is very poor the student will do best when the aid is positioned as low as possible, minimizing the arm lifting required.

Such students are often more independent in aid use when they are standing up.

Low muscle tone cannot be cured, although it can be increased for short periods. However, it does often go with reduced muscle strength—people with low muscle tone may not be asked to do much, and may not participate in sport—and something can be done about that. The long term strategy that assists people with low muscle tone increase independence combines practice in aid use with an exercise program for arms and shoulders.

High Muscle Tone

The student's arm feels tense, and movements are often too forceful, either over-reaching the target or pushing the aid away.

Usually the harder the student tries to perform the more muscle tone increases. The arm may begin loose and gradually become rigid. This problem is often associated with impulsivity (see "Impulsivity" below).

High muscle tone cannot be cured, but its effects can be alleviated. Remedies include

1. shaking the student's arm until it feels floppy
2. pointing to a target close to the body between selections, so that the student's elbow is flexed between selections
3. regular pauses to give the muscles a chance to relax.

Index Finger Isolation and Extension Problems

The student has difficulty in extending the first finger while holding back the other fingers. Users with this problem either point with all fingers extended or use the middle finger (which is the longest). Either method makes accurate selection difficult.

This is a very common problem. If you can't isolate a finger you cannot point accurately to a small target, and this makes it difficult to use a keyboard or even to have many choices on your pictureboard. Remedies vary with the severity, and include the following:

I. An occasional reminder to keep the other fingers back.
2. Asking the aid user to hold a rod in the palm while pointing to encourage flexion of the unwanted fingers (sometimes

this prompts a reflex grasp in which case the index finger will also flex and the aim will be defeated).

3. Physical molding of the student's hand by the facilitator (usually only done for a short period at the start of a training program). When holding the user's hand the facilitator must take care to avoid all contact with the user's index finger (see Figure 2.1 top). Attempts to support the index finger with the facilitator's hand are counterproductive and should be avoided (see Figure 2.1 bottom).
4. Physically restraining the unneeded fingers—a simple method is to use a snug fitting sock. Make a small hole in its toe for the index finger, pull the sock down firmly over the student's hand so that the other fingers are bent and hold it in place by a piece of ribbon or velcro fixed around the wrist. This is a short-term solution—if pointing does not improve within a month further therapy advice should be sought.

A curved or limp index finger may be too weak to push down a key, and may have to be splinted for a short time or a pointer may have to be substituted in the early stages of training. Meanwhile exercises, such as pushing into a ball of clay, can be used to extend and strengthen the finger. It is generally quite easy to achieve independent finger extension; the use of splints slows this down, and they are very much a last resort. Hand molding, too, should be used for only a short period after the initial assessment. If index finger isolation has not improved in a month, further therapy advice should be sought.

Perseveration

The student makes a selection and continues hitting either that selection or adjacent selections inappropriately.

This is a very common problem, though in people with communication impairments it has often gone undiagnosed. The immediate remedy is to break the pattern and pull the student's hand back to the edge of the table after each selection. Gradually, this movement pattern becomes automatic and students withdraw their own hands after each selection. Sometimes providing an alternate target between the student and the aid can assist in the development of the desired movement pattern (e.g., student makes selection 1, hits red dot on table, makes selection 2, hits red dot, makes selection 3, and so forth).

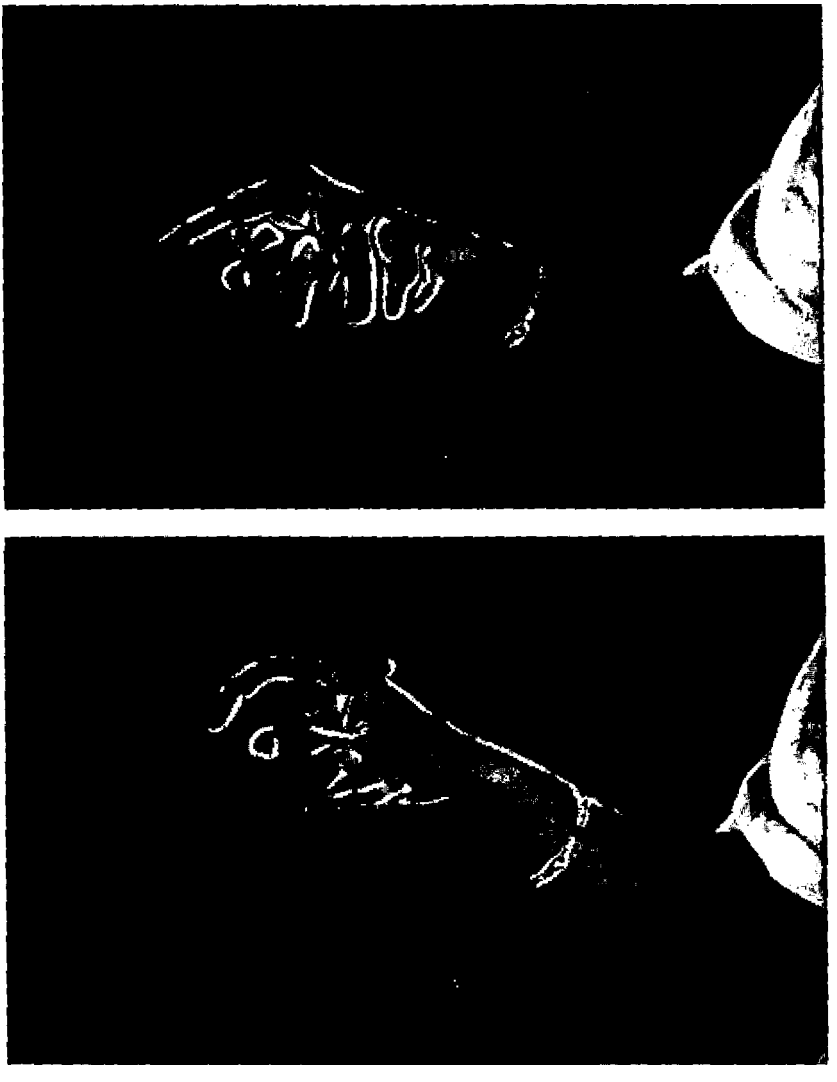


Figure 2.1. Top: Hand molding—the right way. The facilitator does not touch the user's index finger. *Bottom:* Hand molding—the wrong way. The user's index finger curves around the facilitator's fingers.

Perseveration affects the use of communication aids and creates difficulties with, assessment. People who have no speech are often given tests involving pointing, and for a person who has perseveration, these will, not provide a fair assessment.

Using Both Hands for a Task Only Requiring One

The student points to two items simultaneously and it is hard to be sure which item (if either) was actually desired.

Every effort should be made to discover which is the student's preferred hand and all one-handed tasks should be performed with this hand. It may be necessary to restrain the other hand for some time or to devise other strategies to keep it out of the way, for example a student may put it in his or her pocket, use it to hold a clutch purse, or even sit on it.

Tremor

Tremor can either be a continuous tremor or an intention tremor, where the hand is stable while at rest but trembles when the person tries to do something (such as point).

Tremor is very difficult to remedy. In the short term, stabilizing the limb (either by the facilitator holding the student's wrist, or by the student holding one end of a rod held by the facilitator) will assist. A long term program may involve the wearing of wrist weights while using the hands or the performance of exercises as suggested by an occupational therapist or physiotherapist. However, this does not work for everybody. Tremor is reduced by pointing against resistance, and is helped by firm backwards pressure on the wrist.

Radial/Ulnar Muscle Instability

The muscles of forearm, wrist, and hand exert unequal pull on the hand or fingers. Sometimes the index finger swerves to one side as the student goes to point, leading to unwanted selections. The most common problem is for the aid user's index finger to swing across in front of the other fingers. Often the hand also drops down from the wrist thus making the tip of the index finger invisible to its owner, who is then pointing blind.

Any remedy that restores the finger to view will help in the short term:

1. The user points as though pretending to shoot with the index finger.
2. The user holds one end of a rod while the facilitator holds the other in such a way as to ensure that the user's hand does not drop or swing away from the target.

3. The facilitator's hand is used to correct the user's wrist and hand position.

An exercise program to strengthen the student's arm and hand muscles is usually necessary to achieve long-term improvement.

Initiation Problems

The student does not spontaneously reach out to the communication display.

Some people find it very difficult to initiate a movement. A tap on the shoulder may be necessary before they can get up from a chair. As one person spelled out, "I know what you want me to do, but I just can't get it to happen."

A verbal prompt such as "Do you have something to say?" may be all that is required to start communication, though in the earlier stages a physical prompt such as a touch on the elbow is often necessary. It is important that the communication display is always readily accessible, and that any spontaneous movement toward it is reinforced with a positive response.

Impulsivity

The student moves too fast to produce considered responses—starts pointing at the answer before you've finished the question, or points quickly all over the board so that you don't know which item was meant.

This is frequently, but not necessarily, associated with poor eye/hand coordination and the remedy is similar. Slow the student down and refuse to allow any selections made without looking. Maintain a slight backwards pressure, so that the student is always having to push against your resistance to reach the communication display. (This is good practice with all facilitated students other than those with significantly lowered muscle tone, as the resistance has a stabilizing effect and reduces the chance of the communication partner unintentionally directing the user to a selection.) Pull the hand back after each selection.

Proximal Instability

The student's shoulder and trunk position is unstable. Often an overarm pointing action, rather than the more controlled underarm action, is used.

If you want accurate finger pointing you must have the shoulder, which is the origin of the arm movement, properly stabilized. People with muscle weakness often don't have sufficient stability at the shoulder to allow accurate hand movements. A number of exercises can strengthen shoulder muscles. In the short term firm pressure on the shoulder or on the outside of the upper arm may assist. Seating that encourages a stable, upright posture is also important.

Reduced Proprioception

The student moves awkwardly, sometimes undershooting and sometimes overshooting the target.

Proprioception is the sense that lets us know where the parts of our bodies are in space. To make an accurate movement it is necessary to know where you are starting from and to get feedback from your body as the movement proceeds. Reduced proprioceptive feedback is hard to diagnose with certainty, especially in a person with severe communication impairments. Apparently purposeless movements, such as rocking, that increase proprioceptive feedback *may* indicate that an individual has reduced proprioception. Often diagnosis follows treatment—a girl without any other obvious problems improved her pointing significantly when she wore wrist weights. In lieu of any other obvious explanation, it is presumed that the weights gave her more feedback on the position of her hand and arm. Anything that highlights arm and shoulder position will help—weights, pressure, massage.

Lack of Confidence

While, not itself a physical problem nervousness certainly affects physical performance. The most common symptom is reluctance to respond, often combined with lowered muscle tone and reduced eye contact. Encouragement and success are the most effective remedies.

For ease of reference a shorter list of hand function impairments is included in Appendix B.

N.B. For most people with hand function impairments, using a communication aid will be easier if the aid is tilted rather than lying flat on a table.

MOVING TOWARD INDEPENDENCE

The time needed to achieve independent use of a communication aid is influenced by the severity of the problems with which the student started, the motivation of the student, and the availability of skilled, sympathetic, communication partners. As in learning any physical skill, regular practice is vital. (It is probably not coincidental that the students who have moved most rapidly toward independence are those who have transferred into mainstream schools where they have had integration aides available to act as facilitators and pressure to match the quantity of work produced by the other students.)

As soon as a student starts to overcome a problem the assistance given to correct that problem is reduced; for example, a child with very low muscle tone may start communicating with a facilitator giving support under the wrist. With practice, the child's muscles strengthen and the facilitator withdraws support to the forearm. The next step may be to hold the child's elbow, or to lightly hold the sleeve. Whatever the individual variation, the aim is always to withdraw support gradually so that the student continues communicating successfully without loss of confidence.

Students often feel the need for physical contact beyond the time when this is strictly necessary to remedy physical problems. It is important that this need for emotional support is accepted. If it is not, the student may withdraw and stop communicating and the gains made will be lost. A hand on the shoulder usually suffices till this too is gradually faded and the student makes selections without any physical contact from a facilitator. Of course, verbal encouragement is important throughout the whole training procedure and may be necessary even when physical contact is no longer required.

It is important to understand that an aid, user's need for facilitation will vary. When tired or unwell many aid users have reduced physical control and may need more support than usual. Also, an aid user's skills will be affected by nervousness, so a student who does not require any physical contact when communicating in a small group, may need a hand on the shoulder when communicating in public. Often aid users who are starting to communicate with new partners initially appear to regress, seeking a degree of support that may have been discontinued months ago with other partners. This must be accepted if the interaction is to progress. Support can be rapidly faded once confidence is established. Some aid users who can type independently, but slowly, find that they can type much

more quickly with physical contact. This is a problem in the *secondary* classroom where both speed and independence are highly desirable and each situation needs to be resolved individually. In the long term speed will improve with practice. Reducing support is discussed in detail in chapter 7.

LITERACY

Facilitation in itself is not directly connected with typing or literacy. It is a means of training manual selection skills that can be used in any situation in which making choices is necessary—selecting a chocolate from a box, choosing an item from a menu, shopping in a supermarket, pointing to body parts on a doll, matching pictures, and so forth. All of these activities require similar eye/hand skills. Nonetheless, many of the users of facilitated communication are using keyboards and this has been an exciting and unexpected outcome of this program.

Most students who have attended DEAL have had considerable exposure to written language, if not to formal literacy training. However, like Lyn, expressive impairments have prevented any literacy skills they have acquired from being recognized. A I6-year-old named Joe used a typewriter with facilitation to show that he could read and spell. His mother said "Now I know why he takes his father's paper every night!" Many teachers and parents report that students were showing an interest in written material—notices, books, papers, magazines, TV commercials—that they found inexplicable until the students found a means of expression, via facilitated communication training, that enabled them to reveal that they had acquired reading skills. For this reason it is important that students be given open-ended assessments when they enter a communication program and not be prejudged on the basis of previous performance or labels. Literacy is discussed in more detail in chapter 4.

3

Structuring Success

DEVELOPING SKILLS IN COMMUNICATION BY SPELLING

Successful communication, in whatever mode, has three basic requirements.

First, the sender of the message must have the necessary skills. If the communication is via speech, for instance, the speaker must be able to attract the listener's attention, speak clearly and loudly enough to be heard, and have a vocabulary adequate for the message they want to transmit.

Second, the receiver of the message must have a matching set of skills. If the communication is spoken the listener must pay attention, be able to hear (or lipread), and be able to understand the speaker's language.

Third, the total interaction must facilitate the passage of information. In spoken communication, adaptation to the environment may be necessary—you stand closer to your partner and speak more loudly if there is a lot of background noise. The tone of voice and vocabulary have to match the situation as well as the message content. "Quick march!" on the parade ground will generally have a different intonation from "hurry up" addressed to a child, though the two messages have a similar intention.

These three requirements apply to nonspeech communication as much as to spoken communication; however, fulfillment in nonspeech communication has special problems. We learned our sending, receiving, and interactive skills for social communication when we were very young, and because of this we had two advantages—we were unpressured (nobody worried if we made "mistakes") and

we were immersed in a learning environment: Everyone we came into contact with, apart from other infants, had all these skills, and they automatically provided us with appropriate models and reinforcements.

A person starting to use nonspeech communication as an older child or adult is in a very different situation. We tend to be more judgmental of people as they (and we) get older, and the learner is likely to be aware of this and have a well-developed fear of failure. In addition, the learner is not immersed in a learning environment—almost the reverse. The people whom the learner comes in contact with may be unfamiliar with the whole notion of nonspeech communication and are likely to be learning to use the learner's new communication aid or system at the same time he/she is. Correspondingly, the receivers require as much training as the learner does. We are frequently asked why "Joe" doesn't communicate as well outside the therapy setting as he does at DEAL. Generally the answer relates to requirements two and three—the receiver's skills and the interactive strategies used—as much as it does to Joe's lack of confidence in using his new skills and equipment outside the "protected" therapy situation.

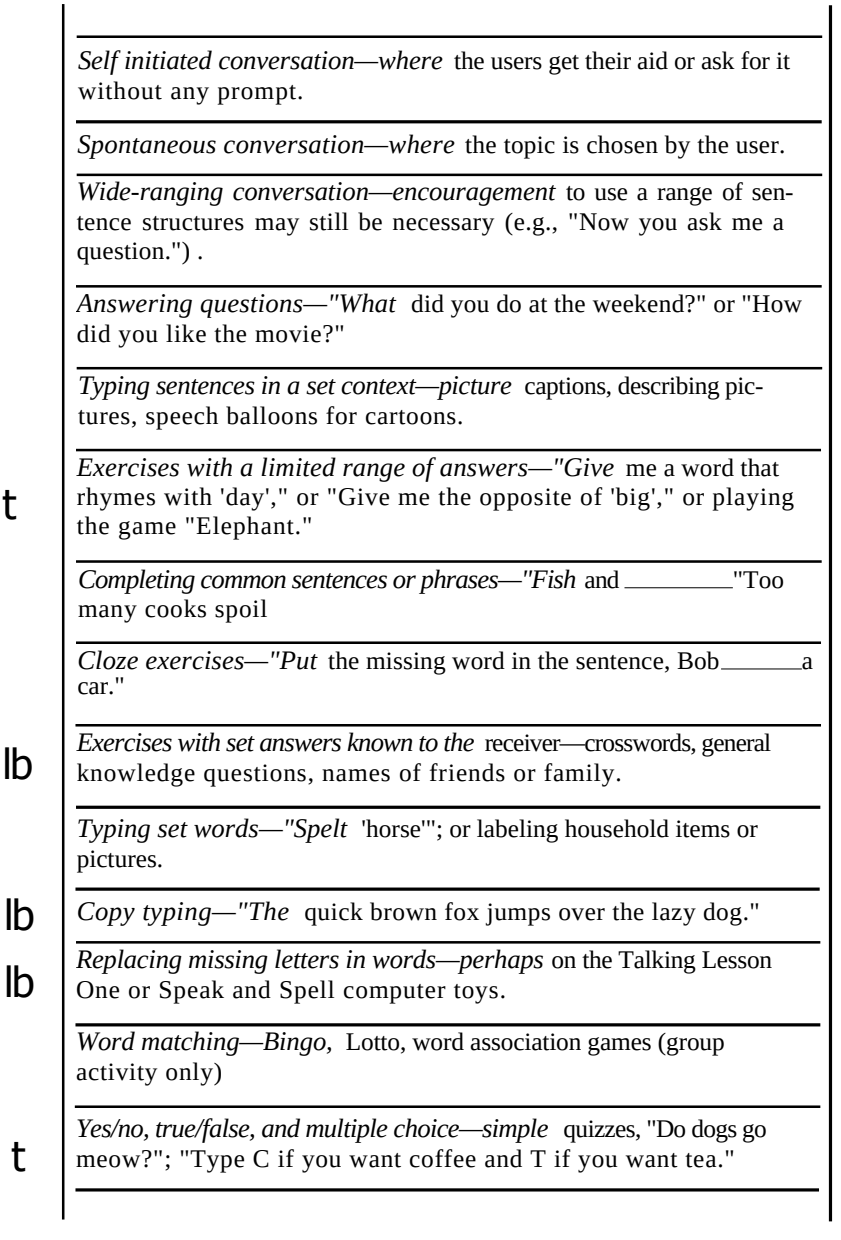
The only way communication aid users can communicate exactly what they want to say, in the words they want to use, is by spelling. Consequently every effort is made to develop aid users' spelling skills. Often spelling will be used in conjunction with another communication mode, such as symbols or signing, to increase speed, but the spelling is vital for true freedom of expression.

If Joe is just starting to use spelling for communication there is a hierarchy of activities that can be used to develop the access and spelling skills (and confidence) Joe needs for free communication, while at the same time Joe's communication partners develop their receiving and interactive skills in what is a new situation for everyone (see Figure 3.1).

This ladder is read and "climbed" from the bottom to the top, with the most predictable, most structured activities at the bottom. We have found that both people starting to use keyboards or letterboards and new facilitators more easily achieve successful interactions when the situation is highly structured and only a small number of responses is possible. This generally applies regardless of the academic skills or age of the individuals involved.

It should be emphasized that this is not a rigid structure to be proceeded through step by step. People may do a range of activities in the same session, they may never do some of the activities, and

Figure 3.1. Climbing the ladder: Activities leading to free communication by spelling.



they may be doing highly structured activities with one partner and communicating relatively freely with another. The only rule is that if an attempt at interaction at one level fails, drop down a level or two.

Once initial success is achieved, individuals should always be encouraged to extend their range of activities, regardless of the amount of physical facilitation (if any) they are receiving. Some aid users are communicating freely and fluently while still receiving wrist support. Others require no physical facilitation but still need to build their skills and confidence by rote spelling tasks. Also it does not matter if the aid used is an alphabet board or a computer, the skills required are similar.

When you start to reduce the level of physical support it is often a good idea to go back to a more structured activity, one in which the person is confident of success. A general rule, in fact, is that if the pressure on the person typing is increased in any way—new staff, spectators, reduced facilitation, ill-health, whatever—reduce the level of task in order to maintain success. As the communication impairments of many people are worsened by their lack of self-confidence the aim is always to set the aid user up for success, and not to expose them to any avoidable failures.

It is important that the content of the activity be varied to suit the age and interests of the person: A child may enjoy a crossword about toys, a young man one about cars, and a young woman one about pop stars. Each person requires the same degree of structure but the content and level of difficulty can still vary.

It should be remembered that the list of activities is concerned solely with the development of spelled communication. It is not a complete list of communication behaviors. It ignores body language and eye contact, for instance, two vital communication skills we need to monitor in ourselves and our students.

4

Literacy—Caught or Taught?

Reading is surrounded by a number of myths:

1. *Reading is a skill that can only be acquired through formal teaching.*
2. *It is necessary to be able to talk before you can read.*
3. *Reading requires higher intelligence than does understanding speech.*
4. *Someone who cannot write, cannot read.*

SPEAKING AND READING

No one teaches a baby to speak. The baby learns from exposure. People make sounds around the baby and, amazingly quickly, the baby attaches meaning to those sounds. The baby starts to understand what the people around it are saying at about the same time as it starts to imitate the sounds they make. Eventually, any neurologically intact baby will learn to speak the language in which it has been immersed.

Those of us who learn to speak as babies have no memory of the process. Because learning to speak and understand speech is a baby skill, a skill achievable with a mental age of I, we overlook how enormously complex it is. Think of it.1 Think of all the different voices, volumes, intonations, and accents the infant is exposed to, not to mention the range of utterances and vocabularies. You say " puss," I say "cat," Nan says "pussycat," Sis says "kitty," and so on. The baby has to work out that we're all talking about the same animal, otherwise known as "Fluff," and the baby has to work it out

quickly. Spoken language doesn't hang around. Once spoken it's gone, and the baby can't say "I beg your pardon."

No hard evidence exists as to how much speech a baby needs to hear in order to start to decode speech, but our language decoders are obviously very efficient instruments. After all, most babies understand quite a lot of spoken words at I year, and they've spent a lot of that year sleeping. Even when they were awake they were unlikely to have people talking to them all the time.

The intrinsic differences between spoken and written language are the modes of transmission and reception. Speech is heard and print viewed. Speech is produced with the mouth and written language with the hands. Speech is auditory and print visual. There is no intrinsic neurological reason why visual language should be more difficult to acquire than auditory language.

One hundred and fifty years ago written language was a second language, learned after speech, with deliberate effort. As the teaching of reading followed the acquisition of speech, it was assumed that the one was necessary for the other, that is, that children could not learn to read until (and unless) they could talk. This view was held despite the existence of numerous deaf people who, following on the example of the Abbe de l'Epee [1], had been taught to read despite their lack of speech. Obviously children who cannot speak cannot read aloud. That does not mean that they cannot decode and understand written material, reading silently (as most of us do most of the time).[2]

Reading aloud is the translation of language from the visual mode to the aural mode—it has nothing to do with comprehension of written language, but depends on a knowledge of the relationships between the written and spoken forms of the language. This has become clearer since the development of the first speech synthesizers, in the 1970s. These translate written text into speech using text to speech algorithms that link specific sounds with specific combinations of letters. Their accuracy, at least in reading written English aloud, depends not only on the algorithms but on the length of the exception tables included with the algorithms. Written English is only partially a phonetic representation of spoken English and for a speech synthesizer to read written English aloud accurately it needs to have access to long lists of words whose pronunciation does not follow a rule such as "trough," "through," " tough," "thought," and "though." It is learning the exceptions that makes reading aloud such a difficult task for children to master, a task that may actually distract them from the more important task

of extracting meaning from the written language. As the speech synthesizer demonstrates, accurate reading aloud can be achieved with no knowledge of the meaning of the text being read.

Written language has an advantage over spoken language. It stays still. Even on the television screen, those ubiquitous brand names are there for 10 or 20 seconds. If that seems a short time, compare it with the half second it takes to *say* "Coca-Cola." Off the screen, on paper, on the can, it can be looked at again and again. This gives more time for decoding, an advantage for anyone whose processing speed is slower than average.

Forty years ago, before television, junk mail, and, supermarkets became universal, there were some children who learned to read before starting school. They were probably children from households where print was valued, where there were books and papers, and where the adults read to the children. Now that virtually every preschool child has considerable print exposure it is likely that the number of children who can read at least some words before they start school will increase.

LEARNING TO READ

Language is language is language—or so it appears. Whatever the differences between Japanese and English, any human child with intact sensory and neurological mechanisms will learn Japanese and English with ease if brought up in a household in which both Japanese and English are spoken. Until recently the written form of English was seen as harder for an English child to learn than spoken Japanese: While it was known that a preschool English-speaking child would pick up Japanese without formal teaching if the child went to live in a Japanese-speaking household, it was still thought that the same child would need to go to school to be taught to read written English.

What is the difference between written English and spoken English, and does the difference explain the difference in method of acquisition? Written English is a visual language and spoken English is an aural language—you look at one, and you listen to the other. There is some relationship between the two, but that in itself has no influence on acquisition methods. There is a relationship between Spanish and Italian, but it has no effect on the acquisition of either in isolation. We know that aural languages can be picked up from exposure—that is the way virtually all human infants learn

their native tongues. The important question is—Can visual languages be picked up from exposure? The answer is unequivocally " yes," and it comes not from research on written language but from research on sign language.

The sign languages used in deaf communities are visual languages and infants brought up in households where all or much of the conversation is conducted in manual sign pick up sign language in the same way that infants in speaking households pick up speech. They understand common signs before they can produce them. They "babble" (or fumble) in sign before producing their first recognizable approximations to adult signs. They simultaneously improve their sign production and increase the number of signs they use in the same way as learning speakers improve their articulation and increase their vocabularies.

The evidence indicates that we are equipped to acquire language, not that we are equipped to acquire a particular language or language in a particular mode. Consider the possibility that decoding print can be learned in the same way as decoding speech—that is, from exposure—and that it requires no more academic ability than decoding speech—that is, the ability of a baby. If so, there is no reason to assume that anyone who has the basic prerequisites of adequate eyesight, exposure to meaningful print, and motivation, will not be able to acquire some literacy skills.[3]

' The significant difference between written and spoken English that-has necessitated different acquisition strategies in the past is not the mode, but the amount of exposure to each mode available in everyday life. Above I said that the relationship between the two was no more significant than the relationship between Italian and Spanish—if you know one language it may make it easier to learn the other, but knowledge of one is not a prerequisite for knowledge of the other. A more illuminating relationship is the relationship between spoken Italian and spoken Latin—both are aural languages; they share many features, but one is usually acquired through exposure and one is only acquired through formal teaching. The difference of course, is the amount of exposure available and its source. In Italy, Italian is spoken wherever you go. While many people know Latin, it is only spoken in special settings, and cannot be learned unless you attend those settings. Italian can he caught, Latin must be taught.[4]

One hundred and fifty years ago, children went to school (if they were lucky) to learn to read. Relatively few homes contained books, and few books were written for or made available to the

young. Newspapers were comparatively expensive and were more often read in clubs than at home. Most lending libraries that did exist charged fees, and did not cater for children. There were no supermarkets, television, or junk mail. The new postage stamps were dear and letters uncommon in most families. Christmas and birthday cards were still to come. Consequently few young children had much exposure to print outside school. They went to school to learn to read, and the school readers were what they read. Before the nineteenth century the proportion of readers in the population was even smaller. Written language was even more restricted in its distribution and the chances of anyone acquiring written language through incidental exposure were insignificant.

The situation now is very different. In our society everyone, regardless of age or social class, is bombarded with written language. Our food and drink comes in packages with printed messages. A trip to the supermarket is a very meaningful reading lesson, supported by floods of advertising on television and through the letterbox. Junk mail, with its combination of words with pictures of familiar objects, is an ideal aid to decoding written language. In addition to junk mail we have real mail—bills and official notices, letters and greetings cards. Nearly every home contains newspapers and magazines, and most contain books. There are thousands of books for preschoolers, and lending libraries are free. The few households that contain little printed matter generally have television sets. Television projects a lot of written language, not just in deliberately educational programs such as Sesame Street, but in commercials, titles, credits, and subtitles. Commercials and titles especially are repetitive, accompanied by speech, and designed for quick recognition.

For the first time in human history large numbers of children are looking at sufficient visual language to be able to catch it, to learn to decode written language through everyday exposure to print. Babies are seeing written language from their cradles (or at least from their baby buggies). Most of them, certainly, do not see as much written language as they hear spoken language. The question is—are they seeing enough written language in meaningful situations (such as on babyfood jars) to crack the code? At what age will they have seen enough written language to recognize at least some words?

Presumably, given the necessary equipment and practice time, they could also learn to reproduce this language without formal teaching. Few parents give babies writing implements, for obvious

reasons, and so first attempts at replication are likely to be delayed in comparfson to first attempts at replicating spoken or signed languages, for which the only equipment required is the infant's own body. Consequently, the commencement of formal education is likely to occur at around the same time as the child first has the opportunity to start to reproduce written language, so it will be hard to separate "caught" from "taught" writing skills, at least until keyboards, which require less coordination and are less "dangerous" than pens or pencils, percolate into the nursery.

READING AND WRITING

Written language may have input advantages over speech, but it has output disadvantages. The print babies see is generally ready-made, Most of the surrounding written language is not produced by the people to whom the babies are closest, and this may reduce its interest and affect the babies' motivation to decode it and to reproduce it. They do not watch the production process in the same way as they see and hear the production process when their parents talk to them (or sign to them), so there is nothing to mimic. indeed, as said above, mimicking the production of written language (as opposed to sign) requires tools—pen and paper—not usually put into the hands of infants.

Writing is an act that requires considerable physical skill. The neuromuscular coordination required to write may not be as great as that required to speak, but it is nonetheless considerable, and the opportunities for practice are fewer.[5] Writing makes substantial demands on motor memory and motor planning. These are often problem areas for people with severe speech impairments, who may have as much difficulty with handwriting (and manual sign) as they do with speech.[6]

Babies understand more words than they can say, and older children and adults with severe speech impairments usually understand *much* more than they can say.[7] Similarly, 6-year-olds can usually read more than they can write, and older children and adults with writing impairments are likely to be able to read much more than they can write. Fortunately there are strategies for producing written language that do not involve handwriting—typing, pointing to letters on alphabet boards, moving magnetic letters or letter blocks (like a typesetter)—all these circumvent motor planning problems. For individuals with more severe physical problems a

large range of spelling strategies that require no hand skills is available. Many individuals who can neither speak nor write have successfully undertaken college education using alternative strategies for producing written language. In the same way that the decoding of print can be disassociated from the ability to read aloud, the ability to spell can be disassociated from the ability to write.

READING AND PEOPLE WITH SEVERE COMMUNICATION IMPAIRMENTS

People with severe expressive problems may have relatively minor or nonexistent input problems. It is vitally important to separate the two. If we judge what goes in, *and* what goes on inside, by what comes out, we are likely to underestimate the potential of people with expressive problems. If we overlook their potential to acquire literacy skills, we are denying them the most powerful alternative to speech available in our society.

Speech and comprehension, spelling and reading, are dependent on different pathways and processes. Just as we understand more words than we ourselves use in everyday speech there can be a discrepancy between the words we are able to read and the words we can spell.

Input/Internal Processes	*Output Processes*
Hearing/Comprehension	Speech
Seeing/Reading	Spelling (writing or typing)

If there is difficulty with the output processes (speech disturbance, inability to coordinate hands for writing) it is hard to tell how well the input processes are working just by listening to or looking at what a person is doing. To establish how much spoken or written language a person can understand it is necessary to use assessments and equipment that circumvent any expressive problems.

The myths about literacy that have dominated our approaches to reading have often led us to overlook the potential of people with disabilities to acquire and use literacy skills. Many individuals with severe communication impairments who have been labeled *as* intellectually impaired have acquired reading skills from exposure. Their families and teachers are in most cases unaware of their skills because their inability to speak or write has prevented them from showing anyone that they can understand written language. Some

individuals have behaviors (such as always buying certain magazines, or sitting down with a newspaper for half an hour every day, or taking a book to bed every night) that in people without disabilities would certainly have been viewed as associated with reading. Because their families and teachers have absorbed all the myths about literacy, because they do not expect these people to have those skills, they often overlook this evidence.

"Paul' has Down syndrome. His mother thought it was so sweet the way Paul imitated his sisters by sitting and pretending to read for an hour when he came home from school each day. He chose age-appropriate books, held them the right way up, turned the pages one-by-one, moved his eyes from left to right and down the page[8], but he couldn't speak well, enough to say what he had read and he could scarcely write at all so his family presumed he wasn't understanding the words on the page. At the age of 12, Paul was given a chance to type for the first time. He revealed good reading comprehension, an excellent vocabulary, and appalling spelling!

To ensure that individuals with disabilities have the opportunity to acquire literacy skills, it is important that they have the same exposure to print as their nondisabled peers. All children should be read to, with the book held in a position where they can see the pictures and the print. Children whose physical impairments prevent them from holding books or turning pages need recipe book stands or pageturners in order to be able to look at books. Children who tear books can be given cheap books, magazines, or junk mail to look at until they are able to care for lkoks.[8] The important thing is to ensure that every child, especially every child with severe communication impairments, has as much exposure to written language as possible. It can do no harm, and may do significant good.

Older children or adults with severe disabilities may have some acquired literacy skills regardless of whether they have had access to formal education. Observers may see incidents or behavior that indicate an interest in or understanding of written language. Maria always looks at the TV guide before she switches on the television, Liz went to the bookshelves and got the book her father had asked for, Tony puts on whatever song the staff ask for even though none of the records have covers, and Dean goes up to the notice board every time a new notice goes up.

Assessment of literacy skills in people who cannot talk or write requires patience and creativity. The materials used must be motivating and age appropriate. Multiple choice activities such as selecting the appropriate written word to complete a sentence, choosing

the cartoon that best matches a caption, or picking the correct written answer to general knowledge questions can be varied to suit different age groups and interests. Individuals with hand function impairments may need to be taught selection strategies such as finger or eye pointing in order to be able to make meaningful responses to multiple choice questions. The absence of effective selection skills should not be taken as indicating anything about the person's actual or potential literacy skills.

Obviously there will be individuals who do not demonstrate literacy skills on initial assessment. Some may have sensory impairments that have affected their ability to pick up on written and/or spoken language without special aids or teaching strategies. Some will have lacked the incidental exposure necessary to acquire written language without formal teaching (this is most likely to apply to people who have spent prolonged time in residential care and individuals whose caregivers are not literate or who do not speak the same language as the community at large). Some people may have had incidental exposure but not have taken any interest in written language, perhaps because they saw it as having no relevance to them. All of these people are likely to benefit from exposure to, meaningful written language, and all are candidates for literacy programs.

The importance of literacy skills to people with severe communication impairments cannot be overstated. Signing can certainly provide a powerful alternative to speech, but it is effective only for individuals with unimpaired handskills who live in signing communities. Most individuals with severe communication impairments have poor handskills and live among nonsigners. The only communication strategy that offers these people access to an unrestricted vocabulary is spelling. Without spelling skills the individual with severe communication impairments is restricted to using picture, sign, or word displays that have a limited vocabulary selected by caregivers, teachers, or therapists, and reflecting their views of what the person wants to say and how they should say it. Even poor spelling or the ability to identify initial letters will significantly expand a communication aid user's vocabulary options. Tina points to the symbol for "animal" and the letter "d"—Tina could be talking about dogs, donkeys, ducks, or dolphins. While her communication partner will have to ask yes/no questions to establish which animal Tina is referring to, this is more empowering than having either only a small number of specific animal symbols available or having to play 20 questions with the whole of the animal kingdom.

Spelling is the only strategy that allows individuals with severe communication impairments to communicate about whatever they choose in the words they choose.

Despite everyone's best efforts there will still be some individuals with severe communication impairments for whom the acquisition of literacy skills is difficult or impossible. Fortunately there are a number of nonspeech communication options such as picture and symbol displays that do not require reading or spelling available for this group. These options are also appropriate for use by young children and individuals in the process of acquiring spelling skills. As lack of speech should not be confused with inability to read, neither should inability to read be confused with inability to communicate Individuals who cannot spell may still need facilitation in order to point accurately to pictures or symbols.

ENDNOTES

An engrossing account of the development of deaf education is given in *Seeing Voices* by Oliver Sacks (Picador, London, 1989).

[2] This was not always the case. It was recorded, correctly or not, that St. Augustine was the first European who could read without moving his lips. The written European languages were developed as ways of recording spoken languages and they were taught as a representation of spoken language whose form varied with the pronunciation and conventions used by the writer. Instead of decoding visual language directly most readers translated text into aural language and decoded that. Direct decoding of written language, without intervening translation to the aural mode, was given impetus by the development of the printing press and the dictionary, which combined to give written language a standard presentation unaffected by changes in spoken language.

[3] That is not to say that there will not be some people for whom reading is difficult or impossible. There will be a small percentage of people who have word blindness in the same way as there will be a small percentage of people who have word deafness.

[4] Of course, this theory of language learning raises questions about what we mean when we say a language is "taught." It may be that a language teacher's role is merely to set up a situation in which the language can be caught—it may be that attempts to teach. language (any language) in the way that second languages were typically taught in my youth, largely by rote learning, were in fact counterproductive, that they delayed acquisition of the inner structure of the language by breaking the language up into externally imposed categories such as irregular verbs. If humans have, as appears to be the case, a knack for acquiring language in infancy,

then it is the acquisition strategies that work so effectively for infants that we should be capitalizing on in teaching all languages, at least for as long as they are effective. (There is evidence that we lose the wonderful language acquisition skills of infancy in later childhood.) While most of us did learn some French, German, or whatever language we were taught in school, we may have done so despite rather than because of the teaching strategies used. The teachers provided us with a little exposure to the language, so we learnt a little of the language. If we were keen students we also learned what ever our teachers taught us. To this day I can decline " voco," down to and including the pluperfect subjunctive passive. Sadly I still cannot decode a sentence of Virgil without a crib. Latin is a dead language, and all I picked up was its bones.

[5] As all the equipment for speech is built in, it is automatic for babies to try and use it, part of the developmental program they are born with. As the equipment for written language is not built in, there is no such automatic attempt to try to write.

[6] Many people who cannot write can type, because typing uses visual rather than motor memory. Of course, they may still have problems with spelling, and may still be able to decode written language better than they can spell it, in the same way as many people without disabilities can read words easily that they find difficult to spell.

[7] And when we are in a non-English speaking country we are likely to understand more than we can say.

[8] Some individuals who do not treat written material appropriately may still have reading skills—Don tore books and magazines because he found it hard to turn the pages, Lyn could not slow down enough to read a whole page, but both had excellent comprehension skills and went on to do well at high school.

5

Do's and Don'ts for Receivers of Nonspeech Communication

- *Do be patient*

We can talk at 150 words per minute; many communication aid users cannot communicate at 150 words an hour.

- *Do be confident*

Any nervousness or doubts on your part will certainly be transmitted to the aid user, often with disastrous effects on their confidence.

- *Do monitor your own communication*

Are you talking down to the aid user? Do you raise your voice when you talk to someone who cannot speak? Does your interaction consist largely of orders and prohibitions?

- *Do use the right method*

Find out exactly how the user accesses the communication aid and how it should be positioned, and be consistent. If possible, observe someone who is communicating fluently with the aid user and ask them to observe your early attempts. Achieve success in small things before aiming for in-depth discussion.

- *Do provide appropriate feedback*

In the early stages of communication it often helps the user if the receiver says each letter or symbol aloud as it is indicated, and repeats the utterance to date at the end of each word. Further on, the user will probably prefer it if their partner does not say the utterance aloud until it is completed (and then only if it is not private).

- *Do pay attention*

It is as important for the aid user to feel that you are interested as it is for you to feel the person you are talking to is listening. If the aid user is inexperienced, monitor the output, and warn the user if you cannot understand it, so that corrections can be made before there is an irretrievable communication breakdown.

- *Do offer word or sentence completions*

Remember, the purpose of aid use is communication, not a spelling test. Most aid users will appreciate it if you comple words wh the mean is obv You can see why this would be heIpf . But do be careful not to jump in too early and put words into the user's mouth.

- *Do look out for abbreviations*

Many aid users use shorthand to speed communication, such as RUOK ("are you ok?"). Some use unconventional or phonetic spelling such as NE for "any." Interpretation is a lot easier if the user is encouraged to put spaces between words—at least then you know where one "word" finishes and the next starts.

- *Do clarify meaning*

Many users produce telegraphic utterances (as I am sure I would in their place). A user whose communication system only has a limited vocabulary obviously has no choice but to make approximations. In these cases it is necessary to play 20 questions to ascertain the user's exact meaning. Make it a practice to ask the user if you've got it right at the end of each utterance—if the aid does not produce written output it is very easy for the receiver to muddle a sequence of words or symbols. The aid user is also as prone to second thoughts and confusion as the rest of us, but has little chance to have a second go if we don't check.

- *Do respond appropriately*

It is easy to get so involved in the process that one forgets that the user wants a response. You may need to ensure tactfully that others around the user also respond. It is very discouraging for someone to expend a great deal of effort to spell "Hi! How are you?" only to be ignored.

- *Do empower the aid user*

Arrange for the aid user to be able to make *real* choices (not just to "choose" to have lunch when it's lunch time anyway!). Act on the

aid user's requests and comments whenever possible, and explain and apologize if it is not possible.

- ***Do encourage aid use everywhere***

Our communication is not restricted to particular times and places. Neither should an aid user's be restricted. Inconvenience is not a good reason to refuse communication. If the situation is really difficult, for example, if the bus is waiting, ask if the communication is urgent (after all, the person may have mislaid something important or need the toilet). If the communication is not urgent, fix another time for a chat *and stick to it.* If there is a practical problem, such as not being able to use an electronic aid in the swimming pool, try and find a practical solution (e.g., a Perspex communication board).

- ***Do encourage the expression of feelings***

Many aid users have used their aids only to make choices or to answer basic questions. They need encouragement to enter into longer conversations and to reveal more of themselves.

- ***Do respect confidentiality***

If an aid user says something clearly not designed for public consumption, resist the temptation to pass it on, no matter how interesting or amusing it is. Remember, adults (and children) have the right not to have everything they say reported to their parents. If the user's aid produces written output make sure the tape is disposed of carefully unless it was produced as part of a specific educational program or you have the user's permission to keep it.

- ***Do keep up your side of the conversation***

Volunteer your opinions. Tell the aid user what you have been doing. It is slow and tiring for the user to ask questions and not unusual for the user to not receive an answer. The aid user is always asked to give information in response to your questions, and expects you to respond in turn

- ***Do recognize the effort and frustration involved***

Using a communication aid to give a message is far more laborious, and far more likely to be misunderstood, than giving the same message in speech. Consequently, it is important that unnecessary or repetitive questions are avoided, such as asking someone what they had for lunch when you just fed them.

- ***Do avoid testing***

Many aid users have very negative attitudes toward questions they perceive as testing and will often deliberately give wrong answers. Testing should be kept to appropriate situations, such as the classroom. After all, we are not required to establish our competence every time we open our mouths. If we were, we might not talk very much. The aid user who feels that every interaction is a test is likely to become resistant to the whole idea of communication. A no-fail question such as "What color do you like best, blue, or pink?" is more likely to get a response than a question such as "What color is the sky?"

- ***Do take the blame for failure***

If the communication attempt is unsuccessful, accept responsibility. After all, you do not have the excuse of having a communication impairment! A statement such as "I'm sorry. I'm not at my best today. Let's have another go tomorrow" helps the aid user to maintain confidence.

- ***Don't be negative!***

6

Getting Physical—Posture and Upper Limb Functioning

Pointing accurately to a small target such as a letter on a keyboard is a very complex task that most of us take for granted. Think of what is involved. First you localize the target, usually by looking at it. Then your brain computes where you are in space, where the target is in space, and the strength and direction of movement needed to hit it. At the same time it instructs your index finger to point, your other fingers to flex, and your arm to extend. If either you or the target is moving, the distance and direction have to be recomputed and adjustments to your movements made after you have started to point.

Top tennis players have brains that are very good at carrying out these recomputations and muscles trained to act at speed. Most of us cannot return Pete Sampras's serves but may still be able to catch a Frisbee. Those of us who cannot catch Frisbees and have difficulty coordinating our movements need to reduce the complexity of the tasks we face as well as work on specific skills.

Accurate pointing is more difficult if either the person pointing or the target is moving, so the easiest way to simplify the task is to make sure that both the person and the target are stable. The first element in providing a stable base from which to move is to provide appropriate seating. The second element is to develop trunk and shoulder control so that the body is maintained in an upright position with the shoulder girdle horizontal and not subject to unpredictable movements. In facilitated communication proximal stability is sometimes increased by the application of firm pressure at the shoulder, but the long-term aim is for each individual to increase his or her own stability so external pressure is unnecessary. Finally,

accurate pointing at a small target or use of a keyboard requires the ability to use one finger in isolation.

GIVE ME A SEAT—I HAVE SOMETHING TO SAY

Stable, functional, and comfortable seating is essential for carrying out everyday tasks such as using a knife and fork and writing or typing. Physical performance is intimately associated with good seating. Poor posture further restricts the ability of people with physical limitations to do tasks and to observe their environment, and may lead to painful physical deformities or retard their overall development. Many individuals who need to use communication aids have significantly impaired hand function that will be further diminished by inappropriate seating.

Children who have not learned or experienced postural stability may have to apply a continuous conscious effort to sitting. Unless they have appropriate postural support their ability to concentrate on tasks such as school work and communication can be severely impaired. With conditions such as cerebral palsy there is also a need to encourage maximum function by inhibiting undesirable movement patterns and reflexes

General Principles of Seating Provision

An appropriate chair will have the following characteristics:

1. Provide stable postural support.This has particular relevance for users of microcomputer systems and/or communication aids, who must have sufficient support and control of their head, trunk, and limbs to enable them to see a display screen and use a keyboard or switches.
2. Allow the person access to a stable working surface (a wheelchair tray or a table) of appropriate height.

Firm Base of Support

The most important aspect of seating is a FIRM BASE OF SUPPORT. Without this any person's hand use is severely impaired. An upright chair of appropriate size that has any padding firmly attached to a rigid seat is most suitable for people using their hands.

The pelvis provides the base of support for the upper body. If

the pelvis is not positioned firmly and symmetrically it will not provide the support necessary for arm movements and may contribute to spinal deformity.

People with lateral instability may be helped by using a chair with a narrow seat and high arms. Care should be taken to ensure that the chair has a wide enough base to prevent it from tipping if the person leans to one side. People who have difficulty maintaining hip flexion, and who tend to slide forward on the seat can be helped by covering the seat with high-friction fabric, such as the webbing that is used to prevent rugs and bath mats from slipping. This fabric may also be used on the work surface to prevent the communication aid from sliding away.

Seating for People with Low Muscle Tone

People .with low muscle tone find it harder to hold up their bodies and arms against gravity. Most people with Down syndrome have low muscle tone, as do many other people with developmental disabilities. Having chairs and tables of a suitable height is especially important and particular attention needs to be paid to those peolple who are shorter than average. A firm base of support will be provided if the following points are followed:

1. The ankles, knees, and hips should be at right angles. The feet should be flat on the floor or a firm surface. If the seat is too high the chair legs should be cut to the correct length or a stable footrest provided. The rungs of a chair do not provide an adequate support for the feet. If the seat is too low blocks under the chair legs may be used to raise it. If this is not possible a firm cushion can be used (several posture cushions are available commercially). If posture cushions (Figure 6.1) are to be used it is essential that they are firmly secured to the chair and do not slip. The best solution is gluing. It is important that the cushion is firm and not too soft, as softness will promote a slumping.
2. The length of the seat should, be long enough to give adequate support to the thighs.
3. The person should be encouraged to sit well back in the chair, not perch on the edge of the seat (Figure 6.2).

People with low tone have their ability to use their hands affected by the height of the work surface or table. If this is too high they

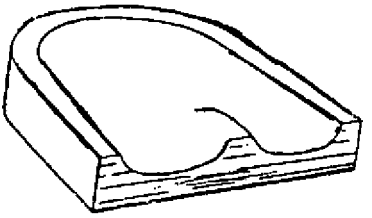


Figure 6.1. Posture cushion (Thera-peutic Pillow International).



Figure 6.2. Use of posture cushion to adjust height and angle of seat.

will tire quickly. Armrests on a chair can provide support for elbows and forearms, but may be cumbersome. If armrests prevent the person from drawing his or her chair close to the table this will result in undue strain and lead to early fatigue.

Tables should be high enough for people to be able to sit close with feet underneath and forearms resting on the table surface. The correct height of the table depends on the task to be undertaken. For writing the forearms should be able to rest comfortably on the table, but for keyboard work the table should be lower, just above the thighs. Alternatively, it may be best for the person to work with the keyboard or communication aid on his or her lap. The ideal way to accommodate the work surface requirements of groups of people who are of different heights and use different chairs is to use adjustable height tables. The most suitable of these allows the angle as well as the height of the table to be•adjusted and have bases that are horseshoe shaped, thus providing unobstructed space for the chair to be wheeled into the open end.

Height adjusters and cushions may be the only way to modify the molded plastic chairs with metal legs unfortunately favored in many schools.

A Quick Checklist for Good Seating

The checklist is useful for ensuring that a person is sitting comfortably and is ready for work. Is the person sitting

1. well back in the chair with spine as close as possible to the middle of the chair back?
2. with feet on a firm base either on floor or footplates with toes pointing to front?
3. with knees in line with hips?
4. with thighs adequately supported—that is, is the seat long enough, ending two fingers short of the back of the knees?
5. with arm rests of the right height, so that the shoulders are not drooping or hunched?
6. with the head facing the task to be undertaken and not the floor or ceiling?
7. with the work surface at the correct height in relation to the seat and to the task to be undertaken?
8. comfortably?

All the answers need to be in the affirmative to optimize hand function.

SHOULDER GIRDLE ACTIVITIES

The muscles of the shoulder, upper body, and arms must be strong to permit good hand function. The muscles of the upper body act as stabilizers so that the hands can perform tasks accurately and effectively. If these muscles are weak a person will find it hard to sustain an activity such as using a keyboard because he will be unable to maintain his hands in the correct position.

Paul has Down syndrome and low muscle tone. Because of this he hasn't played much sport. Correspondingly, his low muscle tone was complicated by low muscle strength–Lhe hadn't been using his arm and shoulder muscles as much, as other children, so they were weaker. When his family realized the problem they started going to the local pool regularly, where Paul swam laps. Also, Paul's father put up a basketball hoop on the garage and Paul spent half-an-hour each evening happily shooting baskets when he came home from school. Not only did Paul's typing improve; he developed skills that helped him to participate successfully in group sporting activities at school.

An important factor in developing and maintaining muscle strength is participation—participation in all those activities of daily life that are routine for children and adults without disabilities, activities such as carrying shopping, housework, and gardening, as well as swimming and ball games. Following is a short list of activities that will strengthen the arm and shoulder muscle groups—obviously there are many others.

- volleyball
- basketball/netball—shooting goals
- swimming
- tug-of-war
- washing the floor on hands and knees with a cloth
- using a squeeze mop
- using a broom, especially outdoors
- raking leaves
- washing windows and mirrors, especially above shoulder height
- putting things on high shelves
- scrubbing the bath or the shower recess
- digging in the garden
- doing pushups
- hanging out the washing or bringing it in (winding the line up high)
- painting large surfaces such as fences or walls
- climbing—gym ladders, monkey bars, climbing frames, or ropes
- squeezing oranges or lemons
- cleaning the cobwebs from the ceiling
- changing light bulbs
- rowing (or using rowing machines)
- weight lifting (or wearing wrist weights while doing other activities)
- upper-body aerobics
- mowing the lawn, with a hand mower
- pushing prams or shopping carts
- fruit picking

If the person has a history of arthritis, fractures, contractures, dislocations, or other painful hand or arm problems, do consult a therapist before undertaking any activities.

People with motor-planning problems may need initial assis-

tance in developing the movement patterns necessary to succeed at specific activities. For example, Don positioned himself behind Tom and placed his hands over Tom's so he could help Tom catch and throw a basketball. He reduced his input as Tom's skills improved.

IMPROVING FINGER-POINTING SKILLS

Despite what our mothers told us, it's not always rude to point. Pointing is a very useful skill and is especially important for people with severe speech impairments, as it offers a powerful means of augmenting their speech. An infant may point at the toy they want, an older child may point at symbols on a communication board, a teenager may type.

For effective finger pointing you need to be able to extend one finger, usually the index finger, of the preferred hand while keeping back the other fingers. You also need to have the eye-hand coordination to line up the finger and the target.

Problems

The main problems we have seen with finger-pointing and some remedies are:

DIFFICULTY ISOLATING ONE FINGER

That is, difficulty extending one finger while keeping the others back. The student should be encouraged to do exercises using only one finger. It may be necessary to hold the other fingers back at first until the isolation becomes habitual. Some children wear an old sock with a small hole cut in it pulled down over the dominant hand and held at the wrist with a tie, so that only the index finger can extend through the hole. This should be used only while using a communication aid or doing pointing exercises. If index finger isolation shows no improvement after a few weeks of exercises, seek further advice from an occupational therapist.

WEAKNESS

That is, there is difficulty stiffening the index finger and applying pressure. Preference should be given to finger exercises requiring pressure, and every effort made to ensure that the finger remains straight when pressing. Splints are used as a last resort in the rare instances where the exercises do not produce sufficient improvement. We do

not encourage the early use of splints or the provision of finger support by facilitators because these strategies are unlikely to result in the strengthening of the finger muscles and therefore entail continued dependency on splinting or facilitation.

WOBBLE

That is, the finger moves from side to side, resulting in uncertainty as to the selection wanted or, if a keyboard is being used, producing typing errors. As for weakness, preference should be given to exercises involving pressure. The stability of the wrist should be assessed as well as the finger. Often the problem with the finger is produced or made worse by the wrist's lateral instability. If this is the case, exercises to strengthen and balance the arm muscles will also be needed.

POOR EYE-HAND COORDINATION

That is, pointing without looking or failing to keep the eyes on the target, resulting in incorrect selections. Any activities involving selection from a set of items may be used for eye-hand coordination practice. Choose materials that are as interesting and age appropriate as possible—say picture books and insert puzzles for a preschooler, jigsaws for a primary student, pop stars and footballers for a teenager. The activities are meant to be fun, not a test. The sole aim is to ensure that when students point they are looking at where they are pointing. It does not matter if the pointing is coactive at the start, as long as the students keep their eyes on the target.

Many individuals have more than one of these problems. Sometimes this means they need to do several kinds of activities to remedy all their difficulties, sometimes it is possible to find an activity that addresses more than one problem. For example, the Touch and Tell, made by Texas Instruments, is a toy with bright picture overlays that speaks when the overlay is pressed. It requires firm pressure to operate it, so it can be used to address weakness and wobble problems as well as provide a good stimulus for eye-hand coordination training.

Some activities require more supervision than others. Care should be taken at the start of all activities to ensure that the movements are being performed correctly—it is, unfortunately, perfectly possible to operate a Touch and Tell with the whole fist without looking at all, but of course no improvement in finger pointing will result. Supervised exercises for 5 or 10 minutes a day usually produces rapid improvement in index finger isolation and strength.

Sometimes caregivers and teachers feel it is easier to give a student a splint or a pointer than do exercises to compensate for index finger isolation and weakness problems. While it is quicker initially, consider the time needed to make and hunt for pointers/splints in the future. If we can improve the students' own hands, we are giving them skills they will have for the rest of their lives. We think it is possible to develop independent index finger pointing skills in almost all individuals with developmental disabilities who do not have severe cerebral palsy or hand deformities.

As students improve their pointing skills it is important to encourage increased independence. Students can be encouraged to point independently to desired foods, drinks or activities when appropriate. The support offered to students using facilitated communication should be reduced as their finger pointing improves. Students who can isolate their index fingers do not require their hands held, though they may still require wrist support to counteract other problems, such as tremor.

Following is a short list of activities that can be used to encourage finger isolation and to strengthen the index finger. All may be done coactively if necessary. Do make sure the student looks at what he or she is doing.

- Poking holes in balls of clay, plasticine, or PlaDoh.
- Poking holes in plastic wrap stretched over a bowl.
- Pushing finger into a balloon. (Watch out!)
- Drawing *with the tip of one finger* in fingerpaint or shaving cream on table or mirror.
- Using toys with push buttons or dials (e.g., toy phones).
- Using educational toys that require pressure to make a selection, e.g., Touch and Tell.
- Pushing holes in soil to plant seeds.
- Pointing to pictures or parts of pictures.
- Pointing to pieces from insert board or jigsaw puzzle to show you what goes where.
- Playing picture lotto, dominoes, and card games where matching items can be indicated by pointing.
- Playing keyboard toys or musical instruments—again, played with only one finger.
- Making collage pictures by pointing to item wanted and then to the place on the paper where it should be pasted.
- Tracing patterns and shapes in wet sand.

Remember to make use of everyday situations (flushing the toilet, turning lights on and off, pressing pedestrian buttons, selecting a TV channel, operating a cassette player, dialing the phone, operating household equipment, etc.) to develop index finger skills. These not only develop pointing skills, they are motivating and necessary activities in their own right.

Reducing Support—Increasing Independence

Facilitated communication training is used with people with severe communication impairments who are not yet able to access a communication aid independently but for whom independent direct access using their hands is a realistic and desirable goal. It is part of a process and not an end in itself.

Communication aid users may initially need physical assistance from their communication partners while they develop specific skills such as index finger isolation. As the aid users' skills increase the amount of physical assistance they receive should diminish. The ultimate aim is for the users to access their communication aids with no physical contact from their communication partners.

This aim is not always achieved. There will be some people who commence facilitated communication training but find that even after considerable training, independent aid access is still impossible, or at least still so slow and arduous so as to severely limit their communication. These people need their communication strategies reviewed. They may change to indirect access (using a scanning system), they may continue with direct access in another modality (eye-pointing, for instance), or they may elect to remain facilitated, perhaps being independent in some situations arid not others.[1] However, this group is a minority and the presumption when starting facilitated communication training should be that the user will eventually move on to independent access.

To ensure that users do not become overly dependent on their facilitators it is important that all facilitators are aware from the start that independence is the goal. It is also important that attempts

are made to fade support as soon as a person starts to use a communication aid successfully with facilitation.

The first step in reducing dependency is for all communication partners to give the minimum support required for communication to succeed. The second step is to ensure that the aid user communicates with as many different partners as possible. In order to successfully fade support it is necessary to know what problem or problems the individual had that needed facilitation in the first place.[2]

Some problems are remedied directly by the facilitation process. Eye-hand coordination problems, for example, usually improve quite rapidly if facilitators consistently refuse to allow aid users to make a selection unless they are looking at their aids. In this case it is easy for facilitators to monitor improvement in users. Facilitators record the number of times each aid user has to be reminded to bring his or her eyes back to the task in a 5-minute period. As soon as it is routine for a user to get through 5 minutes without a reminder physical contact should be withdrawn as quickly as is possible without the aid user regressing. Spoken prompts may initially be needed as a substitute.

Other problems may require other therapy in addition to the communication sessions themselves, or may require the aid user to learn special strategies. Low muscle tone and weak fingers require specific exercise routines or adaptations in daily activities to build up muscle strength. Some aid users who have difficulty isolating an index finger may be able to type without hand support when holding a pen in the palm, of the typing hand with their other fingers. People who have difficulties with perseveration may be helped by learning to hit a dot on the table after typing each letter. [3]

Other factors may also affect independence. Some people have variable muscle tone, and may be able to type independently one day but not the next. Some people are independent in familiar surroundings with familiar people, but out in public become nervous and seek support. It is important to provide the temporary support needed in these situations. Not only does the individual have a right to communicate, the nervousness is only going to be cured by an increase in confidence, and this is unlikely to occur if the person experiences communication failure or frustration when out in public.

Environment is an important factor in independence. A person with a tremor is not going to be helped by sitting on a chair that won't let their feet reach the floor. A person with low muscle tone is far more likely to be independent if the communication aid is

positioned as low as possible, to minimize lifting against gravity. A person who is visually distractible will require fewer prompts to keep his or her eyes on task if facing a wall rather than a window looking on to a busy corridor.

There is a continuum in the provision of facilitation, running roughly through the stages listed below. Some of these stages are illustrated in Figures 7.1a-7.1h.

1. hand molding
2. rod (user holds rod while facilitator holds other end)
3. wrist support
4. forearm support
5. sleeve or elbow support
6. upper arm pressure
7. shoulder pressure
8.. shoulder touch
9. physical contact with another part of the user's body[4]
10. independent access

Each person starting facilitated communication training needs a different level of support. It is important that everyone working with an individual is made aware of his or her particular support needs, and that no one provides more support than the minimum required. Where there are a number of aid users requiring facilitation it is understandably common for staff to adopt a lowest common denominator approach, all users being offered the level of facilitation required by the most dependent because that is guaranteed to succeed with everyone. Such an approach will almost guarantee continued dependence. If fading is to succeed it has to be individualized, has to be applied consistently, and has to start from each individual's baseline level of support.

Dependency may be related to aid and position. Many people with low muscle tone are initially more independent standing up, when they don't have to raise their arms against gravity. Such people may be independent using devices with small keyboards (such as the Canon Communicator) but still require some support when using a larger' keyboard on a computer or typewriter. Some individuals can type without physical contact if their partners hold the communication aid low (and in this situation the partners' direct involvement may also provide emotional support and encouragement).

While independent communication is worthwhile even if it can be used only in certain situations, and while this situational inde-



Figure 7.1a. Hand molding to obtain index finger isolation.

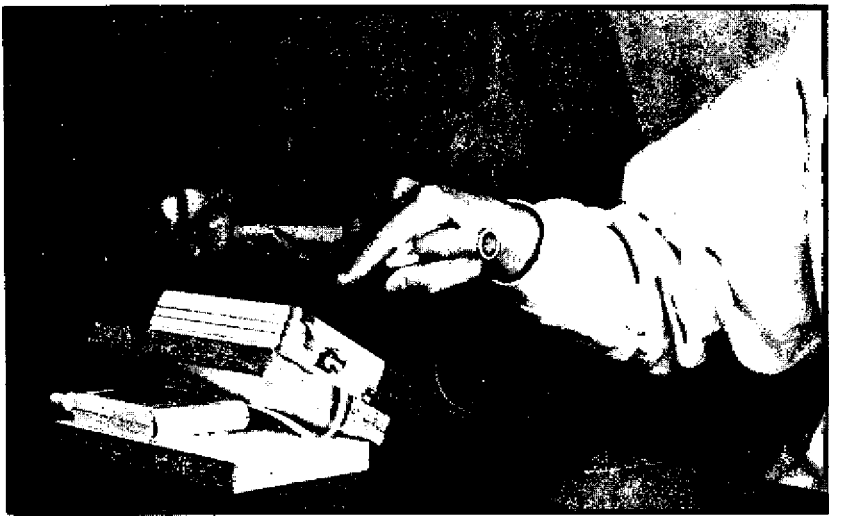


Figure 7. *lb.* User holds *a* rod while facilitator holds the other end.



Figure 7.1c. Wrist support.



Figure 7.Id. Sleeve support.



Figure 7.1e. Elbow support.

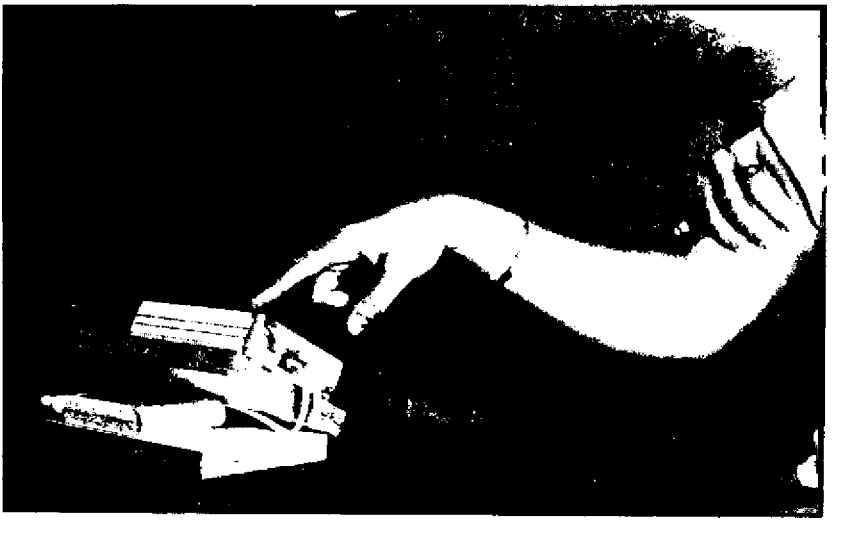


Figure 7.1f. Upper arm pressure.

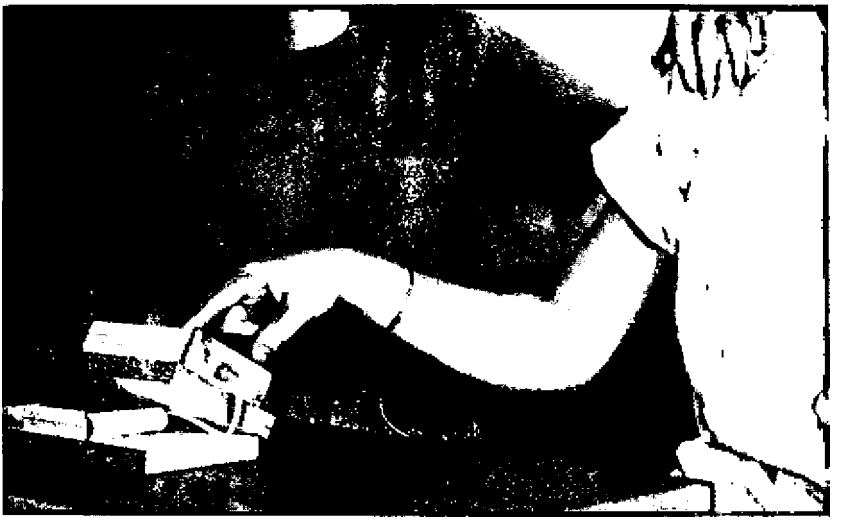


Figure 7.1g. Shoulder pressure.

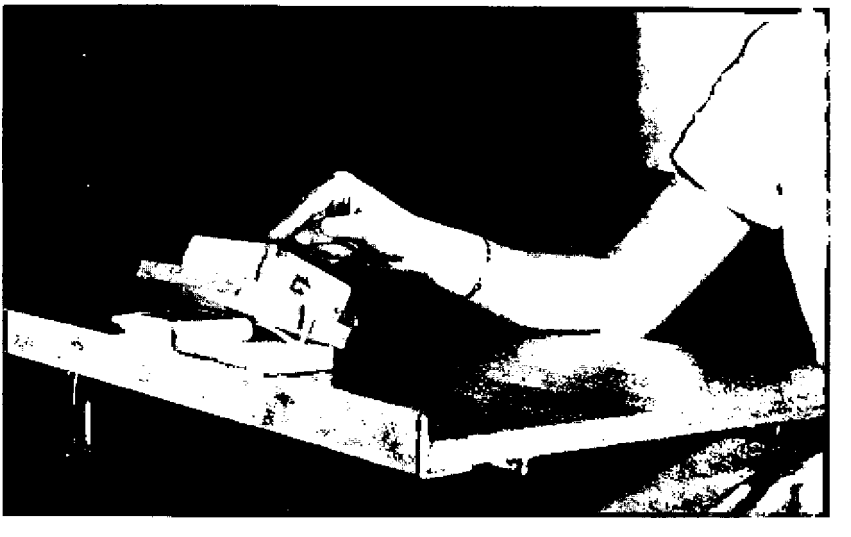


Figure 7.111. Independent access with elbow supported on table.

pendence may be useful in validating a person's communication skills, the ultimate goal for all aid users should be the kind of independence that allows them to access all their communication aids in the most convenient mariner. In the main this will be while the aids are on an appropriate height table. Correspondingly, during the period of fading support it is important to record at each stage the aid or aids that were used, the position of the aid, and the position of the individual—"shoulder touch when seated with Canon Communicator held low," for example—so that meaningful comparisons and evaluations of progress can be made. In order to monitor progress in increasing user independence it is essential to maintain complete records. The records will not only encourage continuance of the program but also identify problems or plateaus so that help can be sought.

The aim of every augmentative communication program is for the students involved to communicate with those around them as fluently and independently as possible. A reduction of support often initially results in a loss of speed and accuracy. It is important to ensure that students understand the aims of the program. They should never be made to feel that fading is a test, and that they have failed if it doesn't work out. Jane, for example, has low muscle tone. She types short sentences well with just a touch on her shoulder. However, she soon tires and starts making many mistakes. When this happens her facilitator offers her more support so she can finish what she wanted to say. Withdrawal of support should be a flexible process and aid users should feel secure in the knowledge that they will never be left unable to communicate.

Independent communication is the best kind, but even the worst kind of communication is much better than none at all. Independence is a valuable skill; communication is a basic human right.

Two model record forms are attached, one for the use of individual facilitators (Figure 7.2) and one for centers such as schools, adult centers, or residential units (Figure 7.3), which need to monitor the performance of aid users with numbers of facilitators. The individual form may either be filled in after every session or at a specific session once a week. The group form should be filled in at least once a month—some centers pass around a folder at their staff meetings containing a form for each person needing facilitation. The person in charge of the communication program should regularly review the updated forms to monitor trends so gaps or discrepancies can be investigated. For example, on the sample form several questions arise: If Joe is using his aid with just shoulder

Figure 7.2

Individual Facilitator's Client Record

Client: Jane Smith *Facilitator:* John Brown

Date	Level of Support	Equipment Used	Position of Client	Position of Equipment	Task
3/2/92	3	Canon	Sitting	Table	X-word
10/2/92	3	"	,	"	Sentence completion
17/2/92	3	”	”	"	Captions
24/2/92	4	"	"	'	X-word
3/3/92	4	"	"	"	Conversa-tion
1013/92	3	Typewriter	"	'	Missing letters
17/3/92	4	Canon	"	"	Cloze exercise
24/3/92	6 (pressure)	"	"	Canon held low	Sentence completion
7/4/92 . _	5	"	"	Table	Captions
14/4/92	5		”		Conversa-tion

The level of support recorded should be the least support at which communication was successful during the session.

Legend: Amount of support required

1. Hand molding
2. Stick
3. Wrist support
4. Forearm support
5. Sleeve or elbow support
6. Shoulder pressure/touch
7. Other body contact
S. No physical contact

\- No opportunity X No success

Figure 7.3

Center:

Client Record

Client: Joseph Blow

Date / Staff Member	9/8	3/9	25/10	29/11		
Kaye	3	3	6	6		
Annette	—	—	—	—		
Catherine	3	3	3	3		
Kerrie	—	—	—	—		
Janice	3	3	x	3		
Laurie	—	—	—	—		
Mark	—	—	—	—		
Linda	—	—	—	—		
Susan	—	3	x	3		
Debbie	—	—	—	—		
Hedda	5	5	—	—		
Don	—	—	—	—		
Veronica	—	—	—	—		

The level of support recorded should be the least support at which communication was successful.

Legend: Amount of support required

1. Band molding
2. Stick
3. Wrist support
4. Forearm support
5. Sleeve or elbow support
6. Shoulder pressure/touch
7. Other body contact
8. No physical contact

\- No opportunity
X No success

pressure from Kaye, why haven't other facilitators reduced their support? Why has Hedda had no opportunity to talk with Joe for 2 months? The number of Joe's communication partners appears to be static: What can be done to involve more staff?

ENDNOTES

I People who cannot access a large display or a keyboard without facilitation may be able to access a smaller number of items independently. This should be encouraged, both because it may lead to independence with the larger displays and because of the empowerment (and protection) it provides immediately. Being able to point to "yes" and "no" independently enables advisors to confirm or deny their facilitated communication. Being able to make clear, reliable selections from four items allows students to answer multiple choice questions.

If there is any doubt, contact the agency or therapist who started the training program.

[3] Individual needs differ, and the appropriate strategies for each individual will vary. Again, the agency or therapist who set up the training program will be able to help.

[4] Sometimes for emotional reasons, sometimes to improve proprioception, and sometimes to maintain on-task behavior; some people with autism, in particular, seem to find it hard to maintain attention without some tangible reminder that they have "work" to do.

8

Word-Finding Problems

WHAT IS A WORD-FINDING PROBLEM?

It is the inability to say or remember the word one wants. Sometimes the wrong word is said; sometimes nothing is said at all. The problem has been likened to going into the pantry in the dark to get a jar of honey and picking up a jar of marmalade instead or being unable to find a jar at all and coming out empty-handed.

We all experience this occasionally. In the supermarket queue you find yourself next to your child's teacher from last year. "Oh," you say, "How nice to see you, Miss Um-Er. Are you still teaching?" After you get home you remember that her name was Miss Gilbert.

You consider yourself reasonably intelligent, but could you remember the answer to questions if you were on a quiz show with a buzzer to push and an audience in front of you?

If you were asked, this minute, to name your neighbor two doors down, the chances are you would say "They're the .. . uh ... urn I'll think of it in a minute."

Can you imagine what it might be like to have this problem all the time?

WHY DOES IT OCCUR?

The use of language requires many functions of the brain to work together. Impaired development or damage of one or more functions or areas of the brain may interfere with the easy production of speech or language. The term expressive aphasia (or dysphasia) may be used in relation to someone with a word-finding problem.

It is thought that written and spoken language have different pathways, one of which may be stronger than the other.

One mode may be affected more than another, and a person may be able to recall words visually more easily than auditorily (or vice versa), and may write them more easily than say them. Words may be more easily recalled automatically, as in singing a familiar song, giving greetings, or swearing, than when the person makes a deliberate effort to remember, because different pathways are used in the brain for reflex or automatic speech than for planned speech.

It is important to note that difficulties with word-finding do not necessarily affect understanding or processing of spoken or written material.

WHICH WORDS ARE MOST DIFFICULT TO FIND?

PrObably the most affected words are nouns, especially proper names. The problem is less noticeable on adjectives because it is easier to find a substitute. If you want to say a truck is "big" you can quickly alter your sentence to say the truck is "huge" or " gigantic" or "massive." It is not so easy to change if you are asked when you go swimming and you can't retrieve the word " Wednesday." Your choices may be to say nothing and be thought not to understand the question, or to say "Thursday" and, hope it doesn't matter that you have got it wrong. Even "yes" and "no" may be a problem, with the person saying "no" when they mean "yes" or vice versa.

ARE THERE ANY COMMON ERROR PATTERNS?

Yes, several. These are the main ones:

1. *Associative*— calling an anchor a hook, for example, based on visual resemblance.
2. *Phonic*— saying "chair" when the wanted word is "chop."
3. *Categorical*— saying another word in the same category such as "pea" for "bean" or "Sydney" for "Melbourne."
4. *Functional*— saying "eat" for "fork" or "do hair" for "comb."
5. *Echoic—like* a cracked record, repeating oneself in an effort to find the correct word, or answering one question correctly and then giving the same answer to the next different ques

HOW DO PEOPLE REACT TO WORD-FINDING PROBLEMS?

THE SUFFERER

Often a person with a word-finding problem does not respond to questions at all, for fear of saying the wrong thing, or says "I don't know" when the true answer may be "I know, but I can't say it,"'or gives an incorrect answer to please people rather than not give an answer at all. They may say the wrong word and be too embarrassed to correct it or still be unable to find the right word even though they know their answer has been wrong. If the problem is severe they will be unable to explain their difficulty. We have strategies like "I know the face, but I can't think of the name" and " Give me a minute and I'll think of it" that the person with a severe problem cannot use.

THE LISTENER

If the nature of the problem is not recognized the listener thinks the person is uncooperative, deaf, or lacking in understanding.

Word-finding problems are not well understood, even by professionals. We all operate on the basis that a person's speech reflects the person's thoughts. For the vast majority of us this is correct, and it is hard to comprehend the difficulties of those for whom this is not true. Having some, unpredictable speech may cause more problems than having none. Sally's teachers punished her for being stubborn every time she failed to answer a question. Of course, the tension this caused made the problem worse. John had problems with "yes" and "no." His teachers decided that the way to make him learn was to act on his responses as though he meant them. John missed ice cream and outings because he said "no" when he wanted to say " yes." It was not surprising when he became a behavior problem.

WHAT TO DO

- Provide a supportive, uncritical environment. Reassure the person that you understand their difficulties.
- Give opportunities for correction. Say "Is that what you meant?" or "Are you sure?"
- Offer another method of communication. Some people can use spelling instead of speech. The different modality helps,

perhaps because it is slower and less automatic. The difficulty may still be present in typing but generally is less than in speech. If this is so, encourage the person not to talk while they are typing. Typing may be more successful than handwriting because people with word-finding problems may also have problems with motor memory and motor planning which impair their ability to write. The worksheet in Figure 8.1 illustrates this.

- Use strategies to assist speech. If you know what the word is that is wanted you may be able to give a clue. For instance, if the word is "chair" you might say "It's got four legs and you sit on it." You may be able to cue the correct word by saying " You sit on a . . ." or you may cue phonically, "You sit on a ch . ." You may also cue by association, by saying "Table and.. . ." All these strategies would have helped Sally and John.
- If the person is getting very uptight, come back to it when more relaxed—it's not the end of the world.
- If the person just can't get something out, it may be a proper name—perhaps you could offer suggestions or alternatives.
- Remember that the person may want so badly to get out his words he may give any word at all if he can't find the right one. Give reassurance and an opportunity to correct.
- If the person can't get the next word when typing read back what has been typed already. Say "You've typed 'He sat on the ...'—that's right, you know what it is."

Remember (teachers especially)—if someone has a word-finding problem, speech is not going to provide an appropriate means of assessing knowledge. Some children with relatively minor word-finding problems can read aloud accurately because the cue given by the written word enables them to overcome their difficulties. Those with more severe problems cannot, though their reading comprehension may be unaffected.

Written language may be less affected than speech. A child asked the capital of the Australia may say "Melbourne" but type " Canberra." Sometimes production of written language is as severely affected as speech production, in which case multiple choice assessment will provide the student's best chance of success. Linda could not say or write the capital of Victoria, but she could select "Melbourne" correctly from a list of the state capitals.

Understandably, lack of confidence is often a pervasive sec-

Figure 8.1. Comparison of spoken, written, and typed responses.

This worksheet was completed by a student using three modes—speech, handwriting, and TYPING . Her spoken replies reflect her marked word-finding problems, and her handwriting shows the effects of motor planning and motor memory problems. Her internal language is more sophisticated than she can display in either speech or writing. It is only when the motor demands of expression are reduced by using a typewriter that she can demonstrate this.

What Happened Next?

The baby pulled the cat's tail.	Get hurt THE CAT SCRATCHES THE BABY
The milk boiled over.	Spilt everywhere IT SPILT EVERYWHERE
The car went through a red light.	Stop immediately MAN COULDN'T STOP HE HAD BAD BRAKES
The policeman knocked on the door and called out:	Shouting very loud STOP MAKING SO MUCH NOISE DONT YOU KNOW ITS LATE
The dentist asked John:	Want your teeth out DO YOU WANT YOUR TEETH OUT
Nt dhr tie, tit.b	
Last week Jane went to the zoo and	Saw some animals at the zoo
SotAir 5D'' 2, aArYG6u5 outu i/e/ Z 0 -v	SAW SOME ANIMALS AT THE ZOO
Tomorrow I would like to eat some food	Eat *some food* EAT SOME FOOD AT MCDONALDS

ondary problem for people with significant word-finding difficulties. Try and imagine what it would be like to be perpetually uncertain about what (if anything) would come out when you tried to talk. To counteract this it is important that those around the person are informed of the problem and that every effort is made to ensure each interaction finishes on a positive note.

People with, word-finding problems should be given access to specialist help. Speech pathologists can advise on strategies that can help them to get their messages across. Options include cueing the person with the initial sound of a troublesome word (if you know what they are trying to say), providing a book of words or pictures for self cueing, or using an augmentative communication strategy such as writing or typing.

9

Assessment of People with Severe Communication Impairment

People with severe communication impairments are often given intellectual or academic assessments by psychologists or teachers who are unaware of the exact nature of their neuromotor impairments and the effect of these on the assessment process. Unfortunately many people with severe communication impairments have been 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 would be restricted.

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. Even more commonly, individuals will be found who require special training or equipment before they can be assessed accurately. These individuals should be given access to these resources without prejudice. The term " unassessable" means just that, and should not be thought of as a synonym for profound intellectual impairment. We all have an obligation to every person we assess to ensure that our testing is fair, and that the tests we use do test what they purport to test—that is, that the vocabulary test is purely a test of vocabulary, not simultaneously a test of visual or hand skills.

SELECTION OF TEST MATERIALS OR STRATEGIES

Choosing an appropriate test or assessment strategy for people with severe communication impairments is not easy. As with all testing,

the first step is to decide what you're testing and why. A standard IQ test is of very little use in ascertaining whether Joe will be able to live independently, and if that's what you want to know then the necessary information is more likely to come from completion of a skills inventory.

The measure used has to be appropriate for the person's age and disability. Developmental screening tests such as the Denver or Bayley, 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. A pediatrician used the Denver Developmental Scale to assess Anne McDonald, a quadriplegic, when she was **17** years old. She failed to reach for the plastic ring he dangled in front of her and he gave her a mental age of 6 months. In addition to overlooking her quadriplegia he had also overlooked the fact that normal teenagers do not grab at plastic rings.

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. The aim is to find a way of assessing the desired skill that does not require responses that are difficult or impossible for the individual with severe communication impairments. In the case of reading, comprehension tests with multiple choice answers are often useful if the student has adequate pointing skills.

Oral Responses

Performance on tests requiring oral responses (such as the WAIS or WISC) is adversely affected by speech impairments and is likely to understate the person's true capacity. People who have unreliable speech due to word-finding problems, aphasia or dyspraxia have special difficulties here, in that the true nature of their impairments may not be recognized 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. 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.

Some people with word-finding problems read aloud more flu-