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EVOLUTION OF THE CONCEPTS AND
METHODS ASSOCIATED WITH EXPLORING
AND MEASURING THE IMPACT OF APHASIA

by

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A thesis submitted in partial fulfilment of the
requirements for the degree of

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Volume 2

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CHAPTER 6

Table 6.1 Manner of involvement of users in research project

Table 1.1
Examples of measures of function

Measure used	Type of instrument	Domains rated*	Method used to obtaining rating	Rater
Barthel Index (Mahoney and Barthel 1965).	Domain specific	Functional status of daily activities: feeding, washing, dressing, continence, and transferring	Observed abilities (what a person can do)	Clinician or other observer
Index of Activities of Daily Life (ADL) (Katz and Akpom 1976)	Domain specific	Functional status of daily activities: feeding, washing, dressing, continence, and transferring	Observed abilities (what a person can do)	Clinician or other observer
Crichton Royal Behaviour Rating Scale (CRBRS) (Robinson 1968)	Domain specific	Functional status of daily activities: mobility, feeding, etc and mental disturbance (e.g. memory, orientation)	Observed performance (what a person actually does)	Clinician or other observer
Functional Independence Measure and Functional Assessment Measure (FIM/FAM) (Stineman et al 1994).	Domain specific	Personal care, mobility and walking, communication and cognition.	Observed abilities (what a person can do)	Clinician or other observer

* = the nomenclature is that used by the authors of the tests.

Table 1.2
Examples of measures of activity and participation

Measure used	Type of instrument	Domains rated*	Method used to obtain rating	Rater
Sickness Impact Profile (SIP) (Bergner 1993)	Generic	Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction.	Questionnaire	Subject of measurement
Nottingham Health Profile (NHP) (Hunt 1986)	Generic	Physical mobility, pain, sleep, energy, emotional reactions, social isolation. Effects of above on work, home, social life, sex life, interests, hobbies, holidays	Questionnaire	Subject of measurement
Short form-36 health survey questionnaire (SF-36) (Ware et al 1993)	Generic	Physical, role, and social functioning, mental health, energy, health perceptions & pain.	Questionnaire	Subject of measurement
McMaster Health Index Questionnaire (MHIQ) (Chambers 1976)	Generic	Social function Physical functions and behaviours	Questionnaire	Subject of measurement
Dartmouth COOP/WONCA function charts (Nelson 1983, Scholten & van Weel 1992)	Generic	Physical fitness, feelings, daily activities, social activities, changes in health and overall health.	Questionnaire	Subject of measurement
Impact on Participation and Autonomy (IPA) (Cardol et al 1999)	Generic	Self-care/ appearance, mobility, leisure, social relations, work, education, family role, financial independence.	Questionnaire	Subject of measurement

* = the nomenclature is that used by the authors of the tests.

Table 1.3
Examples of measures of psychological well being

Measure used	Type of measure	Domains rated*	Method used to obtaining rating	Rater
Self Rating Depression Scale (Zung 1965)	Disease specific	Depression	Questionnaire	Subject of measurement
Hamilton Depression Scale (Hamilton 1960)	Disease specific	Diagnosis of severity of depression	Observer scale	Trained clinician
Beck Depression Inventory (BDI) (Beck et al 1961)	Disease specific	Diagnosis of severity of depression	Questionnaire	Subject of measurement
Hospital Anxiety and Depression Scale (HAD) (Zigmond & Snaith 1983)	Disease specific	Frequency of experiencing symptoms of anxiety and depression	Questionnaire	Subject of measurement
Goldberg's General Health Questionnaire (GHQ) (Goldberg 1978, Goldberg and Williams 1988).	Disease specific	Use in General Practice. Screens for recent onset psychiatric illness	Questionnaire	Subject of measurement

* = the nomenclature is that used by the authors of the tests.

Table 1.4
Examples of instruments that have been described as HRQoL measures

Measure used	Type of measure	Domains rated*	Method used to obtaining rating	Rater
Sickness Impact Profile (SIP) (Deyo et al 1982 and Bergner 1993)	Generic	Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction.	Questionnaire	Subject of measurement
Nottingham Health Profile (NHP) (Hunt 1986)	Generic	Physical mobility, pain, sleep, energy, emotional reactions, social isolation. Effects of the above on work, home, social life, home life, sex life, interests, hobbies, holidays	Questionnaire	Subject of measurement
Short form-36 health survey questionnaire (SF-36) (Ware et al 1993)	Generic	Physical, role, and social functioning, mental health, energy, health perceptions and pain.	Questionnaire	Subject of measurement
McMaster Health Index Questionnaire (MHIQ) (Chambers 1976)	Generic	Social function Physical functions and behaviours	Questionnaire	Subject of measurement
EQ-5D (EuroQol Group 1990)	Generic	Mobility, self care, usual activities, pain/discomfort, anxiety/depression	Questionnaire	Subject of measurement
WHOQoL and WHOQOL-BREF (WHOQOL group 1998a+b)	Generic	Physical health, psychological health, level of independence, social relationships and environment.	Questionnaire	Subject of measurement

* = the nomenclature is that used by the authors of the tests.

Table 1.5
Examples of individualised measures

Measure used	Type of instrument	Domains rated*	Method used to obtaining rating	Rater
Schedule for Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle et al 1992) and Schedule for Evaluation of Individual Quality of Life-direct weighting (SEIQoL-DW) (Hickey et al 1996)	Generic	Domain and relative weighting selected by subject of measurement	Structured interview to elicit important areas of life, rating of current status in each area and relative importance of each of the areas.	Subject of measurement
Patient Generated Index (PGI) (Ruta et al 1994)	Generic	Health-related domains and relative weighting selected by subject of measurement	Structured interview to elicit activities limited by health condition, rate degree of disability, give relative importance	Subject of measurement
Measure Yourself Medical Outcomes Profile (MYMOP) (Patterson 1996)	Generic	Medical symptom, activity limitation and well-being (selected by subject of measurement)	Questionnaire	Subject of measurement

* = the nomenclature is that used by the authors of the tests.

Table 1.6
Examples of measures of impairment for people with aphasia

Assessment	Type of assessment	Domains rated*	Method used to obtaining rating	Rater
Minnesota Test for Differential Diagnosis of Aphasia (the MTDDA) (Schuell 1965)	Language battery	Auditory disturbances, visual & reading disturbances, speech & language disturbances, visuo-motor & writing disturbances, numerical relations	Pen, paper, and spoken tests	Clinician
Boston Diagnostic Aphasia Examination (the BDAE) (Goodglass & Kaplan 1983),	Language battery	Fluency, auditory comprehension, spatial and computational skills, oral reading, repetition, music, reading comprehension, naming, writing, automatic speech	Pen, paper and spoken tests	Clinician
Western Aphasia Battery (the WAB) (Kertesz 1983)	Language battery	Content, fluency, auditory comprehension, repetition, naming, reading, writing, calculation	Pen, paper and spoken tests	Clinician
Porch Index of Communicative Abilities (the PICA) (Porch 1967)	Language battery	Verbal responsiveness, gestural responsiveness, graphic responsiveness, visual matching Notably does not assess auditory comprehension	Pen, paper and spoken tests	Clinician
†Comprehensive Aphasia Test (the CAT) (Swinburn, Porter & Howard - in press)	Language Battery	1. Cognitive screening test, 2. Language comprehension, repetition, spoken naming, reading aloud, writing, 3. Disability Questionnaire	Pen, paper and spoken test	Clinician (cognitive and language section) Person with aphasia (Disability impact section)

Frenchay Aphasia Screening Test (Enderby 1987)	Screening Test	Auditory comprehension, verbal expression, reading, writing	Pen, paper and spoken tests	Clinician
Whurr Aphasia Screening Test (Whurr 1996)	Screening Test	Matching, selecting to auditory commands, repeating, reading aloud, naming, oral description, copying, writing, calculation	Pen, paper and spoken tests	Clinician
Boston Naming Test (Kaplan et al 1983)	Domain specific test	Picture naming	Pen, paper and spoken tests	Clinician
Graded Naming Test (McKenna & Warrington 1983)	Domain specific test	Picture naming	Pen, paper and spoken tests	Clinician
Reading Comprehension Battery for Aphasia (LaPointe & Horner 1979)	Domain specific test	Reading	Pen, paper and spoken tests	Clinician
Psycholinguistic Assessment of Language Processing in Aphasia (the PALPA) (Kay, Lesser & Coltheart, 1997)	Domain specific test (sub tests that measure discrete components within each domain)	Auditory processing, picture and word semantics, spoken sentence comprehension, written sentence comprehension, reading, spelling	Pen, paper and spoken tests	Clinician

* = the nomenclature is that used by the authors of the tests themselves.

† = The CAT is not widely used as it is not yet published. It has been used in research projects (e.g. Bruce et al 2003) and will be referred to in the text of the thesis.

Table 1.7
Examples of measures of function in stroke and rehabilitation medicine

Measure used	Domains rated*	Method used to obtaining rating	Rater
Barthel Index (Mahoney & Barthel 1965).	Functional status of daily activities: feeding, washing, dressing, continence, and transferring	Observed abilities (what a person can do)	Clinician or other observer
Index of Activities of Daily Life (ADL) (Katz & Akpom 1976)	Functional status of daily activities: feeding, washing, dressing, continence, and transferring	Observed abilities (what a person can do)	Clinician or other observer
Functional Independence Measure and Functional Assessment Measure (FIM/FAM) (Stineman et al 1994).	Functional status of daily activities: personal care, mobility and walking, communication and cognition.	Observed abilities (what a person can do)	Clinician or other observer
National Institute of Health Stroke Scale (Brott et al 1989)	Neurological function: vision, consciousness, arm, leg, facial movement, ataxia, sensory loss, neglect, dysarthria, language change.	Observed abilities (what a person can do)	Clinician
Scandinavian Stroke Scale (Scandinavian Stroke Group 1985)	Neurological Function: eye, arm, leg, hand, facial movement, gait, consciousness, orientation, speech.	Observed abilities (what a person can do)	Clinician
Rankin Handicap Scale (Rankin 1957)	Stroke specific. Assign grade on basis of mobility and self care/usual duties.	Subjective (I-V) rating	Clinician
Oxford Handicap Scale (Bamford et al 1988, 1989)	Stroke specific. Assign grade on basis of degree of handicap and independence.	Subjective (0-5) rating	Clinician

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.8
Examples of measures of function in aphasiology

Assessment	Domains rated*	Method used to obtaining rating	Rater
Functional Communication Profile (FCP) (Sarno 1969)	Movement, speaking, understanding, reading, writing	Estimates of ability based on informal interaction/ knowledge of the person with aphasia	Clinician
Edinburgh Functional Communication Profile (EFCP) (Skinner et al 1984)	Speech Gesture Writing	Observed ability everyday communication behaviours	Significant other/relative
Communication Activities of Daily Living (the CADL/CADL-2) (Holland, Frattali & Fromm, 1999)	Reading, writing, using numbers, social interaction, divergent/contextual/non-verbal communication, sequential relationships, humour/ metaphor	Ability ratings in simulation of everyday situations	Clinician
American Speech-Language-Hearing Association Functional Assessment of Communication Skills (ASHA FACS) (1990)	Communication independence: Social communication, communication of basic needs, daily planning, reading writing & number concepts.	Observational scale	Clinician ratings plus judgements made by significant others/relatives
Amsterdam-Nijmegen Everyday Language Test (ANELT) (Blomert et al 1994)	Verbal communicative effectiveness only	Effectiveness ratings of monologues elicited from 20 role play scenarios.	Clinician
Communicative Effectiveness Index (the CETI) (Lomas et al 1989)	Verbal communicative effectiveness Social participation	Estimates of change to pre-stroke performance based on knowledge of the person with aphasia	Significant other/relative

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.9
Examples of measures of participation in stroke and rehabilitation medicine

Measure used	Domains rated*	Method used to obtaining rating	Rater
Sickness Impact Profile (SIP) (Bergner 1993)	Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction.	Questionnaire	Subject of measurement or proxy
Nottingham Health Profile (NHP) (Hunt 1986)	Physical mobility, pain, sleep, energy, emotional reactions, social isolation. Effects of the above on work, home, social life, home life, sex life, interests, hobbies, holidays.	Questionnaire	Subject of measurement
Short form-36 health survey questionnaire (SF-36) (Ware et al 1993)	Physical, role, and social functioning, mental health, energy, health perceptions and pain.	Questionnaire	Subject of measurement
Impact on Participation and Autonomy (IPA) (Cardol et al 1999)	Self care/appearance, mobility, leisure, socials relationships, work, education, family role, financial independence.	Questionnaire	Subject of measurement
Reintegration into Normal Living Index (Wood-Dauphinee et al 1988)	Participation in daily, recreational, social activities, family roles, personal relationships, mobility, self-care, coping skills.	Questionnaire	Subject of measurement
Therapy Outcomes Measures (TOMs) (Enderby et al 1998)	Impairment, disability, 'handicap' and well-being/distress.	Subjective rating based on knowledge of the person who is the subject of measurement.	Clinician
Unnamed (Laman & Lankhorst 1994)	Activities derived from the ICIDH-1 disability codes, with impairments of pain, disfigurement and incontinence added.	Questionnaire	Subject of measurement

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.10
Examples of tools used to measure activity and participation in aphasiology

Assessment	Domains rated*	Method used to obtaining rating	Rater
Communicative Effectiveness Index (the CETI) (Lomas et al 1989)	Verbal communicative effectiveness Social participation	Estimates of change to pre-stroke performance based on knowledge of the person with aphasia	Significant other/relative
Therapy Outcomes Measures (TOMs) (Enderby et al 1998)	Impairment, disability, handicap, well-being/distress.	Subjective rating based on knowledge of the person who is the subject of measurement.	Clinician
Functional Communication Therapy Planner (Worrall 1999)	Social networks, interests and activities, communication activity and styles	Questionnaire/interviews, plus observational rating,	Clinician and person who is subject of measurement

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.11
Examples of measures of well-being in stroke and rehabilitation medicine

Instrument	Domains rated*	Method used to obtaining rating	Rater
General Health Questionnaire (GHQ) (Goldberg & Williams 1988)	Use in General Practice. Screens for recent onset psychiatric illness	Questionnaire	Subject of measurement
Beck Depression Inventory (BDI) (Beck et al 1961)	Depression	Questionnaire	Subject of measurement
Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983)	Depression and Anxiety	Questionnaire	Subject of measurement
Philadelphia Geriatric Centre Morale Scale (Lawton 1975).	Well being and depression	Questionnaire	Subject of measurement
Zung Self Rating Depression Scale (Zung 1965)	Depression	Questionnaire	Subject of measurement
Hamilton Depression Scale (Hamilton 1960)	Diagnosis of severity of depression	Observer scale	Trained clinician
Self-Esteem Scale (Heatherton & Polivy 1991)	Self Esteem	Questionnaire	Subject of measurement
Self Esteem Scale (Rosenberg, 1965)	Self Esteem	Questionnaire	Subject of measurement
Therapy Outcomes Measures (Enderby et al 1998)	Impairment, disability, handicap, well-being/ distress.	Subjective Rating by clinician based on knowledge of the user	Clinician

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.12
Examples of measures of psychological well-being in aphasiology

Measure used	Domains rated*	Method used to obtaining rating	Rater
Zung Self Rating Depression Scale (Zung 1965)	Depression	Questionnaire	Subject of measurement
Hamilton Depression Scale (Hamilton 1960)	Diagnosis of severity of depression	Observer scale	Trained clinician
Beck Depression Inventory (BDI) (Beck et al 1961)	Depression	Questionnaire	Subject of measurement
Comprehensive Psychopathological Scale (Asberg et al 1978)	Psychopathological symptoms and their effects	Semi-structured interview	Clinician
Visual Analogue Mood Scale (the VAMS) (Aitkins 1969)	Depression in those with neurological illness	Visual Analogue Scale	Subject of measurement
Code-Müller Protocols (Code & Müller 1992)	Psychosocial adjustment	Questionnaire	Subject of measurement, relative and clinician (comparisons made between the ratings)
Personal Relations Index (PRI) (Mulhall 1977)	Relationship features between user and spouse: Attitudes, feelings and behavioural states	Semi-structured interview	Subject of measurement or spouse
Affect Balance Scale (Bradburn 1969)	General psychological well-being; equally weighted for positive and negative feelings.	Questionnaire	Subject of measurement
Stroke Aphasic Depression	Depression	Rating scale of	Carer

Questionnaire (Sutcliffe & Lincoln 1998)		observed behaviours	
Psychosocial Well being Index (PWI) (Lyon et al 1997)	Pleasure, meaning & direction in daily life; degree of involvement in chosen daily activities; comfort with/around others	Visual analogue scales	Person with aphasia and caregiver
How I Feel About Myself (cited in Thelander et al 1994)	Well-being. Domains include autonomy, environmental mastery, personal growth, positive relations, purpose in life, self- acceptance.	Questionnaire	Person with aphasia
Visual Analogue Self Esteem Scales (VASES) (Brumfitt & Sheeran 1999b)	Self Esteem	Visual analogue rating scales	Person with aphasia

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.13
Examples of measures of HRQoL in stroke and rehabilitation medicine

Measure used	Domains rated*	Method used to obtaining rating	Rater
Sickness Impact Profile (SIP) (Bergner 1993)	Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction.	Questionnaire	Subject of measurement
Reintegration into Normal Living Index (Wood-Dauphinee et al 1988)	Participation in daily/ recreational/social activities, family roles, personal relationships, mobility, self-care, coping skills.	Questionnaire	Subject of measurement
Quality of life Index-Stroke Version (Ferrans & Powers 1985)	Stroke specific version. Measures firstly satisfaction and then importance of various domains of health and functioning, socio-economic, psychological/spiritual and family life.	Questionnaire	Subject of measurement
EQ-5D (EuroQol group 1990)	Mobility, self care, usual activities, pain/discomfort, anxiety/depression	Questionnaire	Subject of measurement
WHOQoL and WHOQOL-BREF (WHOQOL group 1998a+b)	Wide ranging but include activities of daily life, pain, energy, family life, sex life, finance, satisfaction levels	Questionnaire	Person with aphasia
Burden of Stroke Scale (the BOSS) (Doyle et al 2002)	Domains of functioning, psychological distress associated with specific functional limitations, and ,general well-being in stroke survivors		Subject of measurement
SS-QOL (Williams et al 1999)	Stroke specific. Measures energy, family/social role, language, mobility, mood, personality, self-care, thinking, vision, arm function, work.	Interview	Subject of measurement

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.14
Measures of HRQoL used with people with communication disability

Instruments	Study population	Domains rated*	Method used to obtaining rating	Rater/whose perspective
Sickness Impact Profile (SIP) (Deyo et al 1982, Bergner 1993)	People with stroke	Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction.	Questionnaire	Subject of measurement
Reintegration into Normal Life Measure (Wood-Dauphinee et al 1988)	People with stroke	Participation in daily/ recreational./social activities, family roles, personal relationships, mobility, self-care, coping skills.	Questionnaire	Subject of measurement
Quality of life Index-Stroke Version Stroke (Ferrans & Powers 1985)	People with stroke	Stroke specific version. Measures satisfaction and importance of various domains of health and functioning, socio-economic, psychological/spiritual and family life.	Questionnaire	Subject of measurement
Short Form 36 (SF36) (Ware and Sherbourne 1992)	People with Head and Neck Cancer	Physical, role, and social functioning, mental health, energy, health perceptions and pain.	Questionnaire	Subject of measurement
General Health Questionnaire (12 item version) (Goldberg and Hillier 1979)	People with Head and Neck Cancer	Use in General Practice. Screens for recent onset psychiatric illness	Questionnaire	Subject of measurement
Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis 1975, 1983)	People with Head and Neck Cancer	Generic measure of psychological and social adjustment to illness in medical patients and/or relatives.	Semi-structured interview	Subject of measurement
Functional Assessment of Cancer Therapy – General head and neck (FACT-G) (Cella 1993)	People with Head and Neck Cancer	Disease specific instrument measuring quality of life: Physical symptoms and functional status, spiritual well-being	Questionnaire	Subject of measurement
Voice Handicap Index	Head and Neck	Functional, physical and emotional consequences of	Questionnaire	Subject of

(Jacobsen et al 1997)	Cancer	voice impairment		measurement
LSI-A (Life Satisfaction Index) (Neugarten et al 1961)	People with traumatic brain injury	Psychological well-being: zest of living, mood tone and congruence between desired and achieved goals	Questionnaire	Subject of measurement
Functional Independence Measure (FIM/) (Stineman et al 1994).	People with traumatic brain injury	Functional status of daily activities: personal care, mobility and walking, communication and cognition.	Observed abilities (what a person can do)	Clinician or other observer

* = the nomenclature is that used by the authors of the tests themselves.

Table 1.15
Examples of measures of HRQoL used with people who have aphasia

Measure used	Domains rated*	Method used to obtaining rating	Rater
Geriatric Evaluation of Relative's Rating Instrument (GERRI) (Schwartz 1983)	Cognitive, mood and social functioning.	Questionnaire	Relative or caregiver.
Functional Life Scale (Sarno et al 1973)	Activities of daily living, cognition, home/outside activity, social interaction.	Observed abilities (what person can do)	Clinician.
Caregivers Burden Interview (Zarit et al 1980)	Sense of burden	Questionnaire	Relative or caregiver.
Dartmouth COOP/WONCA function charts (Nelson 1990, Scholten and van Weel 1992)	Physical fitness, feelings, daily activities, social activities, changes in health and overall health.	Questionnaire	Person with aphasia
Short form-36 health survey questionnaire (SF-36) (Ware et al 1993)	Physical, role, and social functioning, mental health, energy, health perceptions and pain.	Questionnaire	Person with aphasia or clinician
Sickness Impact Profile (SIP) (Bergner 1993)	Work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication, social interaction.	Questionnaire	Person with aphasia or clinician
Behaviour, Emotion, Attitude Communication Questionnaire (Thelander et al 1993),	Behaviour, Emotion, Attitude Communication	Questionnaire	Person with aphasia
Affect Balance Scale (Bradburn 1969)	General psychological well-being; equally weighted for positive and negative feelings.	Questionnaire	Subject of measurement
How I Feel About Myself (cited in Thelander et al 1994)	Well-being. Domains include autonomy, environmental mastery, personal growth, positive relations, purpose in life, self-acceptance.	Questionnaire	Person with aphasia

Table 2.1
Procedures undertaken during the development of the DQ

Stages and phases	Process	Iteration	No. of PWA involved	Nature of involvement of PWA	Purpose	Where details are shown
<u>Stage 1 Indirect user involvement Phase 1</u>	Write original instrument based on clinical experience	Original DQ draft 1			Construct instrument	Appendix 2.2
	Administer DQ	DQ draft 1	15	Participants in administration plus offering unsolicited comment	Pre-test items	
	Modify tool	DQ draft 2				Table 2.3
<u>Phase 2</u>	Administer DQ	DQ draft 2	15	Participants in administration plus offering unsolicited comment	Pre-test items	
	Seek expert colleague advice		1 (4 SLTs)	Expert advisor	Obtain expert opinion	
	Modify tool	DQ draft 3				Table 2.4
<u>Phase 3</u>	Administer DQ	DQ draft 3	10	Participants in administration plus offering unsolicited comment	Pilot instrument	
	Modify tool	DQ draft 4				Table 2.5
	Administer DQ	DQ draft 4	40	Participants in administration plus offering unsolicited comment	Field test instrument	
	Modify tool	DQ draft 5				Table 2.6
	Administer DQ	DQ draft 5	47	Participants in administration plus offering unsolicited comment	Field test instrument	
<u>Stage 2</u>	Conduct focus	DQ draft 5	7	Expert advisors	Obtain expert	

Direct user involvement	groups with DQ users (SLTs & people with aphasia)		(plus 9 SLTs)		opinion	
	Modify tool	CDP draft 1				Table 2.11
Stage 3 Direct user consultation	Group interviews		13 (7+6)	Expert informants	Include users - ensure content validity	
	Individual in depth interviews		13	Expert informants	Include users - ensure content validity	
	Convene advisory group		3 (plus one non-aphasic family counsellor)	Expert advisors	Include users - ensure content validity	
	Modify tool	CDP draft 2				Table 5.3
Stage 4 Clinical usability	Field testing	CDP draft 2	23 (15 SLTs)	Participants in administration plus solicited comment		
	Modify tool	CDP draft 3				Table 5.12 and Appendix 5.26

Table 2.2
Rationale for DQ item inclusion

Question	Original rationale
	All items are rated by the person with aphasia and therefore represent that person's perception of the situation.
Q 1-4	Situations and people who commonly facilitate or hinder <i>comprehension</i> for someone who has aphasia. The items focus on varying degrees of intimacy and familiarity between speakers, and the number of people taking part in the exchange.
Q 5-8	Situations and people who commonly facilitate or hinder <i>talking</i> for someone who has aphasia. The items focus on varying degrees of intimacy and familiarity between speakers, the physical situation and the number of people taking part in the exchange.
Q 9-12	Common literacy-based activities, which vary in the amount and accessibility of the text to be <i>read</i> .
Q 13-16	Common literacy-based activities, which vary in the amount and complexity of the text to be <i>written</i> .
Q 17-19	The acknowledgement, anxiety and functional relevance of the reported challenges in everyday life.
Q 20-23	The extent to which the difficulties reported above had an impact have on everyday life.
Q 24-31	Emotional states commonly reported as being associated with having aphasia.
Q 32-33	Levels of satisfaction with current and future life.

Table 2.3

Changes made between the DO drafts 1 & 2

(following administration of DQ with 15 people with aphasia)

Type of change	Changes made.	Question/ headings	DQ draft 1	DQ draft 2	Rationale for changes
Inclusion & accessibility.	Mode of administration	Whole tool	(self completion)	(therapist-administered)	To ensure ratings are by the person with aphasia (not caregiver). Ease of administration
Acceptability.	Reworded	Q1	understand YOUR WIFE/ HUSBAND	your FAMILY	To be relevant to those not married.
Accessibility.	Reworded	Q2	understand ONE OTHER PERSON	A STRANGER	To specify which other person.
Accessibility.	Reworded	Q3	understand A SMALL GROUP of people who are NOT YOUR FAMILY	A SMALL GROUP	Simplification of language.
Acceptability & accessibility.	Reworded after re-conceptualisation	Q4	understand TV or RADIO	TV	Elimination of double question (...or...), as ability may vary between the two options.
Accessibility.	Reworded	Q6	find the right words/put sentences together when talking to SOMEONE YOU DON'T KNOW	A STRANGER	Simplification of language.
Acceptability & accessibility.	Reworded after re-conceptualisation	Q7	find the right words/put sentences together when talking to CLOSE FRIENDS	A SMALL GROUP	Reduction of ambiguity. Focusing on number of people rather than intimacy of relationship.
Accessibility.	Reworded	Q14	spell/write OTHER SINGLE	other single words (EG.	Use of exemplar.

			WORDS	A SHOPPING LIST)	
Accessibility.	Reworded	Q15	spell/write A LETTER OR CARD	A LETTER	Deletion of double questions (...or...).
Acceptability & accessibility.	Reworded after re-conceptualisation	Q16	spell/write AN OFFICIAL FORM (e.g. a household bill)	an official LETTER (e.g. a letter or complaint of enquiry)	Reduction of ambiguity. Forms do not necessarily require any writing, can be ticked/crossed.
Acceptability & accessibility.	Reworded after re-conceptualisation	*Q19	Does your communication AFFECT YOUR DAILY LIFE	Deleted	Repetitive given Q20-23 which are 'Which aspects of the difficulty affect your daily life ...'
Acceptability	Reworded after re-conceptualisation	Heading	EMOTIONS:	DISTRESS:	New title intended to convey the negative emotions associated with aphasia (will be revisited).
Acceptability	New rating introduced:	Emotion section	none – a little – a lot	5 (Always, a lot) 4 (sometimes, a lot) 3 (always, a little) 2 (sometimes, a little) 1 (never)	Dissatisfaction with rating based solely on intensity of emotion. Needed temporal element to convey consistency of emotional state.
Acceptability	Reworded after re-conceptualisation	*Q30	ACCEPTING	HOPELESS	Seen as patronising/ superficial. More commonly expressed emotion introduced.
Acceptability	Reworded after re-conceptualisation	*Q31	PLEASED	PESSIMISTIC	Seen as patronising/ superficial. More commonly expressed emotion introduced.
Acceptability	Reworded after re-conceptualisation	Q33	NEGATIVE	DISSATISFIED WITH LIFE	Seen as superficial. More commonly expressed emotion introduced.

Questions or items that are not mentioned were not changed between iterations.

* the numbers on this table for draft 1 do NOT correspond to the numbering on the original DQ draft 1 shown in figure 2.1. The numbering has been changed from the original in this table to increase clarity of this table. The item content and wording does not vary between figure 2.1 and this table.

Table 2.4

Changes made between drafts 2 & 3 of the DQ

(after 'expert' colleague consultation and administration with 15 people with aphasia)

Type of change	Changes made.	Question/ headings	DQ draft 2	DQ draft 3	Rationale for changes
Accessibility & acceptability	Mode of administration	Whole tool	Spoken administration only	Help-sheets introduced	Reduce barrier that comprehension impairment might present.
Accessibility & acceptability	Method of scoring	Whole tool	5 (unable) to 1 (no problem)	4 (Unable) to 0 (no problem)	Felt that 0 (rather than 1) denoting 'no problem' was clearer .
Acceptability	Rewording after re-conceptualisation	Q1	Understand your FAMILY	THE PERSON YOU ARE CLOSEST TO	Reducing ambiguity. Main focus is degree of intimacy.
Accessibility	Rewording	Q2	Understand A STRANGER	SOMEONE YOU DON'T KNOW AT ALL	Simplification of language.
Accessibility	Rewording	Q3	Understand A SMALL GROUP	IN A SMALL GROUP OF PEOPLE	Reducing ambiguity.
Acceptability	Rewording after re-conceptualisation	Q4	Understand the TV	SOMEONE IN AUTHORITY E.G. A DOCTOR OR BENEFITS OFFICER	Elimination of ambiguous item dependent on the programme. Introduction of new concept. Strengthen notion of hierarchy within each section.
Accessibility	Rewording after re-conceptualisation	Q5	find the right words/put sentences together when talking to YOUR FAMILY	THE PERSON YOU ARE CLOSEST TO	Reducing ambiguity.

Accessibility	Rewording	Q6	find the right words/put sentences together when talking to A STRANGER	SOMEONE YOU DON'T KNOW AT ALL	Simplification of language.
Accessibility	Rewording after re-conceptualisation	Q8	find the right words/put sentences together when talking to ON THE PHONE OR BEHIND A GLASS BARRIER e.g. post office/ticket office	UNDER PRESSURE OR IN A STRESSFUL SITUATION	Reducing ambiguity (these situations may lack relevance for an individual PWA).
Acceptability	Rewording after re-conceptualisation	Heading	HANDICAP:	EMOTIONAL IMPACT:	Rejection of the assumption of negative emotions relating to aphasia
Acceptability & accessibility	Rewording after re-conceptualisation	Q19	Have you LOST CONFIDENCE in yourself as a result of your communication	Have you lost confidence as a result of your communication?	Simplification of language.
Acceptability.	New concept introduced.			Do you feel other people understand what's wrong?	Lack or presence of empathy seen as relevant to explore.
Acceptability.	New concept introduced.			Have you lost any self esteem as a result of your communication difficulty?	Expansion of the self-image concept.
Acceptability.	New concept introduced.			Do you feel isolated as a result of your communication difficulty?	Expansion of the self-image concept.
Acceptability & accessibility	Rewording after re-conceptualisation	Q25	DEPRESSED	SAD	Felt depressed had unhelpful connotations.
Acceptability.	New concept introduced.			Lonely	Suggested as a relevant concept to include.

Questions or items that are not mentioned were not changed between iterations.

Table 2.5

Changes between the DQ drafts 3 & 4

(following after 10 administrations of the DQ with people with aphasia,)

Type of change	Changes made.	Question/ heading	DQ draft 3	DQ draft 4	Rationale for changes
Acceptability	Rewording	'Activities' questions i.e.Q1-16	'how DIFFICULT is it for you to...'	'how EASY is it for you to...'	Attempt to reduce the causal connection between impairment and disability.
Accessibility	Rewording	Q2	Understand SOMEONE YOU DON'T KNOW AT ALL	Understand SOMEONE YOU DON'T KNOW	Simplification of language.
Acceptability & accessibility	Rewording after re-conceptualisation	Q3	Understand IN A SMALL GROUP of people	Small group of FRIENDS	Comments by PWA* that ease of communication dependent on <i>who</i> was in the group/degree of intimacy.
Acceptability & accessibility	Rewording after re-conceptualisation	Q7	find the right words/put sentences together when talking to A SMALL GROUP	Small group of FRIENDS	Comments by PWA* that ease of communication dependent on <i>who</i> was in the group/degree of intimacy.

Acceptability & accessibility	Rewording after re-conceptualisation	Q11	read and understand AN OFFICIAL FORM (eg a bill)	an official LETTER	Reduction of ambiguity. Forms thought variable more in amount of <i>reading</i> necessary.
Acceptability & accessibility	Rewording after re-conceptualisation	Q15	spell/write A LETTER	spell/write a letter TO A FRIEND	Increased specificity as ease of writing dependent on <i>who</i> was being written to.
Acceptability & accessibility	Rewording after re-conceptualisation	Q17 to Q20	Which aspects of the difficulty affect your daily life ...	I want to find out how the communication difficulties you've just told me about affect your daily life, (<i>reiterate an example of where they have difficulty</i>) how much does that affect you on a day to day basis?	Clarification of issue. Need to highlight focus PWA on the activities they had previously described, and how they were barriers to daily life.
Accessibility	Rewording	Q21	Do you feel you have any DIFFICULTIES WITH COMMUNICATION since your stroke	HOW WOULD YOU RATE your communication difficulties since the stroke?	Simplification of language in an attempt to establish if PWA perceived aphasia as a disability
Accessibility	Rewording	Q22	If you have any difficulties - do they WORRY YOU	DO THESE difficulties worry you?	Simplification of language.
Acceptability	Item deleted	Q23	Do you feel OTHER PEOPLE UNDERSTAND what's wrong?		Degree of understanding by others dependent on many factors. Very variable. Rating therefore felt invalid.

Accessibility	Rewording	All emotions questions	Could you indicate which words describe how you feel about your communication since your stroke?	We're going to look at how that makes you feel. I'm going to suggest some feelings and I want you to indicate if you ever feel this emotion. If you do, how much?	Attempt to reduce the formality of the style of questioning. Attempt to break the assumption of negative emotions associated with aphasia.
Acceptability	Item deleted	Q30	LONELY		Repetitious. Too close to isolated.

PWA* = people with aphasia

Questions or items that are not mentioned were not changed between iterations.

Table 2.6

Changes made between the DQ drafts 4 & 5

(after extensive piloting with 47 people)

Type of change	Changes made	Question	DQ draft 4	DQ draft 5	Rationale for changes
Acceptability	Rewording after re-conceptualisation	Q3	Understand a small group of FRIENDS	Understand 3 or 4 friends OR FAMILY	Specifying the number involved to reduce ambiguity. Highlighting that either social group could be equally intimate.
Acceptability	Rewording after re-conceptualisation	Q7	Find the right words/put sentences together when talking with a small group of FRIENDS	Find the right words/put sentences together when talking with 3 or 4 friends OR FAMILY	Specifying the number involved to reduce ambiguity. Highlighting that either social group could be equally intimate.
Acceptability	Rewording after re-conceptualisation	Q9	Read and understand SINGLE WORDS	Read and understand A SINGLE WORD	Reduce ambiguity. Attempt to highlight that focus is reading a word in isolation.
Acceptability	Item deleted	Q33	Optimistic		Confusion by both poles of same concept being asked.

PWA* = people with aphasia

Questions or items that are not mentioned were not changed between iterations.

Table 2.7
Target sampling characteristics for user field trial
focus group of people with aphasia

Criteria	Groupings	Target
Number of people		8
Gender	Male	4
	Female	4
Race	White	
	Non-white	At least one
Age	AP in their 40s	At least one
	AP in their 50s	At least one
	AP in their 60s	At least one
	AP in their 70s	At least one
Duration of living with aphasia	Less than one year	4
	More than 18months	4
Living Status	Living alone	4
	Living with family/partner	4
Severity of impairment of expression	Severe	At least one
	Mild	At least one
Type of impairment of expression	Fluent	At least one
	Non-fluent	At least one
Severity of impairment of comprehension	Moderate	At least one
	Mild	At least one

Table 2.8
Sampling characteristics for the SLT user field trial focus group

Criteria	Groupings	Target
Number of therapists		9
Gender:	Male	At least one man
	Female	
Age	> 40	At least one
	<40	
Experience	Under 2 years	3
	2-5 years	3
	Over 5 years	3
Type of work	Acute	3
	Rehabilitation	3
	Community	3
Location of work	Metropolitan	
	Non-metropolitan	At least one

Table 2.9
Sampling success for user field trial focus group
of people with aphasia

Criteria	Characteristics	Target	Actual	Achieved
Number of people		8	7	√
Gender	Male	4	4	√
	Female	4	3	√
Race	White		6	√
	Non-white	At least one	1	√
Age	AP in their 40s	At least one	1	√
	AP in their 50s	At least one	2	√
	AP in their 60s	At least one	1	√
	AP in their 70s	At least one	3	√
Duration of living with aphasia	Less than one year	4	2	√
	More than 18months	4	5	√
Living Status	Living alone	4	4	√
	Living with family/partner	4	3	√
Severity of impairment of expression	Severe	At least one	1	√
	Mild	At least one	2	√
Type of impairment of expression	Fluent	At least one	2	√
	Non-fluent	At least one	5	√
Severity of impairment of comprehension	Moderate	At least one	4	√
	Mild	At least one	3	√

Table 2.10

Sampling characteristics for the user field trial

focus group of SLT

Criteria	Characteristics	Target	Actual	Achieved
Number of therapists		9	9	√
Gender	Male	At least one man	1	√
	Female		8	√
Age	> 40	At least one	0	X
	<40		9	√
Experience	Under 2 years	3	3	√
	2-5 years	3	4	√
	Over 5 years	3	2	√
Type of work	Acute	3	2	√
	Rehabilitation	3	4	√
	Community	3	3	√
Location of work	Metropolitan		8	√
	Non-metropolitan	At least one	1	√

Table 2.11

Changes between the DQ (draft 5) & the Communication Disability Profile¹ (draft 1)

(after administration of DQ draft 5 with 47 people with aphasia and consultation with user focus groups)

Type of change	Changes made.	Question/headings	DQ draft 5	CDP draft 1	Rationale for changes
Acceptability and accessibility	Rewording after re-conceptualisation	Q1 to Q16	Compared with before your stroke, how easy is it for you to...	Since your stroke how easy is it for you to..	Phrasing questions positively. Simplifying the language.
Acceptability and accessibility	Reordered	Q1-4	'Talking' section now comes first		Talking felt to be the most pertinent area and the one that PWA* were anticipating talking about.
Accessibility	Reworded.	Q1	Find the right words/put sentences together when talking to THE PERSON YOU ARE CLOSEST TO	TALK to the person YOU ARE closest to	Simplify the language.
Acceptability and accessibility	Reordered to come after question relating to person closest to them.	Q2	Find the right words/put sentences together when talking to SOMEONE YOU DON'T KNOW	TALK with 3 OR 4 FAMILY OR FRIENDS	Keeping questions relating to familiar people together.
Accessibility	Reworded.	Q3	Find the right words/put sentences together when talking to SOMEONE YOU DON'T KNOW	TALK to someone you don't know	Simplify the language.
Acceptability and accessibility	Reworded.	Q4	Find the right words/put sentences together when talking UNDER PRESSURE OR IN A	TALK IF YOU ARE STRESSED	Simplify the language. Reduce ambiguity by deletion of double question (or).

¹ The term Communication Disability Profile (or CDP) relates to the DQ in its next stage of its development. These changes are detailed in chapter 5.

			STRESSFUL SITUATION		
Acceptability	New item for each communication activity section	Q5, 12, 19, 26.	This question appears at the end of each communication activities section (talking, understanding, reading, writing).	Any other situations or things that make <i>TALKING (etc.)</i> difficult?	Reduce the prescriptive nature of the tool. Allows PWA to bring own experiences to the dialogue.
Acceptability	Reordered (as above), also reworded and rescaled.	Q6, 13, 20, 27.	This question appears at the end of the communication activities within each section (talking, understanding, reading, writing).	So you've told me that its most difficult for you when...but that ... is easier, is that right? What's that like on a DAY TO DAY basis?	Wording was simplified. Wording changed to enable rating by use of one scale only as suggested by PWA & clinicians.
Acceptability and accessibility	Reordered to be included in each communication activity section.	Q7, 14, 21, 28.	This question appears at the end of the communication activities within each section (talking, understanding, reading, writing).	Does that WORRY YOU?	Enable rating using one scale
Acceptability and accessibility	Reordered to come after question relating to person closest to them.	Q9	Understand SOMEONE YOU DON'T KNOW	3 OR 4 FAMILY OR FRIENDS	Keeping questions relating to familiar people together
Acceptability and accessibility	Rewording after re-conceptualisation	Q11	Understand the SOMEONE IN AUTHORITY e.g. a doctor or a benefits officer	Understand WHEN YOU'RE UNDER PRESSURE	Reducing ambiguity (the exemplar situations may lack relevance for PWA). Reducing prescriptive nature.
Accessibility	Reworded.	Q15	read and understand A SINGLE WORD	Read and understand a single word LIKE A WORD ON A LIST	Addition of real life exemplar.
Accessibility	Reworded.	Q16	read and understand SHORT PHRASES (e.g. a newspaper headline)	Read and FOLLOW a newspaper headline	Simplified language.
Acceptability and accessibility	Reworded and reordered	Q17	read and understand AN OFFICIAL LETTER	Read and follow A PIECE IN A PAPER	Simplified language. PWA suggested hierarchy was different.
Acceptability	Reworded and	Q18	read and understand AN	Read and FOLLOW AN	Simplified language.

and accessibility	reordered		ARTICLE IN A PAPER OR A PAGE IN A BOOK	OFFICIAL LETTER	PWA suggested hierarchy was different.
Accessibility	Reworded	Q22	spell/write OTHER SINGLE WORDS (e.g. a shopping list)	Spell other single words LIKE a shopping list	Simplified language.
Acceptability and accessibility	Reworded	Q16	spell/write AN OFFICIAL LETTER (e.g. a letter or complaint of enquiry)	write an official letter	Deleted exemplar to simplify question and reduce prescriptive nature of the tool.
Acceptability and accessibility	Deleted item		HOW WOULD YOU RATE your communication difficulties since the stroke?		Seen as redundant. Previously a lead-in question for the impact on daily life section. This section has now been spread over rest of tool.
Acceptability		Heading	DISTRESS	EMOTIONAL CONSEQUENCES	Attempt to move away from negative assumptions.
Accessibility	Rubric reworded	Emotions section	We're going to look at how that makes you feel. I'm going to suggest some feelings and I want you to indicate if you ever feel this emotion. If you do, how much?		
Acceptability and accessibility		Q29	Have you LOST CONFIDENCE as a result of your communication?	Are you confident about your communication?	Moved to be with other 'emotion' questions. Positive pole used.
Accessibility	Reworded.	Q30, 31, 32	FRUSTRATED, SAD, ANGRY	Does your communication make you <i>frustrated, sad, angry</i> ?	
Acceptability and accessibility	Rewording after re-conceptualisation	Q33		Do you feel in control of your communication?	Positive pole used in attempt to reduce the negativity of this section.
Acceptability	Item deleted		HELPLESS and HOPELESS		Reduce the negativity of the questioning. Neutral version added in Q35.
Acceptability	Item deleted		UNFAIR		Reduce the negativity of the

					questioning. In contrast to other emotions Qs, recognition that little action could be taken if PWA did feel it was unfair.
Acceptability	Reworded.	Q34	STUPID	Some people feel stupid because their communication has changed, do you ever feel stupid?	Enable acknowledgement of masked competence.
			PESSIMISTIC		Reduce the negativity of the questioning. Neutrally worded in Q35.
Acceptability and accessibility	Rewording after re-conceptualisation	Q35		When you look to the future how do things look?	Reduce the negativity of the questioning. Neutral wording used.
Acceptability and accessibility	Rewording after re-conceptualisation	Q36	DISSATISFIED WITH LIFE	How do things look today?	Reduce the negativity of the questioning. Neutral wording used.
Acceptability	Un-rated item <i>added</i>	Q37		Do you have people who are important to you?	Reduce the negativity of the tool.
Acceptability	Un-rated item <i>added</i>	Q38		Are there things you enjoy at the moment?	Possibility of ending on a positive theme.

PWA* = people with aphasia

Questions or items that are not mentioned were not changed between iterations.

Table 4.1
Sampling characteristics of group interview SLT participants

Criteria	Characteristics	Achieved
Number of people with aphasia		13
Gender	Male	9
	Female	4
Ethnicity	White	11
	Non-white	2
Age	AP in their 40s	1
	AP in their 50s	2
	AP in their 60s	8
	AP in their 70s	2
Duration of having aphasia	Less than one year	3
	More than 18months	10
Living Status	Living alone	5
	Living with family/partner	8
Expressive impairment	Severe	2
	Mild	6
Expressive type	Fluent	3
	Non-fluent	10
Receptive ability	Moderate	3
	Mild	10

Table 4.2
Sampling characteristics of the individual in-depth interview participants

Criteria	Characteristics	Target	Actual	Achieved
Number of people with aphasia		20	13	X
Gender	Male	50%	6	√
	Female	50%	7	√
Ethnicity	White		12	√
	Non-white	At least one	1	√
Age	AP in their 40s	At least one	1	√
	AP in their 50s	At least one	4	√
	AP in their 60s	At least one	7	√
	AP in their 70s	At least one	1	√
Duration of having aphasia	Less than one year	50%	11	X
	More than 18months	50%	2	X
Living Status	Living alone	At least one	9	√
	Living with family/partner	At least one	4	√
Expressive impairment	Severe	At least one	4	√
	Mild	At least one	5	√
Expressive type	Fluent	At least one	3	√
	Non-fluent	At least one	10	√
Receptive ability	Moderate	At least one	3	√
	Mild	At least one	10	√

Table 4.3
Biographical details of the expert advisory group

	Harry	Sue	John	Gwen
Age	48	47	68	48
Sex	Male	Female	Male	Female
Ethnic background	White	White	White	White
Duration of aphasia	14 years	13 years	7 years	N/a
Type of aphasia	Non fluent (mild word finding & comprehension difficulties)	Non fluent (mild word finding & comprehension difficulties)	Fluent (significant difficulty with comprehension & expression)	N/a
Current job	Counselling	Counselling	Not employed	Family support worker
Duration of working with PWA* (described in their own words)	10 years counselling/support	On & off since 1993, doing workshop with Chris Ireland - counsellor since 1999	Learning the internet, pushing for Bristol (second Connect site), talk a lot, try to help people, teaching at groups	At Connect, 1 year Stroke Assoc., Family Support Worker (1 year) Dysphasia Support Organiser (2 and 1/2 years)

* PWA denotes people with aphasia

Table 5.1
Changes to the participation section as a result of direct user consultation (stage 3)

Artist's Version	Original wording	Advisory panel comments relating to the <i>picture</i>	Advisory panel comments relating to <i>wording</i>	Advisory panel comments relating to <i>concept</i>	Outcome
Version 1	How does that get in the way for you in everyday life? (appendix 5.1)	Inaccessible	Unacceptably negative.	Ill-defined	Redraw. Rethink concept of participation. Expand section. Reword.
Version 2	How is talking in everyday life? (appendix 5.2)	Inaccessible and obscure	Inaccessible, obscure.	Ill-defined	Reconsider procedure for this section. Delete picture.
	What makes talking worse? (appendix 5.3)	Inaccessible	Conceptually inadequate.	Ill-defined	Redraw. Rethink concept of participation. Expand section. Reword.
	What makes talking easier? (appendix 5.4)	Accessible and acceptable	Conceptually inadequate.	Ill-defined	Picture-final version Rethink concept of participation. Expand section. Reword.
	Are there people who make talking easier? (appendix 5.5)	Too difficult to identify specific people, non-family not represented.	Conceptually inadequate.	Ill-defined	Redraw. Rethink concept of participation. Expand section. Reword.
Version 3	How are things you WANT to do?	Minor amendments to details.	Needed discussion to refine wording.	Acceptable and accessible.	Minor changes to increase accessibility/acceptability of picture. (appendix 5.6) Minor changes to perfect wording.

	How are things you HAVE to do?	Acceptable and accessible	Needed discussion to refine wording.	Acceptable and accessible	Picture-final version. (appendix 5.7) Minor changes to perfect wording
	How are things at HOME?	Acceptable and accessible.	Needed discussion	Needed minor amendments to details	Minor changes to increase accessibility/acceptability. (appendix 5.8)
	What HELPS? (introducing the concept)	Already finalised			(appendix 5.4)
	WHO helps? (identifying specific facilitators)	Acceptable and accessible.	Needed discussion to refine wording.	Needed discussion around issue of race.	Picture-final version. (appendix 5.9) Minor changes to perfect wording
	What THINGS help? (identifying specific facilitators)	Minor amendments to details.	Needed discussion to refine wording.	Needed minor amendments to details	Minor changes to increase accessibility/acceptability. (produced appendix 5.10 – final version). Minor changes to perfect wording.
	What makes it HARDER? (introducing the concept)	Minor amendments to details.	Needed discussion to refine domains	Needed minor amendments to identify domains to be included.	Minor changes to increase accessibility/acceptability of picture. (produced appendix 5.11 – final version). Minor changes to perfect wording.
	Who makes it harder?	Acceptable and accessible.	Needed discussion.	Acceptable and accessible.	Picture-final version. (appendix 5.12) Minor changes to perfect wording
	What makes it harder? (identifying	Minor amendments to details. Need for additional	Needed discussion.	Highlighted insufficiency of barriers.	Redraw picture, add more barriers to original drawing. (produced appendix 5.13 then final

	specific barriers)	picture.			version appendix 5.14) Add new picture (with several amendments) depicting behaviours that act as barriers in conversation (final version appendix 5.15)
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Table 5.2
Comparison of the structures of CDP drafts 1 and 2

CDP 1	CDP 1	CDP 1	CDP 2	CDP 2	CDP 2
Domain	Item content	Method of rating	Domain	Item content	Method of rating
Disability self-rating:			Talking		
1. Talking	4 communication activity items	One stage	Activities	4 communication activity items	One stage
	1 open-ended item	One stage			
	1 participation item	One stage			
	1 anxiety item	One stage	Expressing yourself		
2. Understanding	4 communication activity items	One stage	Activities	4 communication activity items	One stage
	1 open-ended item	One stage			
	1 participation item	One stage			
	1 anxiety item	One stage	Understanding		
3. Reading	4 communication activity items	One stage	Activities	4 communication activity items	One stage
	1 open-ended item	One stage			
	1 participation item	One stage			
	1 anxiety item	One stage	Reading		
4. Writing	4 communication activity items	One stage	Activities	4 communication activity items	One stage
	1 open-ended item	One stage			
	1 participation item	One stage			
	1 anxiety item	One stage	Writing		
			Activities	4 communication activity items	One stage

			Participation	3 participation items (things have to do, want to do and at home)	One stage
			External influences	4 items identifying facilitators & barriers (what helps, what hinders)	Not rated
Emotions	8 items	Two stage	Emotional consequences		
	1 item relating to significant others	Not rated	1. Self image	6 items	Two stage
			2. Feelings	6 items	Two stage
			3. Satisfaction	2 items	One stage
	Total items	37 items	Total items	41 items	

Table 5.3
Changes between CDP drafts 1 & 2

Type of change	Changes made.	CDP draft 1	CDP draft 2	Rationale for changes
Accessibility and acceptability.		Written text with written help-sheets	Inclusion of pictures throughout for every question, and every phase of explanation.	
	Rewording to increase specificity.	Since your stroke how easy is it for you to:	Q1-4 Since your stroke, during the last week, (picture) how easy is it for you to:	Increase psychometric robustness.
Accessibility.	Reworded item. Item order changed.	Talk to someone you don't know?	Talk with a <u>group of friends?</u>	Reordered on advice of panel, and in line with endorsement frequencies
Accessibility.	Reworded item. Item order changed.	Talk to 3 or 4 family or friends?	Talk to a <u>stranger, someone you don't know?</u>	Reordered on advice of panel, & in line with endorsement frequencies
Acceptability.	Reworded item.	Talk if you are stressed?	Talk <u>under pressure?</u>	Place emphasis on environment not individual
Acceptability. Accessibility.	Items moved to form a new section. Section expanded as detailed below (*)	What's that like on a day to day basis?		Having these items after each section was repetitive. It also erroneously assumed that PWA could distinguish effect of <i>each</i> modality (talking, reading etc.) on participation.
Acceptability. Accessibility.	Items moved to form a new section. Section expanded as detailed below (o)	Any other people or situations that are difficult?		Having these items after each section was repetitive. Again erroneously assumed that PWA could distinguish effect of different people on <i>each</i> modality (talking, reading etc.)
Acceptability	New section introduced.		Express yourself with <u>the person closest to you</u>	Enable people who use non-verbal methods to demonstrate their competence Validate the experience of communicating through nonverbal means.
Acceptability. Accessibility.	New section introduced.		Express yourself with a <u>group of friends</u>	See above

Acceptability. Accessibility.	New section introduced.		Express yourself with <u>someone you don't know</u>	See above
Acceptability. Accessibility.	New section introduced.		Express yourself <u>if you are under pressure</u> "	See above
Accessibility.	Reworded on advice from panel.	Understand the person closest to you (use person's name)?	Understand <u>a stranger, someone you don't know</u>	
Accessibility	Reworded on advice from panel.	Understand 3 or 4 family or friends?	Understand <u>in a group</u>	
Accessibility.	Reworded on advice from panel.	Read and understand a single word like a word on a list?	Read and follow one <u>word</u>	Concept now supported by picture.
Accessibility.	Reworded on advice from panel.	Read and follow a newspaper headline?	Read and follow a <u>headline</u>	
Accessibility.	Reworded on advice from panel.	Read and follow piece in a paper?	Read and follow a <u>whole story in a paper</u>	
Accessibility.	Reworded on advice from panel.	Spell/write your name and address?	Write your <u>name?</u>	
Accessibility.	Reworded on advice from panel.	Spell other single words like a shopping list	Write <u>other single words</u> like a list?	Concept now supported by picture.
Acceptability. Accessibility.	*Expanded participation section. Reworded on advice from panel.	*What's that like on a day to day basis?	*How are things you <u>have</u> to do?	Conceptually ill-defined.
Acceptability. Accessibility.	Expanded participation section.		How are things you <u>want</u> to do?	Reworded on advice from panel.
Acceptability. Accessibility.	Expanded participation section.		How are things <u>at home?</u>	Home seen as crucial to well being and identity
Acceptability. Accessibility.	oExpanded external influences section. Reworded on advice from panel.	oAny other people or situations that are difficult?	<u>WHO helps?</u>	Conceptually ill-defined. Redefine components relating to external influences

Acceptability. Accessibility.	Expanded external influences section – new item.		What <u>THINGS</u> helps?	See above
Acceptability. Accessibility.	Expanded external influences section – new item.		WHO makes it <u>harder</u> ?	See above
Acceptability. Accessibility.	Expanded external influences section – new item.		<u>WHAT</u> makes it <u>harder</u> ?	See above
Accessibility.	Changes to manner of presentation. Reworded on advice from panel.		Do any of these show living with aphasia makes you <u>feel</u> ?	Giving some element of choice to people with aphasia
Accessibility.	Reworded on advice from panel.	Are you confident about communicating?	Does living with aphasia make you feel <u>less confident</u> ?	Disliked word ‘communication’. Attempt to break the causal link between impairment and disability.
Acceptability.	Reworded on advice from panel.	Do you feel in control of your communication?	Does living with aphasia make you feel <u>less in control</u> ?	Stress that control relates to life situations NOT communication ability.
Acceptability Accessibility	New concept on advice from panel.		Do you feel <u>able</u> ?	Positive expression of construct of competence. Wording on advice from panel.
Acceptability. Accessibility.	Original concept reintroduced. Reworded on advice from panel.		Does living with aphasia make you <u>isolated</u> ?	
Acceptability. Accessibility.	Original concept reintroduced. Reworded on advice from panel.	Some people feel stupid because their communication has changed, do you ever feel a bit daft ?	Does living with aphasia make you <u>embarrassed</u> ?	Focus on emotional consequence of misperceived competence.
	New concept introduced and worded on advice from panel.		Do you feel <u>valued</u> ?	Positive expression of construct of respect

Accessibility. Acceptability.	Reworded on advice from panel.	Does your communication make you angry ?	Does living with aphasia make you ever feel <u>angry</u> ?	Reduce causal link between impairment and disability.
Accessibility. Acceptability.		Does your communication make you frustrated ?	Does living with aphasia make you <u>frustrated</u> ?	Reduce causal link between impairment and disability.
Accessibility. Acceptability.	New concept introduced and worded on advice from panel.		Do you feel <u>determined</u> ?	Positive expression of construct of determination
Accessibility. Acceptability.	Reworded on advice from panel.	Does your communication make you sad ?	Does living with aphasia make you <u>unhappy</u> ?	
Accessibility.	Reordered. Reworded on advice from panel.	Does that worry you ? (but added four times at the end of each communication activity section)	Does living with aphasia make you feel <u>worried</u> ? (asked once only)	Concept confined to single question only.
Acceptability.	New concept introduced and worded on advice from panel.		Do you feel <u>content</u> ?	Positive expression of construct of contentment
Acceptability.	New concept introduced and worded on advice from panel.		What is <u>fun</u> for you?	Enabling expression of positive aspects of current life
Acceptability	New concept introduced and worded on advice from panel.		Is there <u>anything else</u> that is <u>important</u> to you about living with aphasia? Anything you feel we haven't covered?	Reduce prescription.
Acceptability.	New concept introduced and worded on advice from panel.		Is there <u>anything</u> you would like to say about your <u>life</u> now?	Reduce prescription.

Questions or items that are not mentioned were not changed between iterations.

Question numbers have been omitted. There is significant variation between the drafts in which question numbers relate to items, they were therefore seen to be unhelpful.

Table 5.4

Endorsement frequencies for communication activity items in the DQ (draft 4)

Item	N at twelve month	Mean at twelve months
Talk-closest	35	1.61
Talk-stranger	35	2.26
Talk-group	28	2.29
Talk-pressure	35	2.79
Comp-closest	35	0.6
Comp-stranger	35	1.26
Comp-group	35	1.59
Comp-authority	30	1.65
Read-word	35	0.96
Read-headline	35	1.5
Read-official	35	2.31
Read-article	35	2.43
Write-name	35	1.21
Write-word	35	1.76
Write-friend	35	2.86
Write-official	35	3.26

Table 5.5
External influences expressed in qualitative interviews

Item within the CDP	Exemplar from the qualitative in-depth interviews
<i>PEOPLE that HELP or HINDER – talking/understanding</i>	
Partner	Wife, partner, partner encouraging AP to think for themselves, partner offers clues, husband supplies word
Brother/sister	Brother
Son and daughter,	Daughter helps, one son good, one son not, difference between sons
Granddaughter/son/other children	Grandchildren easy, children better
Friend/neighbour	Friends at work, old friend fantastic, neighbour, friends – rejection , friends less relaxed than family, two good friends treat me the same, friends very helpful
Other people/health/social care	Nurse wrote letter to the bank, speech therapy, volunteer, surveyor
People look away	Try to get away, people don't listen
Interrupting	Talk over me, interrupted
Looking bored/ attentive	Negative attitudes, interested in conversation, keeping interested
Noisy/busy	Too much going on gets in the way
Far away	Added/agreed by advisory panel
Two talking at once	They talked and not to me
Cover face	Added/agreed by advisory panel
Speak quickly	Talks quickly
Other barriers/facilitators	Picks out one person in a group to talk to when groups problematic, someone speaks for me others filling in words
<i>THINGS that HELP– talking/understanding</i>	
Listen to me	Interested in conversation, friendly and interested, respect, positive attitudes, positive reactions help
Telling people (help cards)	Tell people had a stroke, pretence at being non-aphasic, fine telling close friends about aphasia –not others, helped to tell people

Extra time	Talking - extra time, patience, he was impatient
Pictures	Added/agreed by advisory panel
Writing things down	Someone scribing, writes things down in bank, write instead of speak
Other facilitators	Talks one to one, picks out one person in a group, simplifies language, takes deep breaths, rephrasing, thinks before speaking, use of first letter, repetition, talking slow and posh, rabbit on when stuck for word, writing instead of speaking, having a laugh about it
<i>THINGS that HINDER - talking /understanding</i>	
Glass barrier	Added/agreed by advisory panel
Queues	Added/agreed by advisory panel
Phone	Phone
Upset	Agitated, vicious circle, worse if upset, struggling makes it worse
Tired	Tiredness, worse when tired
Other barriers	Others filling in words, changing topic of conversation
<i>Things that HELP - reading/writing</i>	
Someone helping	Someone scribing at history class, volunteer helps spelling by doing crosswords, neighbour fills in betting slips
Speaking books	Listen to radio, listens to taped books
Extra time	Extra time, extra time for reading
Dictionary	Dictionary
Large print	Print better than writing
Computer	PC (computer) – can self-correct
Other facilitators	Reading to self at night, re-reading, reading out loud, using a piece of paper as a guide, leaving writing and coming back to it
<i>Things that HINDER- reading/writing</i>	
Glass barriers	Added/agreed by advisory panel
Queues	Added/agreed by advisory panel
Wrong hand	Added/agreed by advisory panel

Upset	Added/agreed by advisory panel
Under pressure	Added/agreed by advisory panel
Tired	Added/agreed by advisory panel
Too much	Multi-tasking

Table 5.6
Emotional constructs from which to select

Emotional construct	Origin	Other words used to refer to construct *
<i>Less control</i>	Interviews	Helpless, incapable, dependent, being trapped
<i>Less confidence</i>	Interviews/DQ	Lost confidence
<i>Embarrassed</i>	Interviews/?DQ	Embarrassed, (?self esteem)
<i>Isolated</i>	Interviews/DQ	Isolated, excluded, being ignored, unloved, rejected, neglected
<i>Angry</i>	Interviews/DQ	Angry, mad
<i>Frustrated</i>	Interviews/DQ	Frustrated
<i>Sadness</i>	Interviews/DQ	Sad, depressed, unhappy, down a bit
<i>Anxiety</i>	Interviews/DQ	Anxious, frightened, worried
<i>Able</i>	Interviews/?DQ	Can't do things, incompetent, a nutter, not being normal (?self esteem), stupid
<i>Valued</i>	Interviews/?DQ	Lack of respect, being small, lower down (?self esteem)
<i>Determined</i>	Interviews	Determined
<i>Contented</i>	Advisory panel	Sense of loss, being whole
<i>Independent</i>	Advisory panel	
<i>Uptight</i>	Interviews	Uptight
<i>Shocked</i>	Interviews	Shocked
<i>Tired</i>	Interviews	Tired, exhausted, knackered
<i>Proud</i>	Interviews	Proud
<i>Hopeless</i>	Interviews/DQ	Hopeless
<i>Unfair</i>	Interviews/DQ	Unfair
<i>Optimistic</i>	Interviews/DQ	Pessimistic, optimistic
<i>Satisfied with life</i>	Interviews	Positive attitude, dissatisfied with life

* = Both positive and negative aspects of the construct are mentioned

italics = those ultimately selected

?DQ = emotional constructs that could be subsumed within the self esteem question of the DQ.

Table 5.7
Sampling characteristics for the London field trial SLTs

Criteria	Groupings	Target	Actual
Number of therapists		10-15	15
Gender	Male	At least one man	0
	Female		15
Age	20-29	At least one	3
	30-39	At least one	5
	40-49	At least one	3
	50+	At least one	4
Experience	Under 2 years	At least one	1
	2-5 years	3	4
	Over 5 years	3	10
Type of work	Acute	At least one	3
	Rehabilitation	3	5
	Community	3	7
Location of work	Metropolitan		15

Table 5.8
Biographical details of pilot-test participants (people with aphasia)

Characteristic	Number
Number of administrations:	23
Age:	
Under 40	0
41-50	2
51-60	7
61-70	6
over 70	8
Sex:	
Male	12
Female	11
Ethnicity:	
White British	19
Asian	1
Afro-Caribbean	3

Table 5.9

Reported experiences of pilot testers (people with aphasia) on CDP administration

Views regarding OVERALL PROCEDURE:	Number
- Positive (those asterisked rated the content as appropriate but added comments that suggest limitations – see below)	21
- Negative	0
- Unable to comment	2

Area of interest	Comments (verbatim transcription taken from the feedback forms)
<u>CONTENT and overall perception:</u>	<p>Content was relevant</p> <p>Found it very helpful</p> <p>Thought it was useful</p> <p>Identified with the emotions illustrated</p> <p>She seemed to enjoy it, in that she was engaged and keen to respond</p> <p>Very thought-provoking – enabled her to discuss concerns re: future, think in structured way about impact of aphasia in different settings (tumour)</p> <p>She liked the fact that it addressed areas of her life that weren't usually addressed</p> <p>Felt it really focussed on her as a person and overtly respected her point of view</p> <p>Put (us) on the right track</p> <p>Commented that some situations were not appropriate to him (didn't ever do the shopping or go to the bank)</p> <p>Some sections were positive using encouragement and feedback e.g. domains 1-20</p> <p>Others were negative e.g. barriers; emotional consequences, lifestyle/participation (dependent on</p>

	<p>mood - patient's whole performance in therapy changes, depends on whether feeling positive or negative. Overall a mixed picture.</p> <p>Thought was helpful to talk about emotions</p> <p>Both liked the emphasis on THEIR perspective and that it was respectful of them</p> <p>Brought up fact that he did not think his partner always understood the difficulties he experienced (useful)</p> <p>* some situations were variable e.g. talking with a group of friends could be easier but sometimes not</p>
<p>FORMAT: - general</p>	<p>Felt pictures were useful – easy to identify with</p> <p>Seemed easy to do</p> <p>Happy to comply but because of expressive difficulties unable to comment about procedure but seemed to find it helpful</p> <p>Both liked the pictures</p> <p>Both liked the no 'right/wrong' aspect</p> <p>Liked the pictures –very helpful</p> <p>Scales useful</p> <p>Commented that some situations the rating varied</p> <p>*Emotional scale – more confusing</p> <p>*Not prepared to be pigeon-holed, especially in the emotions section</p> <p>* emotions scale complicated – took time to accept it</p> <p>She was happy that the procedure was accessible to her. Because it was pictures she did not strain herself trying to produce words to express herself, especially in the emotions section which are more difficult to express at times</p> <p>Found it hard to cope to cope with the 'barriers' section – wanted to rate each one. He also found participation section difficult to score and finally we scored each area separately (NB Patient is single, living on own, no mobility problems but 'relatives' section a bit tricky).</p>
<p>- length:</p>	<p>Good</p> <p>* found it exhausting (this person had an untreatable brain tumour)</p> <p>Not too long</p>

Table 5.10
Reported experiences of therapists during CDP pilot testers

Views regarding OVERALL PROCEDURE:	Number
No. of SLTS reporting that there was one or more people they chose not to administer the CDP with	7
CONTENT: <ul style="list-style-type: none"> - Appropriate (those *ed rated the content as appropriate but added comments that suggested limitations) <ul style="list-style-type: none"> - NOT appropriate 	20 3
FORMAT: <ul style="list-style-type: none"> - Easy to use (those asterisked rated the format as easy to use but added comments that suggest limitations) <ul style="list-style-type: none"> - NOT easy to use - Variable (see comments below) 	16 1 (this SLT only had the opportunity to administer the CDP once) 5

Area of interest	Comments (verbatim transcription taken from the feedback forms)
Reasons for NOT administering the CDP or stopping once started	Significantly reduced comprehension Very early stages of recovery Client anxious - overwhelmed by any form of assessment Client could not understand the purpose of the assessment-unable to relate situations to self (very recently acquired aphasia) Concern that person would be unable to differentiate between problems due to aphasia and problems due to

	<p>shingles</p> <p>Chose not to do with people who had aggressive high grade tumours currently undergoing treatment</p> <p>In-patients – too soon after CVA e.g. poor attention, distress</p> <p>It was not age appropriate, he was a young stroke patient who could express himself well. He also had a lot of unresolved issues relating to his relationship with his wife and wanting to go back to work. He also did not relate well to other people with strokes as he saw them as all old and had nothing more to do in life compared with him who still had his whole life ahead of him. The pictures mainly depicted an older person who had a stroke therefore it was difficult for him to related or he may feel depressed by this.</p>
<p>CONTENT: - general</p>	<p>Some situations he avoids or has never done</p> <p>Generally very good</p> <p>Participation section was really important section for him</p> <p>Content good and relevant as shown by strong reaction to some of the pictures and questions</p> <p>Content was appropriate</p> <p>Content relevant with the opportunity for him to elaborate</p> <p>*Opens up several other issues for client that SLT not necessarily able to deal with</p> <p>Pictures were very appropriate – identified well with them and also the ‘what helps’.</p> <p>Felt pictures were useful – easy to identify with</p> <p>Felt all content relevant</p> <p>Felt participation section was over too quickly and was rather generalised</p> <p>‘worried’ and ‘content’ queried by both participants</p> <p>One client commented that single word and headline reading varied - sometime she could and sometimes she couldn’t</p> <p>Mostly apart from emotional factors; patient insight heightened by the negative changes</p> <p>Items were relevant but perhaps need to choose/omit some if patient becomes anxious</p> <p>The items were relevant to all situations that an aphasic person may experience post stroke</p>
<p>- aphasia separate from other areas:</p>	<p>Looking to the future brought up general issues i.e. the uncertainty she was feeling about future strokes.</p> <p>Still participating actively in daily life however emotional issues have greatest impact</p> <p>*Found it difficult to explain looking only at aphasia and not mobility problems in case of impact on participation.</p>

	<ul style="list-style-type: none"> * Had some difficulty explaining only looking at aphasia NOT mobility fatigue * Fatigue experienced in CVA also has big impact so not always easy to distinguish. * Difficult to isolate dysphasia from other difficulties e.g. hemiplegia and hearing loss * Required cues ++ to rate linguistics of writing (tended to focus on mechanics-dyspraxic) <p>Some areas not relevant because housebound and physical impairment having more impact on daily life.</p>
<p>FORMAT: - general</p>	<p>Easy to use Scoresheet simple Relatively easy to use We couldn't have covered the ground without this format Scoring was good , Easy to use Fairly easy – domains 1-20 for example – but not the barriers section or emotional consequences section.</p>
<p>- Structure:</p>	<ul style="list-style-type: none"> * Initially difficult using lots of pictures but got easier, difficult reading from the script * Initially difficult switching between pictures and scale – settled down with time * Too many pictures initially however, this did get easier * Difficulty underst. emotions positive rating, rating each participn domain, * Not sure if rating one or 3 emotions pictures * did get a bit lost (no page numbers, asking for totals for the participation sections) * At times my explanations were a bit wordy <p>Lots of information presented e.g. the groupings of things you want to do and then the rating scale Fewer laminated sheets to choose from or combining one/two</p>
<p>- Length:</p>	<p>I think the CDP is an appropriate length Tended to elaborate on each section so the TIME taken increased * Can be quite time consuming * took a long time to administer and long time to respond (cognitive problems) Felt needed to spent more time discussing the last section (when and why do you feel that) Took longer than anticipated and would have liked to have spent more time going into 'when are things better and why?' Need to discuss with PWA that administration may be lengthy</p>

	<p>Very lengthy to do in one session – might be tempted to skip the discussion which we felt was very very useful (inoperable tumour)</p> <p>Took 1 and ½ hours – one session (inoperable tumour)</p> <p>Exhausting but liked the fact that it enabled him to give HIS perspective – he surprised his wife (positive) (brain tumour)</p> <p>Do sections only of the CDP rather than in entirety</p> <p>Both clients had mild expressive aphasia and it took 2-3 sessions to complete</p> <p>Took time to elicit the scores – undertaken over 2-3 sessions – shorter format would be helpful</p>
- Script/scoresheet:	<p>Further instructions would have been good for scoring</p> <p>Once mastered the script relatively straightforward</p> <p>Easy to use though verbatim text could be improved with boxes, upper case etc.</p> <ul style="list-style-type: none"> * could instructions be bigger or somehow more obvious * Found it difficult reading from a script felt this affected the interaction * + and – on scoresheet - not immediately apparent what it means <p>Not sure that quantification was terribly relevant – would look at which emotional issues there were rather than lumping them all together – though I can see some merit in quantifying in this way</p> <p>Scoring was OK once patient was focused</p>
- Accessible:	<p>Felt would be able to use with all abilities</p> <p>Emotional scales took time and practice – definitely needed repetition and gesture</p> <ul style="list-style-type: none"> * Don't know that he understood the 'understanding' section. * When administered at home appropriate table space required and tricky keep using all cue cards * table space tricky esp. at home * additional questions in emotional section were very difficult with client with severe aphasia * some confusion over which end of the scale to use, needed lots of repetition (cognitive changes so slower at grasping task) <p>Unable to convey difference between talking and expressing your self (memory problems)</p> <p>Couldn't understand the 'able' picture</p> <p>Accessible but a bit fiddly with using different pages.</p>
- Acceptable:	<p>Less 'flow' in barriers section – not all situations applied</p>

	<ul style="list-style-type: none"> *Occasionally the person wanted to score in between ratings *Floundered a bit talking about things you have to do – client wanted to talk about each one specifically * emotional scale - very complex and difficult to be black and white in such a grey area (found I was able to discuss the issues re; the scales BUT adds to already lengthy consultation) <p>Wanted to be placed between scale points</p>
- General comments:	<ul style="list-style-type: none"> *hadn't used it for weeks started expression section inappropriately *became easier with use/familiarity * On occasion responded in a 'concrete' way as opposed to the concept as a whole (cognitive impairments) <p>People with memory problems = recapping on previous sessions very difficult if done over no. of sessions</p>
RELEVANT TO CLINICAL PRACTICE?	<p>I think you have devised a very useful and well thought out instrument. The comments are mere suggestions</p> <p>CDP used on client who had previously identified conversation with wife as a problem (so did the SPPARC programme – unsuccessful – wife reported they never have had big conversations (pre-morbidly). Was hoping that CDP would clarify this) and it did – it showed that conversations were OK</p> <p>It enabled us to discuss some issues more and highlight others e.g. confidence was a bigger issue than I had realised.</p> <p>Nice comparison between their in-patient stage...there can be quite a shift and that's implied but you can reflect that</p> <p>Really useful (to do serially) showed them the numbers and we negotiated what we were going to do...seeing it in front of them in a concrete way was really useful</p> <p>It has lead on to further discussion and moving away from impairment towards living with aphasia</p> <p>It was a gentleman I know quite well but there were still a few surprises</p> <p>Both felt it was directly relevant to their daily lives/living with aphasia</p> <p>Highlighted issues within their support/family network and their individual coping skills</p> <p>Gave 'objective/formal' structure as a forum for discussing emotional issues – increased confidence to address these BUT perhaps needs to be done in separate session – difficult to return to sensitive areas that may not need dealing with as is uncovered/revealed</p> <p>Information useful, provided additional information that helped in subsequent sessions</p> <p>Definitely guided management as I knew what the main concerns were and could use that in treatment</p>

	<p>Both information gained and process were useful Helped to bring out the positives and for the person to reflect on them Useful to get an immediate and emphatic reaction – show you what’s really important PWA expressed an interest in working on writing which he had not articulated before despite me knowing him well over a long period of time Gave me specific ideas re; advice to family based on HIS experiences rather than my viewpoint as a therapist The CDP enabled him to be more assertive in expressing his views. I've enjoyed doing it and haven't come across anything which covers such a lot of ground (from the aphasic person's perspective) so neatly. It's different, and highly useable. NO did not provide me with additional information possibly due to knowing the client very well and so had already investigated these areas For this patient the CDP confirmed information already obtained or deduced. Did not guide my management but gave me further insight. Definitely useful in the community setting to highlight areas which client themselves was concerned about/wanted to work on Directed team goals i.e. – transport and shopping Identified several issues that were not previously recognised by the SLT to be important for client (therefore very beneficial)</p>
INFORMING PRACTITIONER?	<p>Helps you reflect on why some people with severe aphasia adjust well while others with mild aphasia are very negative about their skills I was surprised and interested by the occasional strength of feeling expressed e.g. barriers section. Helped me to understand the impact of people interrupting/looking away I can be really confident that apparently simple things really do make a big, positive difference (e.g. people talking slowly) Someone’s perceptions of their skills can be very different to their actual skills NO – made me feel quite positive about previous practice as it appears the areas have been covered though not in such a structured way (this SLT only had the opportunity to administer the CDP once) More holistic approach – addressing what they want to do as opposed to focussing on impairment biased Recognising that what you see as a clinician to be the area of difficulty may not be what is important for</p>

this person

Assessment will be useful as adjunct to other areas of assessment

Interesting that most able client (able because had most access to language) scored least on domains (don't think this was because of increased awareness)

Did highlight with someone with mild aphasia the huge impact on their ability to participate in activities and how affected everything they did/wanted to do

Made me very keen to do more education/teaching in hospitals, nursing homes, day centre on aphasia and facilitating communication highlighting increased difficulties understanding different accents and need to use strategies

Makes you think about the need to inform the general public more – difficulties with bus drivers etc. despite being shown ADA card

Appendix 6.13

Consent form used in this project (page 2)

It won't affect my speech therapy.

There is **NO DANGER**



no danger

Everything is **confidential**.

No one will know what I said.



Do you agree to **take part** in the project?



YES



NO



Signed:

Date:

Name in **CAPITALS**:

Signature of Kate Swinburn:

Table 5.11
Suggestions to be taken to advisory group following pilot testing

Manner of change	Suggested changes
Content	1. Female version of 'what is fun for you' picture
	2. Condense who helps and who hinders into ONE picture but have MULTIPLE pictures (ethically diverse as for scales)? And maybe have a 'who makes it better' and 'who makes it worse' picture thumbs up and thumbs down? Add to the who is important picture Delete Q42 – important people
	3. Delete 'someone helping you' from help page because maybe already covered in who is important?
	4. An acute stage page (for participation ? – calling nurse, ward rounds? ordering from menu – see aphasia handbook?, and/or external influences) - ? is this appropriate
	5. Remove lightening strike on 'during the last week' page
	6. Change order so that self image comes AFTER emotional state
	7. 'Content' and worried' are opposites of same construct – choose another positive one
Format	1. Rate EACH of the participation domains separately (but they felt the CDP was an appropriate length so would have to reduce somewhere?). If so how ? introduce using all on one page and then have one per page?
	2. Page numbers on pictures
	3. Section dividers
	4. Relocate 'work' so that it is less prominent in participation section
	5. Add ? to anywhere where ..and anything else – 7. external influences particularly
	6. Smaller stimulus sheets for scales and during the day cards ? flip chart? Maybe double backed so that during the last week appears above each time and the scale appears below each time
	7. LOOK carefully at emotions rating esp last 2 future and ?
Wording	1. 'lonely' for 'isolated' (isolation can be desirable)
	2. Check wording of participation section (see Megan Q21/22/24)

	3. Emphasis change of scale
	4. Change 'a lot' to 'very'
	5. Pages 34 and 32 delete 'how are' so that focus on here are things you might want to do
Other comments	Exhausting, too many pictures, neither positive nor negative but not a useful experience

Table 5.12

Changes to the CDP draft 2 after advisory group ratification of pilot testing suggestions

Type of change	Changes made.	CDP draft 2	CDP draft 3	Rationale for changes
Acceptability	Extra item added (not rated)	No mention of present mood state	'Overall, how are you today?'	Acknowledgement that current mood can significantly influence all rating, and that some recording of this should be attempted
Accessibility	Wording change in introduction and throughout	'Since your stroke, during the last week'	'During the last week'	'Since your stroke ', sometimes led to conversation being side-tracked. 'During last week' was shorter and more focused
Accessibility and acceptability.	Rating of participation section	'So overall, how is talking for all those things you <u>have</u> to do?' (Sweep hand across all the pictures)	'How is work - can you show me on the scale?' (Rate each domain separately)	PWA* and SLTs reported that a summary rating was difficult to explain and administer and unpopular
Accessibility and acceptability.	Reorder pictures	'Work' is the first item to be addressed in how are things you HAVE to do section	'Work' becomes the last item in this section	The majority of PWA no longer work. Though important to be able to rate and then discuss and why this might, thought to be challenging to have it given such prominence
Accessibility and acceptability.	Condense 'who helps' and 'who hinders' into ONE 'who is important' picture but have MULTIPLE	Two pictures each rated - 'who helps' and 'who hinders'	One 'who is important' picture	Duplication of information avoided Reduces length of tool

	ethically diverse pictures			
Accessibility and acceptability.	Reordering of self confidence and emotional states	Emotions associated with self image (such as feelings of competence, control and confidence) came before emotional states (such as frustration, anxiety and determination)	Emotional states begin the exploration of emotions	Those emotional states most immediately associated with having aphasia should be explored first. Emotions that may RESULT from these feelings (self image emotions) should follow Less threatening to begin section with emotional states
Acceptability	Wording change	'isolated'	'lonely'	PWA commented that you may CHOOSE to be isolated (on your own) but that you would not choose to be lonely
Accessibility and.	Addition of a large ? whenever the PWA's individual situation is tapped	Is there anything else? (no graphic representation)	Is there anything else about X that is important? (graphic representation using ?)	Emphasizing that CDP will not have covered everything that might be pertinent to the PWA PWA's contributions are as significant as the pre-determined categories
Accessible and acceptability	Change the rating of the emotional section to a one stage rating process	Two stage rating only (Appendix 4.3a page 72-3)	One-stage rating (Appendix 4.3a page 74)	Some PWA* and SLTs reported that emotional rating was difficult to administer Advisory group choose one stage rating (Appendix 4.3a page 74)
Accessible	Format change to presentation of 'during the last week' picture	Presented as a separate laminated sheet	Presented within the body of the tool, on page above the one being rated (when book is open there will be	Some commented that physical manipulation of so many pieces of information was difficult

			two pages visible – one on top and one below)	
Additional pictures for 'what do you enjoy?'	New pictures added. Presented all on double-spread page to enable 12 pictures with male/female interspersed	Male dominated activities	Added some activities that were female-orientated.	Several pilot testers commented that this page was male-dominated

Table 5.13
Origins of the modifications between DQ5 and CDP2

Domains explored	Examples in DQ5	Examples in CDP2	Type of modification	Modification attributable to whom?
Communication activities	4 modalities (Understanding, Talking, Reading, Writing) 4 items per modality (all rated)	5 modalities (added modality of Expressing Yourself) 4 items per modality (all rated)	Reordering of domains (each modality the following domains: activities, participation, external influences)	Suggested by SLT focus group Confirmed by advisory panel
Participation	4 items (all rated) (one Q per modality; what's that like on a day to day basis?)	3 items (three Qs; things you have to do, things you want to do, at home?)	1. Introduction of concept to expand participation section. 2. Modifying, perfecting and selecting domains and items for expansion of participation section 3. Modifying, perfecting and selecting rating for participation section	1. Reviewing literature on participation/discussion with researcher 2. In-depth interviews 3. Advisory panel
External influences	None	4 items (none rated)	1. Introduction of concept of external influences section 2. Modifying, perfecting and selecting items for external influences section	1. Expert SLT 2. In-depth interviews 3. Advisory panel
Emotional consequences	9 emotional constructs (Self image Qs separated from feelings section) All expressed negatively	14 emotional constructs (Self image subsumed into emotional section) 8 expressed negative, 4 expressed positive, 2 expressed neutral	1. Modifying and selecting the items for emotional consequences section 2. Reconsidering the concepts behind the emotion Qs 3. Selecting items and perfecting presentation of items	1. Advisory panel (supported by data from in-depth interviews) 2. Advisory panel 3. Advisory panel
All	All items negatively expressed, questionable accessibility and acceptability	Accessibility, acceptability and wording all seen as appropriate by the advisory panel	Modification to wording <ul style="list-style-type: none"> - accessibility & acceptability - negativity 	Advisory panel
All	None	Pictures used to support every concept and question within the CDP2	1. Introduction of concept to use pictures 2. Modifying, perfecting and selecting of pictures	1. Both user focus groups 2. Advisory panel

Table 5.14
Table to show the factor analysis for the DQ

Domain	Factor 1
Variance accounted for (n=60)	63%
<i>Disability associated with comprehension</i>	.696
Disability associated with expression	.817
Disability associated with reading	.808
Disability associated with writing	.800
Intrusion	.911
Self Image	.769
Emotional Impact	.735

Table 5.15

Table to show test-retest on the DQ

Domain/section	r	n
Disability associated with comprehension	0.881	18
Disability associated with expression	0.608	17
Disability associated with reading	0.863	17
Disability associated with writing	0.901	17
Intrusion	0.789	17
Self Image	0.871	18
Emotional Impact	0.929	18
Disability Total	0.973	16
Handicap	0.936	17
Disability total	0.978	15

Table 5.16
Cronbach's Alpha data on DQ for people who have lived with aphasia for a year

Domain/section	alpha	n	item s
DQ (total)	0.95	42	33
Sections:			
Activities	0.9	41	16
Participation	0.79	51	4
Emotional consequences	0.94	42	13

Table 6.1
Manner of involvement of users in research project

Stage and phase	Process	No. of PWA involved	Purpose	Level & type of involvement of PWA
Stage 1 - Phase 1	Write original instrument based on clinical experience	0	Construct instrument	None (professionally conceived concepts and construction)
	Administer DQ	15	Pre-test items	Respondents
	Modify tool	0		None
- Phase 2	Administer DQ	15	Pre-test items	Respondents
	Seek expert colleague advice	1	Obtain expert opinion	Advisor
	Modify tool	0	Ensure face validity	None
- Phase 3	Administer DQ	10		Respondents
	Modify tool	0		None
Stage 2	Conduct focus groups with DQ users (SLTs & people with aphasia)	7	Obtain expert opinion Ensure face/content validity	Consultants
	Modify tool	0		None
	Administer CDP 1	40	Field testing	Respondents
Stage 3	Group interviews	13 (7+6)	Ensure content validity	Respondents
	Individual in depth interviews	13	Ensure content validity	Consultants
	Convene advisory group	3	Ensure validity of research process	Advisors
	Modify tool	3		Advisors
Stage 4	Pilot testing (CDP draft 2)	23	Establish clinical usability	Participants in administration plus solicited comment
	Modify tool	3	Ensure validity of research process	Advisors

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(All appear sequentially)

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Appendix 2.8a Consent form for DQ focus group (people with aphasia) page 1

Appendix 2.8b Consent form for DQ focus group (people with aphasia) page 2

CHAPTER 4

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Appendix 4.2 Topic guide for individual in-depth interviews

Appendix 4.3a The CDP – draft 2 (include 12 rating scales)

Appendix 4.3b The CDP – draft 2 score sheet

Appendix 4.4 Feedback form 1 for usability study

Appendix 4.5 Feedback form 2 for usability study

CHAPTER 5

Appendix 5.1 How much does it get in the way - original draft

Appendix 5.2 How much does it get in the way - second draft

Appendix 5.3 What makes it worse (concept) - original draft

Appendix 5.4 What helps (concept) - original and final draft

Appendix 5.5 WHO helps? (specific) original draft

Appendix 5.6 Things you WANT to do original and final draft

Appendix 5.7 Things you HAVE to do - original and final draft

Appendix 5.8 At HOME original and final draft

Appendix 5.9 WHO helps your talking? (specific) second draft

Appendix 5.10 What THINGS help? (specific)

Appendix 5.11 What makes things HARDER (concept) second draft

Appendix 5.12 WHO makes talking HARDER (specific)

Appendix 5.13 What THINGS makes it HARDER (specific) original draft

Appendix 5.14 What THINGS makes it HARDER (specific) final draft

Appendix 5.15 What THINGS makes talking HARDER (specific) conversational barriers

Appendix 5.16 Talking under pressure - original draft

Appendix 5.17 Looking to the future – original draft

Appendix 5.18 Looking to the future – final draft

Appendix 5.19 Original unhappy-worried-content picture

Appendix 5.20 Concepts that appear in the qualitative interviews

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Appendix 5.23 PWA pilot comments to show to advisory group

Appendix 5.24 SLT pilot comments to show to advisory group

Appendix 5.25 Example of how pilot suggestions were taken to advisory group

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Appendix 5.27 Options for one-stage rating scale condensed
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CHAPTER 6

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Appendix 6.2 Email to Sue
Appendix 6.3 Issues for consideration to John
Appendix 6.4 Rating scale – option 1
Appendix 6.5 Rating scale – option 2
Appendix 6.6 Rating scale – option 3
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Appendix 6.12 Consent form used in this project (page 1)
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Appendix 2.1

The Comprehensive Aphasia Test

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- A) THE COGNITIVE SCREEN
1. Line bisection
 2. Semantic memory
 3. Word fluency
 4. Recognition memory
 5. Gesture object use
 6. Arithmetic
- B) THE LANGUAGE BATTERY
- Language comprehension
7. Comprehension of spoken words
 8. Comprehension of written words
 9. Comprehension of spoken sentences
 10. Comprehension of written sentences
 11. Comprehension of spoken paragraphs
- Repetition
12. Repetition of words
 13. Repetition of complex words
 14. Repetition of non-words
 15. Repetition of digit strings
 16. Repetition of sentences
- Spoken naming
17. Naming objects
 18. Naming actions
 19. Spoken picture description
- Reading aloud
20. Reading words
 21. Reading complex words
 22. Reading function words
 23. Reading non-words
- Writing
24. Writing: copy
 25. Writing picture names
 26. Writing to dictation
 27. Written picture description

Appendix 2.2

DISABILITY QUESTIONNAIRE

Name:

Date:

Please read the following questions. Think about them carefully then circle the number that you think best describes how you feel. We are particularly interested in the **effects of the stroke on communication and how easy or difficult it is for you to do things SINCE your stroke**. Thank you for completing the questionnaire.

Disability

UNDERSTANDING SPEECH

Unable/Very
Difficult

Easy
No problem

Compared with before your stroke,
how difficult is it for you to

(5) < ----- > (1)

- | | | | | | | |
|----|---|---|---|---|---|---|
| 1. | understand your wife/husband | 5 | 4 | 3 | 2 | 1 |
| 2. | understand one other person | 5 | 4 | 3 | 2 | 1 |
| 3. | understand in a small group of people who are not family | 5 | 4 | 3 | 2 | 1 |
| 4. | understand TV or radio | 5 | 4 | 3 | 2 | 1 |

TALKING

Unable/Very
Difficult

Easy
No problem

Compared with before your stroke,
how difficult is it for you to

(5) < ----- > (1)

- | | | | | | | |
|----|---|---|---|---|---|---|
| 5. | find the right words/put sentences together when talking with your family | 5 | 4 | 3 | 2 | 1 |
| 6. | find the right words/put sentences together when talking to close friends | 5 | 4 | 3 | 2 | 1 |
| 7. | find the right words when speaking with someone you don't know | 5 | 4 | 3 | 2 | 1 |
| 8. | find the right words when talking on the phone or behind a glass screen e.g. post office/ticket office | 5 | 4 | 3 | 2 | 1 |

(if you avoid any of these situations put down 5)

READING	Unable/Very Difficult					Easy No problem
Compared with before your stroke, how difficult is it to	(5) < -	-----				> (1)
9. read and understand single words	5	4	3	2	1	
10. read and understand a short phrase (e.g. newspaper headline)	5	4	3	2	1	
11. read and understand an official form e.g. a bill	5	4	3	2	1	
12. read and understand an article in the paper or page in a book	5	4	3	2	1	

WRITING	Unable/Very Difficult					Easy No problem
Compared with before your stroke, how difficult is it to	(5) < -	-----				> (1)
13. spell/write your name and address	5	4	3	2	1	
14. spell/write other single words	5	4	3	2	1	
15. spell/write a letter or a card	5	4	3	2	1	
16. Complete an official form e.g. a household bill	5	4	3	2	1	

HANDICAP	Yes A lot					No None
	(5) < -	-----				> (1)
17. Do you feel you have any difficulties with communication since the stroke?	5	4	3	2	1	
18. If you have difficulties – do they worry you?	5	4	3	2	1	

19.	Does your communication affect your daily life?	5	4	3	2	1
20.	Which aspects of the difficulty affect your daily life?					
-	reading	5	4	3	2	1
-	writing	5	4	3	2	1
-	understanding	5	4	3	2	1
-	talking	5	4	3	2	1

EMOTIONS

21. Could you indicate which words describe how you feel about communication since your stroke?

	Very	a little	not at all
frustrated			
depressed			
angry			
unfair			
helpless			
stupid			
accepting			
pleased			
optimistic			
negative			

Thank you for completing the questionnaire.

Please return to

Oct 1993

Appendix 2.3

The DQ rating scale

Unable

Very
difficult

Difficult

OK

Same
as
before

4 <-----> 3 <-----> 2 <-----> 1 <-----> 0

X

✓

Understand

- Person closest to you
- A Stranger
- 3 or 4 friends or family
- Speaking quickly or someone in authority - doctor or benefits officer

Appendix 2.5

Example of a DQ help-sheet introduced (page 2)

How these problems affect you on a

Day to Day basis

Get in the way of everyday life

Appendix 2.6

Cronbach's alpha scores for the DQ draft 5

Domain	Number of participants	Number of items in each section	Alpha score
DQ as a whole	42	33	0.95
Sub-scaled:-			
Activities	41	16	0.9
Impact	51	4	0.79
Emotional conseq	42	13	0.94

Appendix 2.7a
Information sheet for user field trial focus group

INFORMATION SHEET

Kate Swinburn
(Speech and Language Therapist)
Richmond Rehabilitation Unit,
Evelyn Rd. Richmond TW2 9TF SURREY
Phone: 0171-228-8400



This is a **project** about **how** your **talking problems** affect your **life**.

It is **NOT** **speech therapy**.

The project is looking at **how speech therapists** look at your **talking difficulties**.

An **assessment** has been written

It asks **lots of questions**.

It looks at **how** your talking **gets in the way** of day to day life.

It has **questions** about **how you feel** about your talking difficulties.

You can **answer** the questions **just by pointing** if you want.

The tool is called a **Rating Scale**.

You will be **asked** what you think of the rating scales.

Your **views** are **really important**.

Your **thoughts** about it will help to make the rating scale better.

This will be the **first time** views of **people with talking problems** have been **included** in developing a tool.

If you would like to help - **here's what will happen:**

- **Kate Swinburn (a speech therapist)** will come to see you
- She will do the **rating scales** with you

Appendix 2.7b Information sheets for people with aphasia user field trial focus group - page 2

later on ...

- 6 weeks later you will come to join other people with talking problems.
- You will be picked up and taken home by taxi.
- The group will run at City Dysphasic Group, Goswell Place, near the Angel.
- Susie Parr (a different speech therapist) will run the group.
- You will chat with everyone about the rating scales.
- The group will take about 2 hours.

If you don't like it, you can STOP.

If you change your mind, you don't have to COME.

No one will ask any questions.

Your speech therapy will not change if you stop.

● If you want to take part:

- talk to (name of the relevant speech therapist)

(she will make all the arrangements)

OR

- ring Kate Swinburn on 0171-228-8400
(say "I'm phoning about the rating scales project")

This project has been looked at by.....Ethics Committee (they check the project is fair and good).

They say it can go ahead.

Appendix 2.8a
Consent form for people
with aphasia user field trial focus group
- page 1

CONSENT FORM

Kate Swinburn,
Speech and Language Therapist,
Richmond Rehabilitation Unit,
Evelyn Rd, Richmond.

Telephone 0171 228-8400



The project has been explained.

YES



NO



I understand what I have to do.

YES



NO



I spoke to about the pr

I can STOP at any time.



Appendix 2.8b
Consent form for people
with aphasia user field trial focus group
- page 2

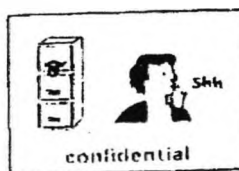
It won't affect my speech therapy.

There is **NO DANGER**



Everything is confidential.

No one will know what I said.



Do you agree to take part in the project?



YES



NO



Signed:

Date:

Appendix 4.1
Communication Disability Profile (draft 1)

*"I'm going to ask you some questions. They look at how you **feel** about communication.*

*There is no right or wrong. It is **your** view of how things feel since the stroke. I'll ask a question and then I'll also show you a scale like this. Let's try an example. Since your stroke, how easy is it to chat to a friend.*

"so if;

chatting is very easy, the same as before your stroke point here;

if you cannot chat at all you would point here;

but maybe its somewhere in between " (sweep hand across scale).

Disability self-rating.

Talking

*"Let's look at you **talking** - finding your words and saying a sentence.*

Since your stroke how easy is it for you to:

- | | | |
|-----------------|---|------------------|
| 1. | <i>talk to the person closest to you (use person's name)</i> | Rating: |
| Comments | | 0 1 2 3 4 |
| 2. | <i>talk to someone you don't know</i> | Rating: |
| Comments | | 0 1 2 3 4 |
| 3. | <i>talk to 3 or 4 family or friends</i> | Rating: |
| Comments | | 0 1 2 3 4 |
| 4. | <i>talk if you are stressed"</i> | Rating: |
| Comments | | 0 1 2 3 4 |

5. *any other people or situations that are difficult reinstated?* (transcribe)

"so you've told me that its most difficult for you when...but that ... is easier, is that right?"

6>(*M) *what's that like on a day to day basis?*

Comments

Rating:

0 1 2 3 4

7.(*S) *does that worry you ?*

Comments

Rating:

0 1 2 3 4

Understanding

*"So you've told me about talking ... this next section is about you **listening** and understanding when other people talk to you. So this is **not** you talking, its you **following** what's said to you.*

Since your stroke how easy is it for you to:

8. *understand the person closest to you (use person's name)*

Comments

Rating:

0 1 2 3 4

9. *understand someone you don't know*

Comments

Rating:

0 1 2 3 4

10. *understand 3 or 4 family or friends*

Comments

Rating:

0 1 2 3 4

11. *understand when you're under pressure*

Comments

Rating:

0 1 2 3 4

12. *any other people or situations that are – difficult reinstated(transcribe)*

"so you've told me that its most difficult for you when...but that ... is easier, is that right?

13>(*M) *what's that like on a **day to day** basis?*

Comments

Rating:

0 1 2 3 4

14.(*S) *does that **worry you?***

Comments

Rating:

0 1 2 3 4

Reading

"So we've discussed talking and understanding, now lets look at reading. This is reading in your head not reading aloud

Since your stroke how easy is it for you to:

15. *read and understand a **single word** like a word on a list*

Comments

Rating:

0 1 2 3 4

16. *read and follow a **newspaper headline***

Comments

Rating:

0 1 2 3 4

17. *read and follow **piece in a paper***

Comments

Rating:

0 1 2 3 4

18. *read and follow **an official letter***

Comments

Rating:

0 1 2 3 4

19. *any **other situations** or things that make reading difficult (transcribe)*

"so you've told me that its most difficult for you when...but that ... is easier, is that right?

20(*M) *so how is reading on a **day to day** basis?*

Comments

Rating:

0 1 2 3 4

21(*S) *does that worry you ?*

Comments

Rating:

0 1 2 3 4

Writing

(pre-morbid literacy practices will significantly influence this section and must be borne in mind when choosing whether to administer this section and with interpretation of this section)

"Lets have a look at writing – NOT holding the pen – the spelling. What about spelling words ?

Since your stroke how easy is it for you to:

22. *spell/write your name and address*

Comments

Rating:

0 1 2 3 4

23. *spell other single words like a shopping list*

Comments

Rating:

0 1 2 3 4

24. *write a letter to a friend*

Comments

Rating:

0 1 2 3 4

25. *write an official letter*

Comments

Rating:

0 1 2 3 4

26. *any other situations or things that make writing difficult? (transcribe)*

"so you've told me that its most difficult for you when...but that ... is easier, is that right?

27(*M) *so how is writing on a day to day basis?*

Comments

Rating:

0 1 2 3 4

28(*S) *does that worry you ?*

Rating:

Comments

0 1 2 3 4

Emotional consequences

We're going to talk about your mood now. Since your stroke:

29. *are you **confident** about communicating? (+)*

Rating:

Comments

0 1 2 3 4

30. *does your communication make you **angry**? (-)*

Rating:

Comments

0 1 2 3 4

31. *does your communication make you **frustrated**? (-)*

Rating:

Comments

0 1 2 3 4

32. *does your communication make you **sad**? (-)*

Rating:

Comments

0 1 2 3 4

33. *do you feel **in control** of your communication? (+)*

Rating:

Comments

0 1 2 3 4

34. *some people **feel stupid** because their communication has changed,
do you ever **feel a bit daft**? (-)*

Rating:

Comments

0 1 2 3 4

35. *when you **look to the future**, how do things look? (neutral)*

Rating:

Comments

0 1 2 3 4

36. *how do things **look today**? (neutral)*

Rating:

Comments

0 1 2 3 4

37. *do you have **people who are important to you**? (+) (do not rate)*

Appendix 4.2
Topic Guide for in-depth interviews/living with aphasia

Introduction

(include consent for recording)

- "Tell me about yourself and those you live with"

Impairments

- "Tell me a bit about **what happened** when you had your stroke?"
- "how did it affect you?"
- "when did you first notice your talking had changed"
- "who explained it to you"
- "what was the most important thing that has changed since the stroke?"
 - o physically
 - o communication
 - o reading & writing
 - o speech
 - o understanding,
 - o other ways (probe mood)
- "do you have a name for all of that?"
- "is...their term.. important to you"
- "Have you heard the term 'dysphasia-what does it mean do you think?"

Probe:

- o other people's reactions
 - in hospital,
 - when discharged
- o your reaction
 - in hospital,
 - when discharged
- "do you think you've got a problem with your talking?
...to what extent.
...what makes you say that?"

Participation-based changes

"did these changes affect **every day life** for you after the stroke?"

- in what way?"
- "what's the most important thing that (their term) has stopped you doing?"
- "What do you still do now...What did (their term) stop you doing?"

Probe:

- o friends
- o family
- o social life
- o hobbies
- o work
- o how you felt about yourself
- o other people's reactions
- o emotions
- o ?result of dysphasia or other things
- "when you meet someone for the first time do you tell them?"
- "what is it that makes you ?unhappy/sad/lonely (whatever they've said)?"
- "Can you tell me how things have changed over this year?"
- "has anything good come out of it?"

Barriers and facilitators

- "What/who has **helped** you to **live with** these changes?"
- "What/who makes it **easy** or **more difficult**?"

Probe

- o family
 - o friends
 - o environment
 - o attitudes
 - o mood
 - o therapy
 - o anything about you as a person that helped
 - o anything in the past
 - o specific things that you do when you can't find a word/follow what
 - o someone's said to you
-
- "Some people have talked about feeling disabled? Do you feel that you are disabled?"
 - "why are you/or are you not disabled?"
 - "Is there anything important about the effects of dysphasia that we haven't discussed?"

Thank yous

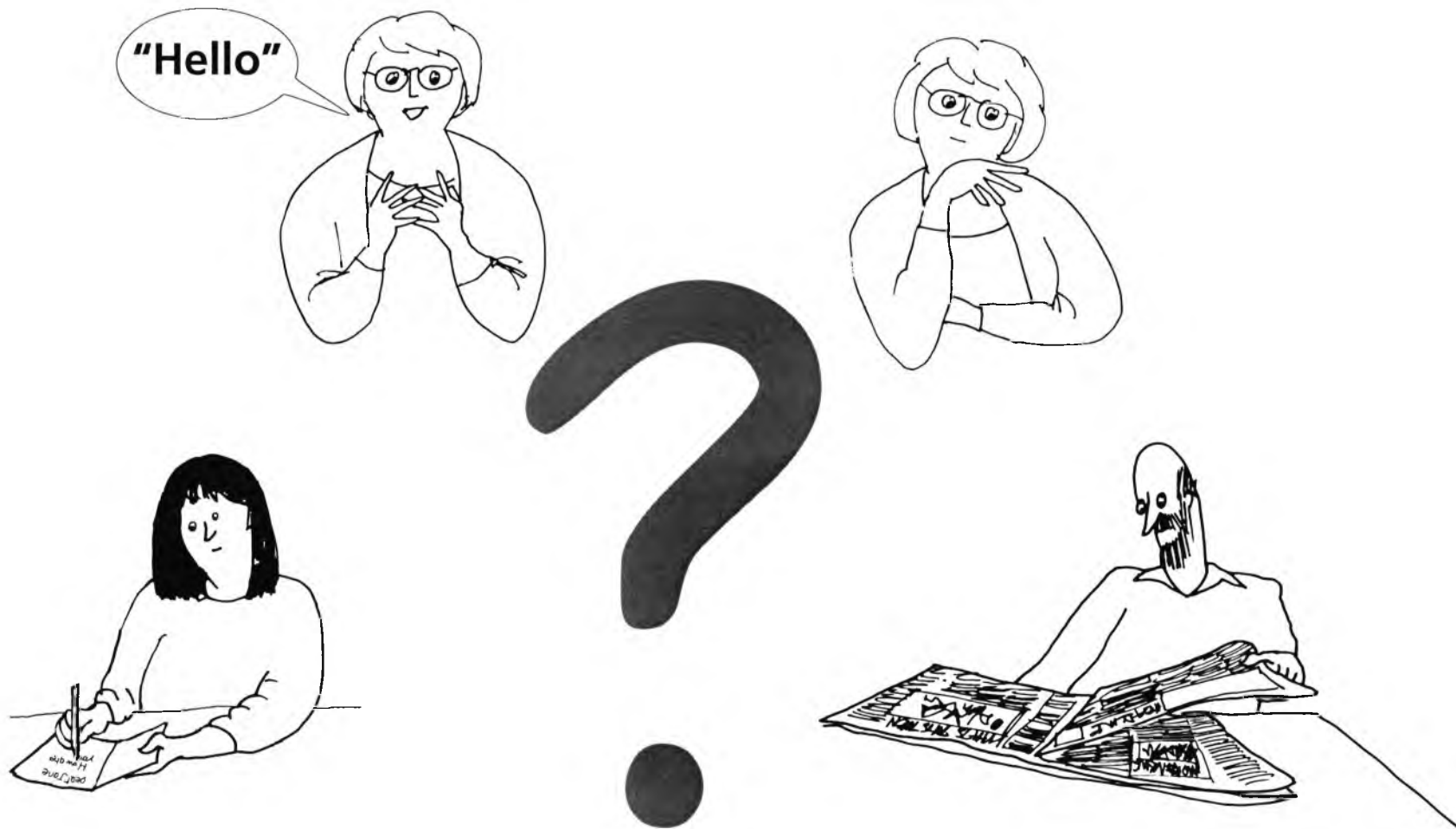
Appendix 4.3a
The CDP (draft 2-pilot test version)

Communication Disability Profile

Conceived and written by **Kate Swinburn** with **Sally Byng**

Designed and drawn by **Caroline Firenza**

Aphasia

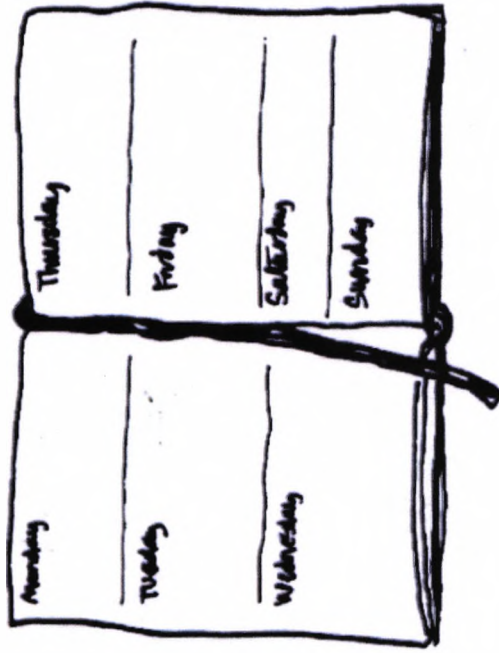


What you **do**

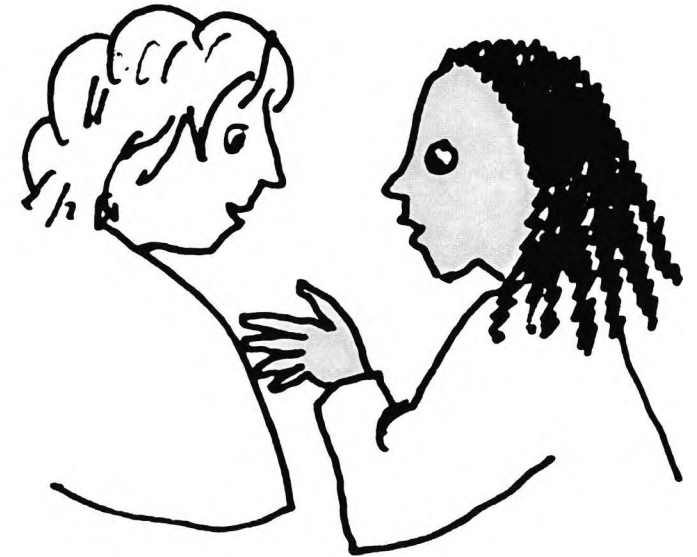
How you **feel**



During the last week...



How easy is it for you to **chat** to a friend?



Talking



How easy is it for you to **talk** to...?



How easy is it for you to **talk** with a **group of friends**?



How easy is it for you to **talk** to a **stranger**?



How easy is it for you to **talk under pressure**?



Expressing yourself



How easy is it for you to **express** yourself with...?



How easy is it for you to **express** yourself
in a **group**?



How easy is it for you to **express** yourself with a **stranger**?



How easy is it to **express** yourself **under**
pressure?



Understanding



How easy is it for you to **understand**...?



How easy is it for you to **understand** a **stranger**?



How easy is it for you to **understand** in a **group**?



How easy is it for you to **understand**
under pressure?



Reading



How easy is it for you to **read one word** only?



How easy is it for you to **read** a **headline**?



How easy is it for you to **read a whole story** in a newspaper?



How easy is it for you to **read** an **official letter**?



Writing



How easy is it for you to **write your name?**



How easy is it for you to **write** a **list**?



How easy is it for you to **write** a letter to a **friend**?



How easy is it for you to **write** an **official letter**?



Aphasia



How are things you **have** to do?



Work



Money



Health



Transport

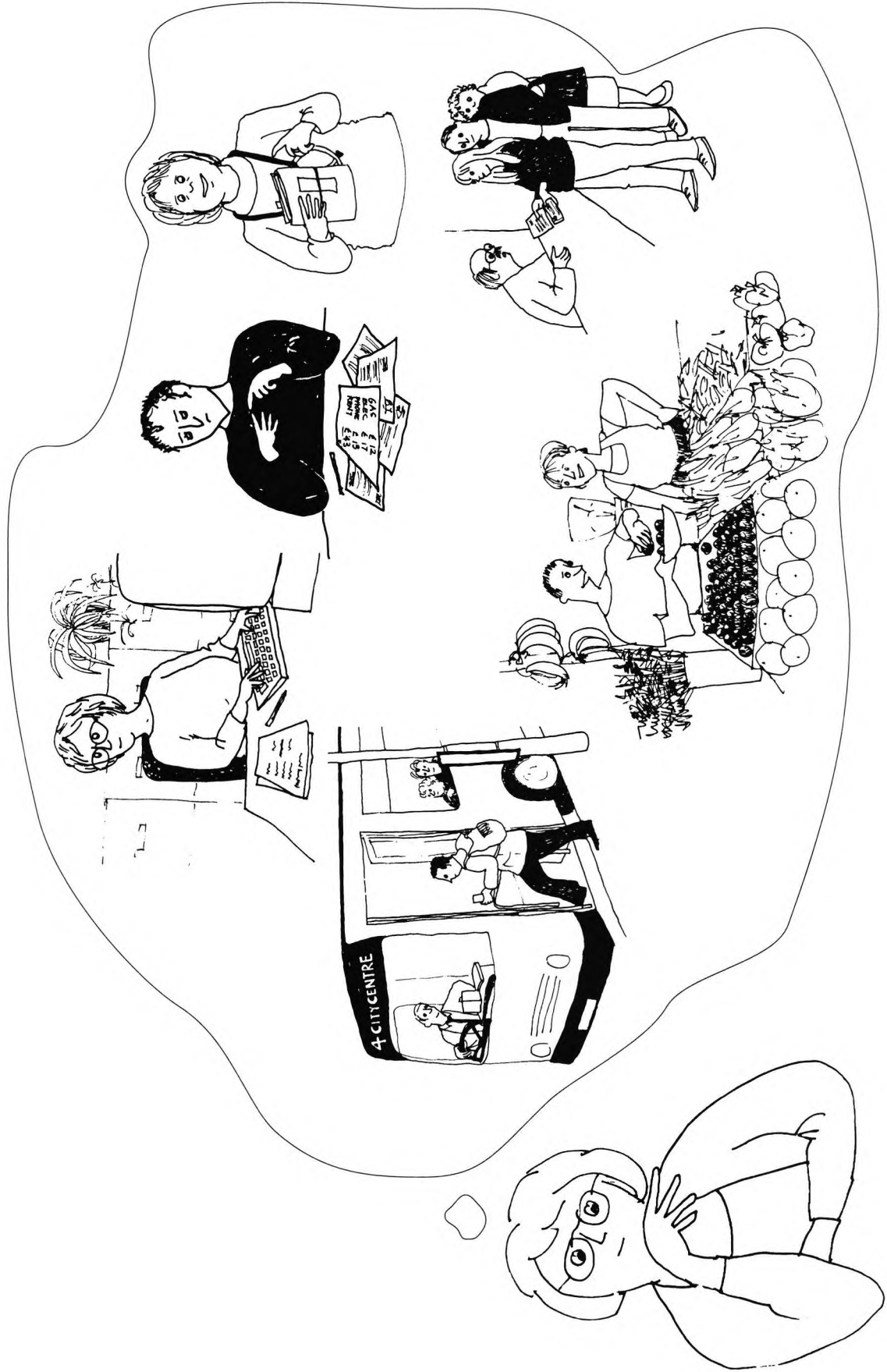


Shopping



Business

How are things you **have** to do?



How are things you **want** to do?



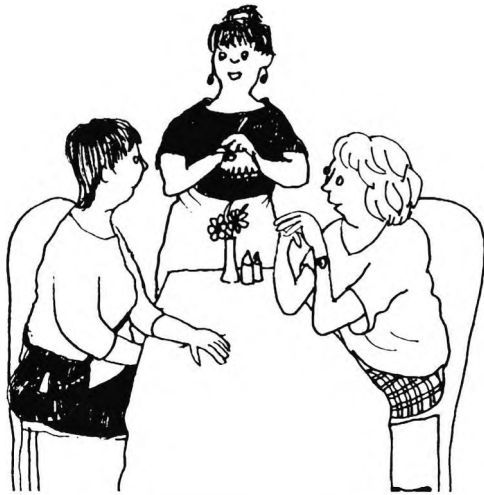
Hobbies



Clubs



Holidays



Going out

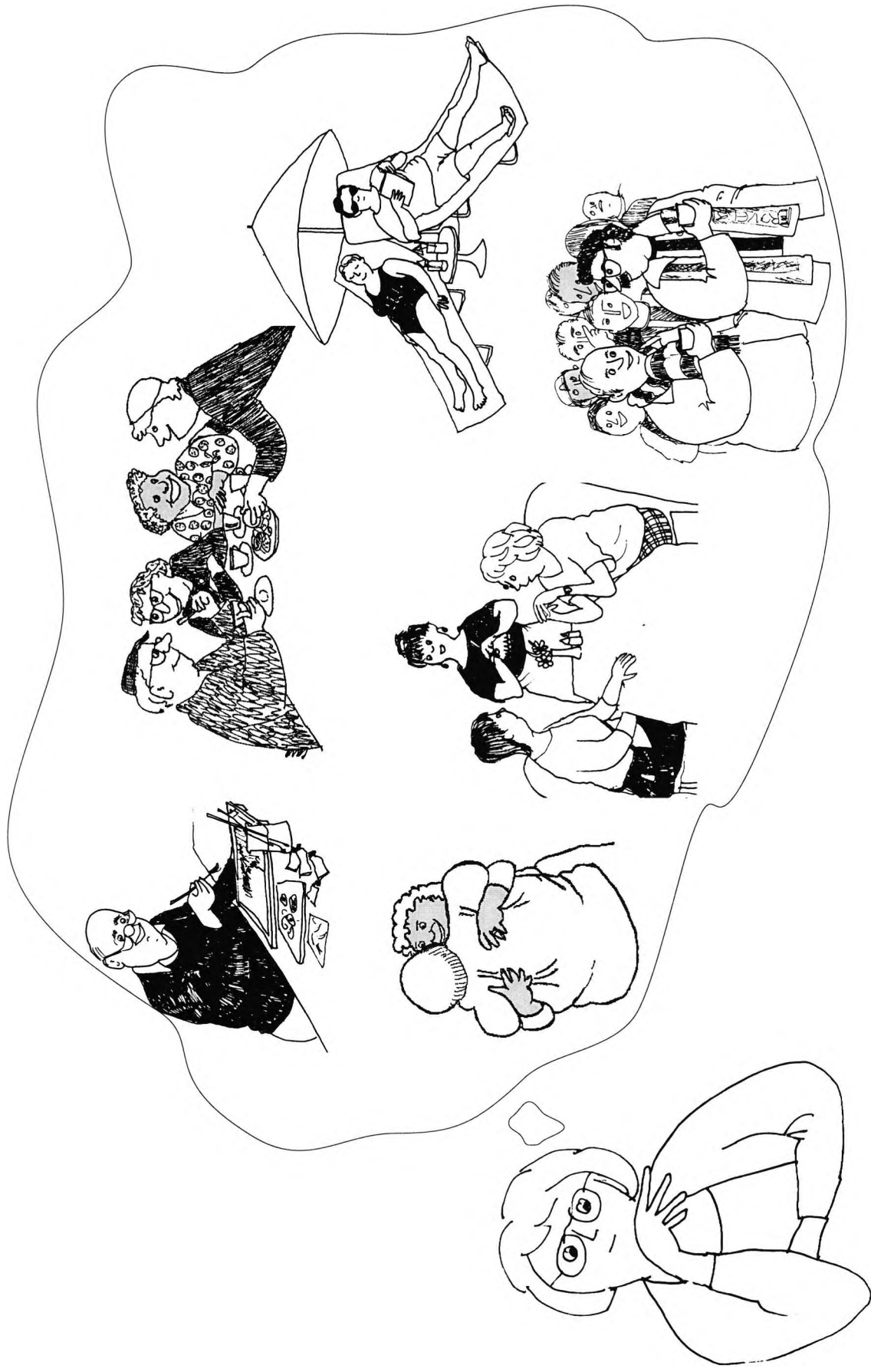


Meeting friends

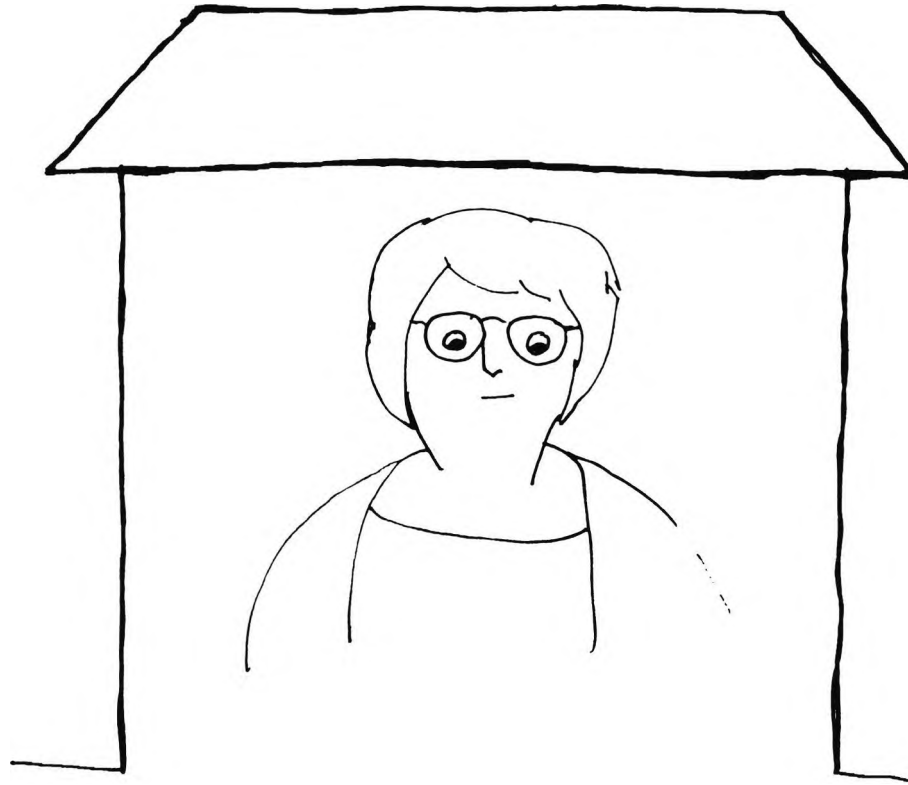


Relationships

How are things you **want** to do?



How are things at **home**?



What helps?



Who helps you?



Who **helps** you?



Who **helps** you?



What **things** help you?



Listen to me



Telling people



Extra time



Pictures



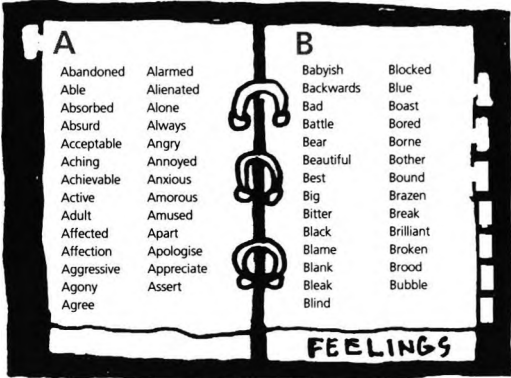
Write things down

What **things** help you?

Someone helping



Dictionary



Speaking books



Computer

What makes it **harder**?



Who makes it **harder**?



Who makes it **harder**?



Who makes it **harder**?



What makes it **harder**?



Glass barriers

Queues



Being under pressure

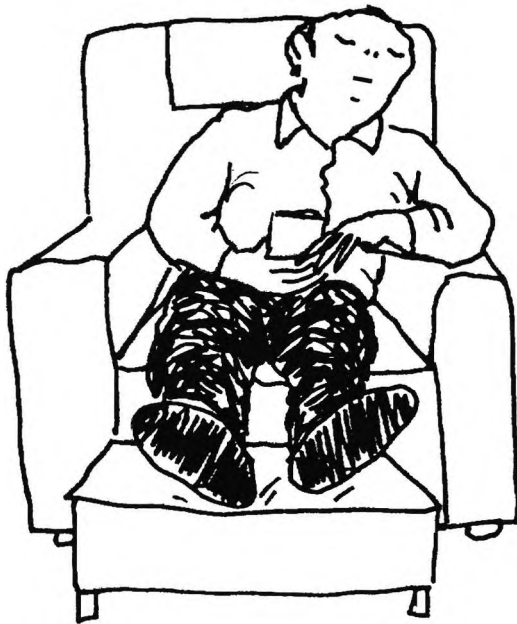


Being upset



The wrong hand

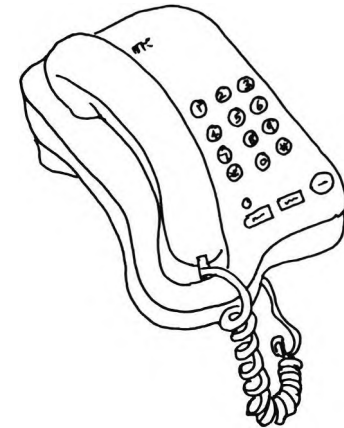
What makes it **harder**?



Being tired



Too much



Telephones

What makes it **harder**?

Two people talking at once

Speaking quickly

Look away

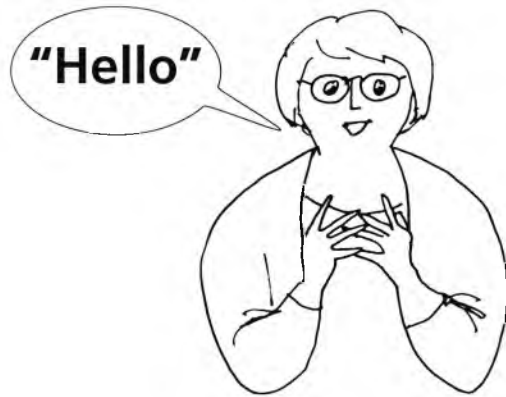
Noisy/busy

Interrupting

Far away



Aphasia



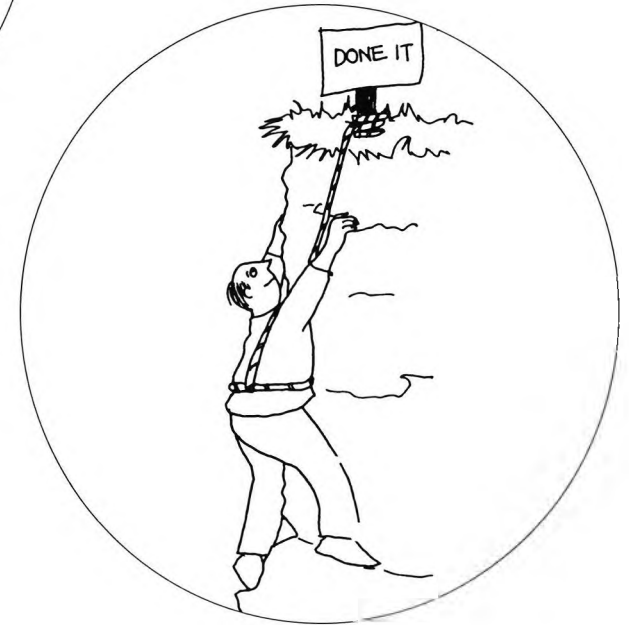
How does that make you **feel**?



Frustrated



Angry



Determined

Unhappy



Content



Worried

Less confident

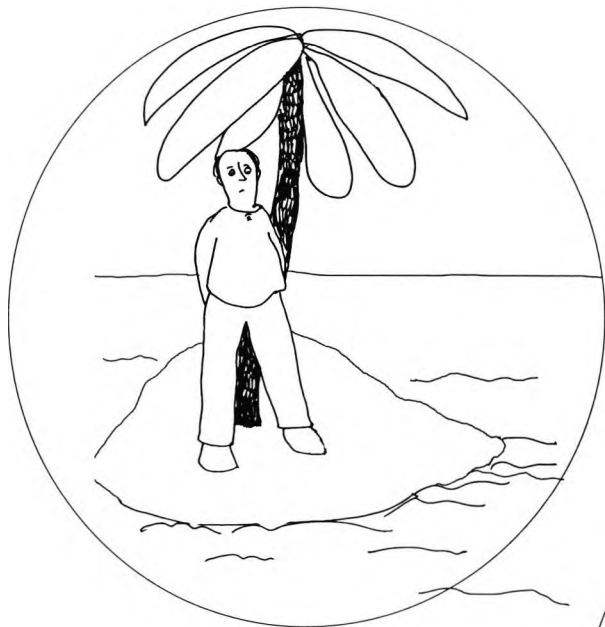


Less control



Able

Isolated

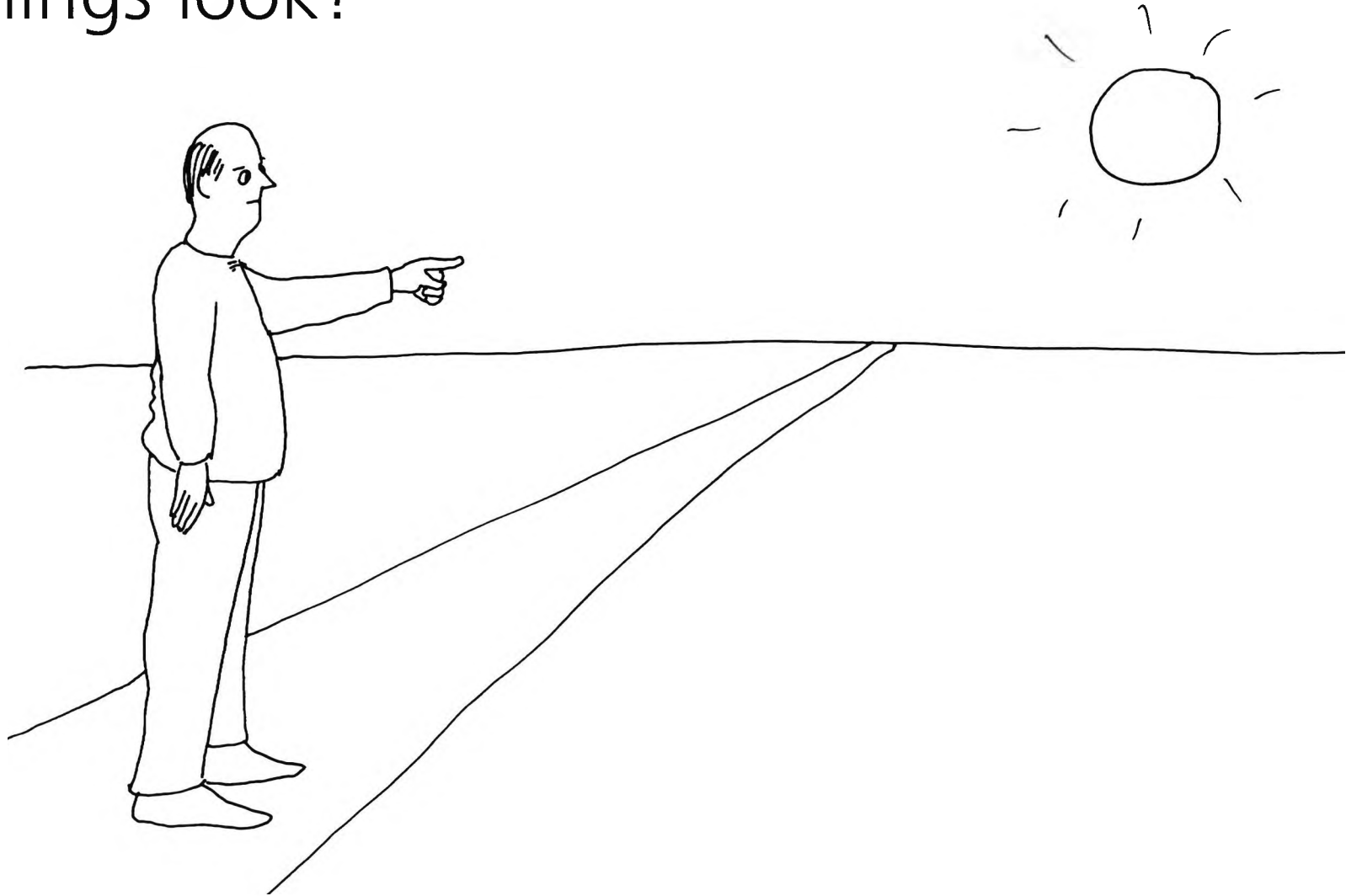


Valued



Embarrassed

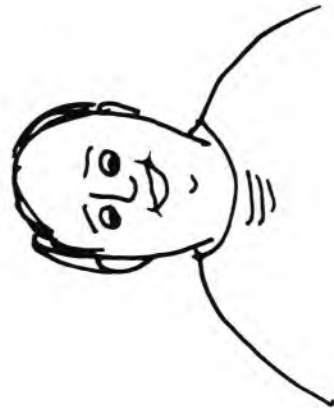
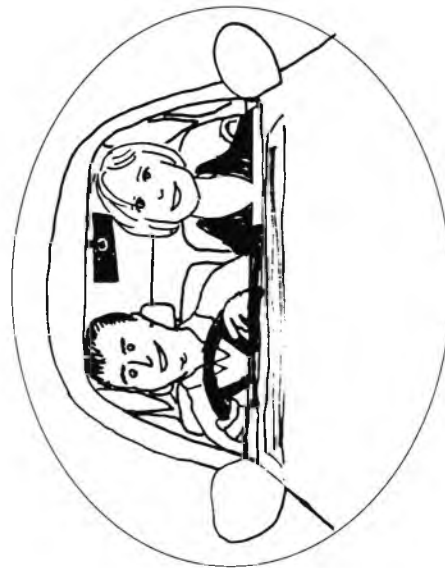
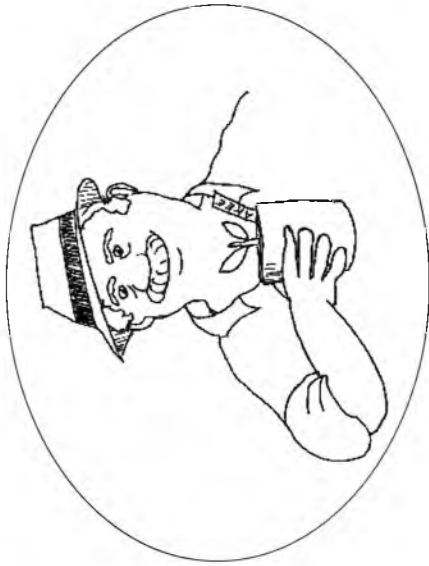
When you look to the **future**, how do things look?

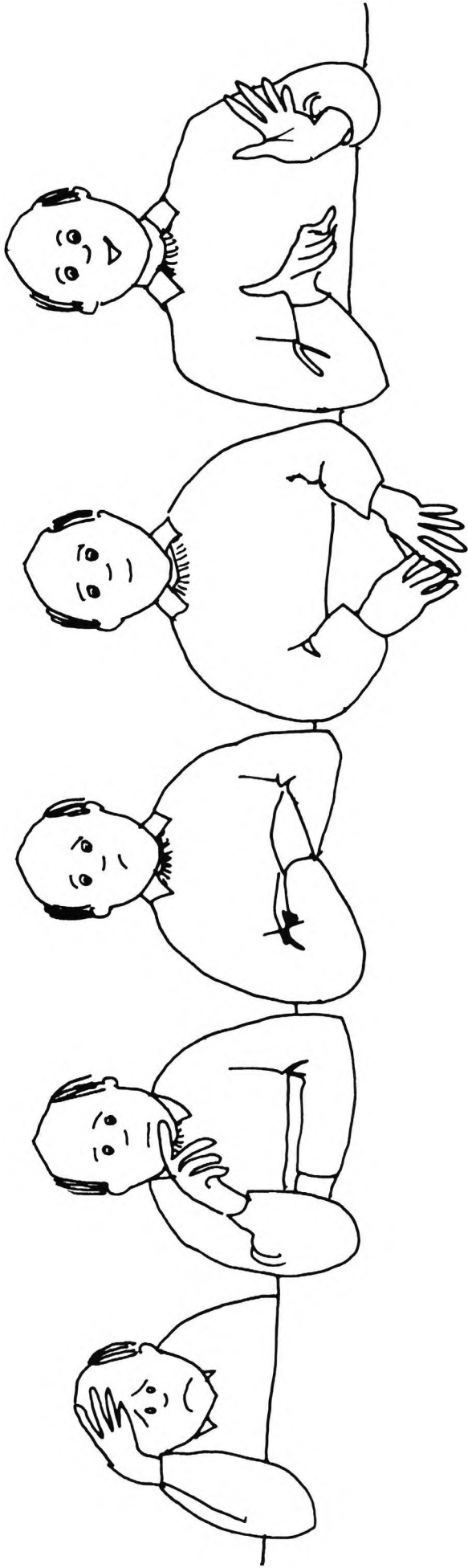


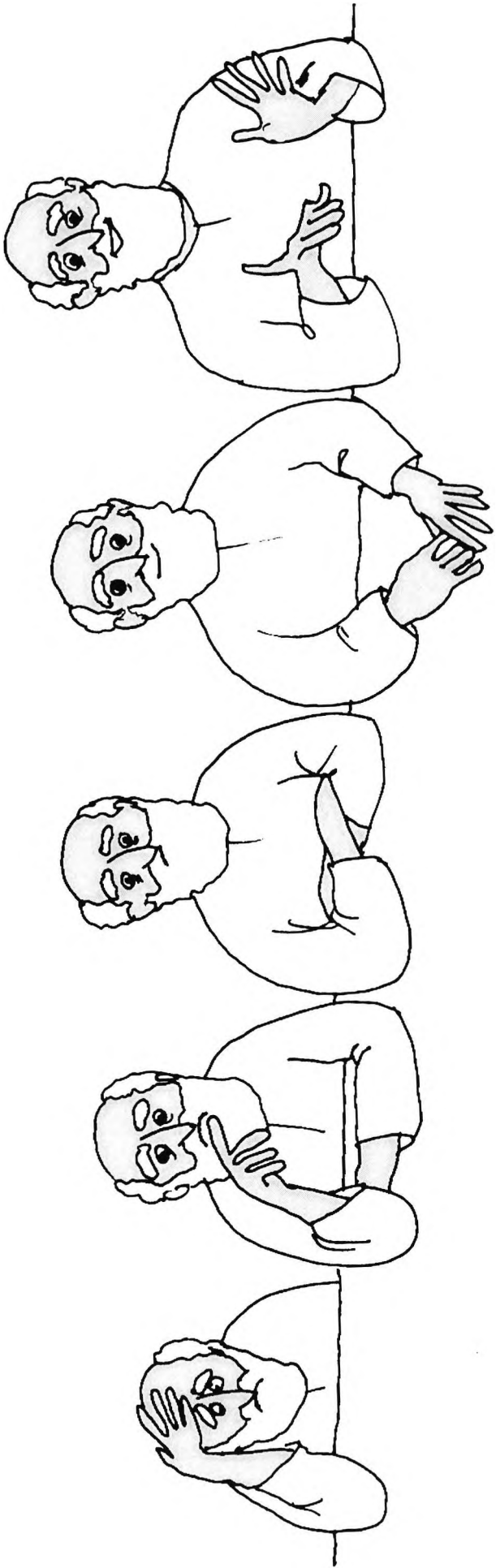
How do things look **today**?

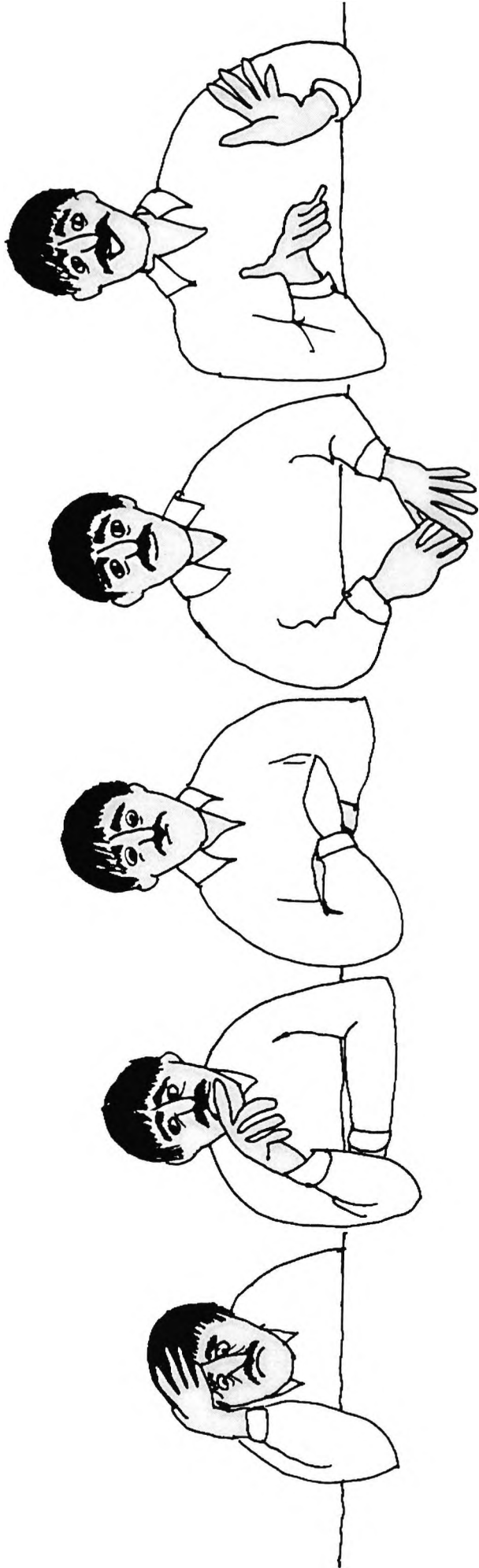


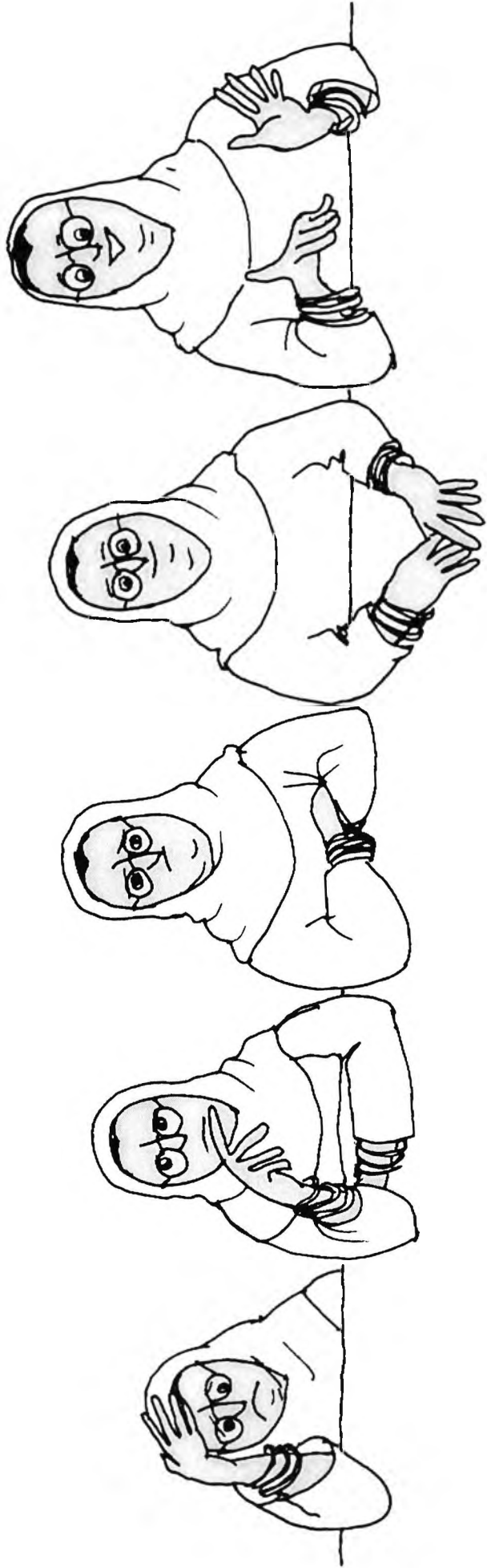
What is **fun** for you?

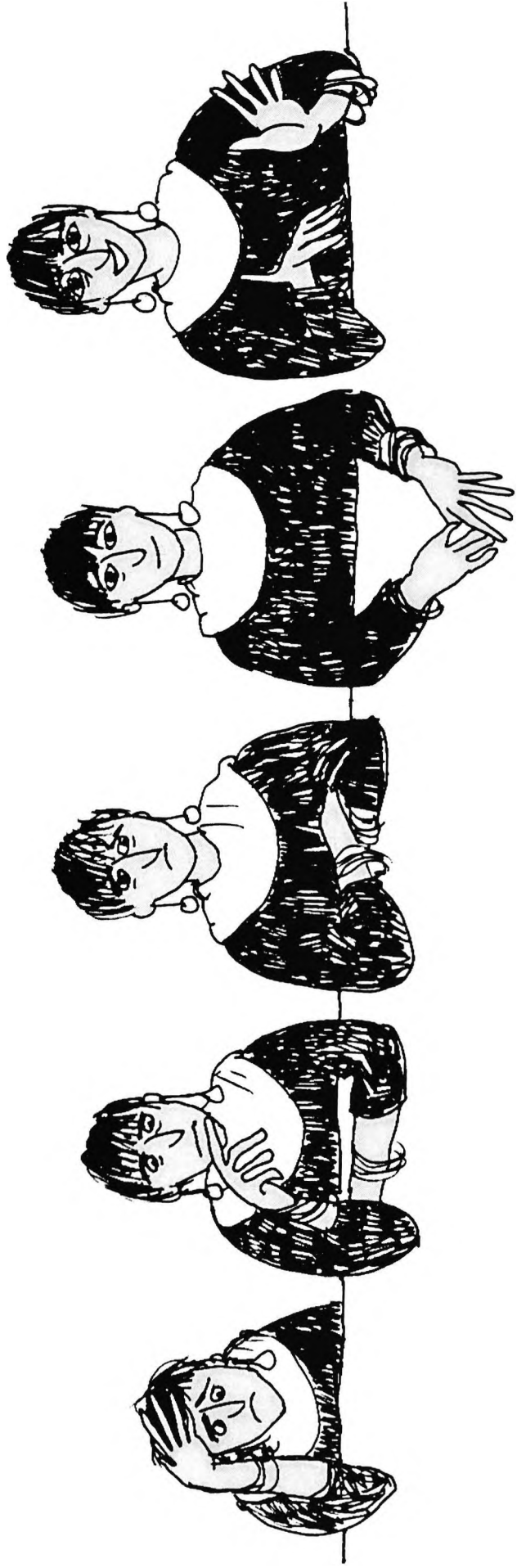


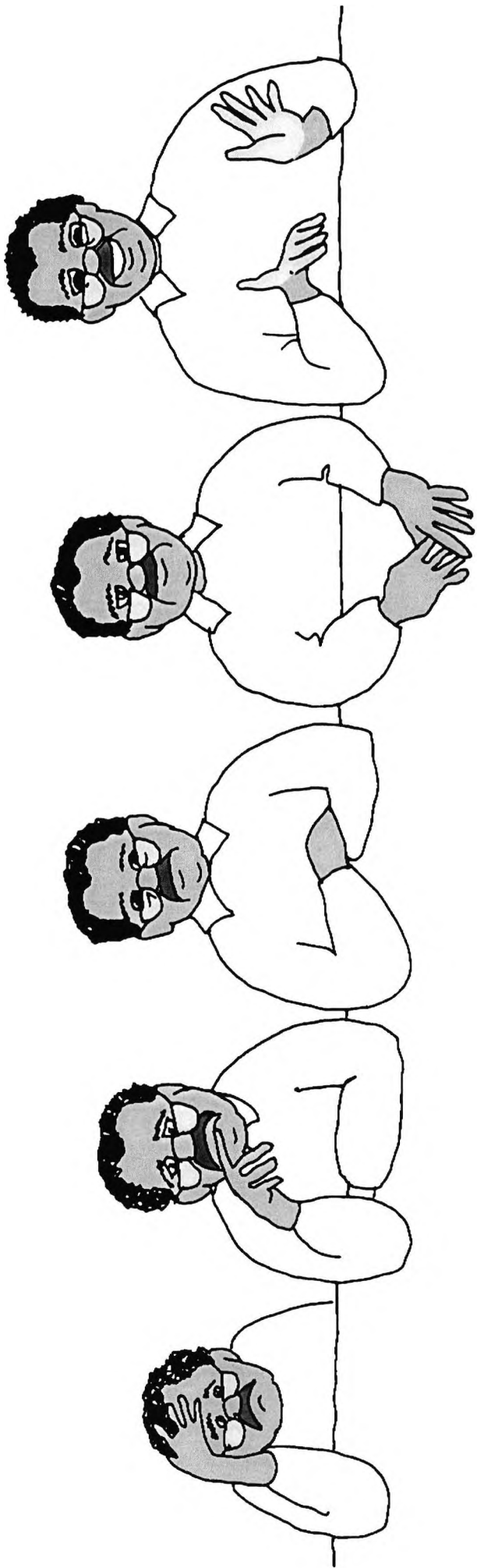


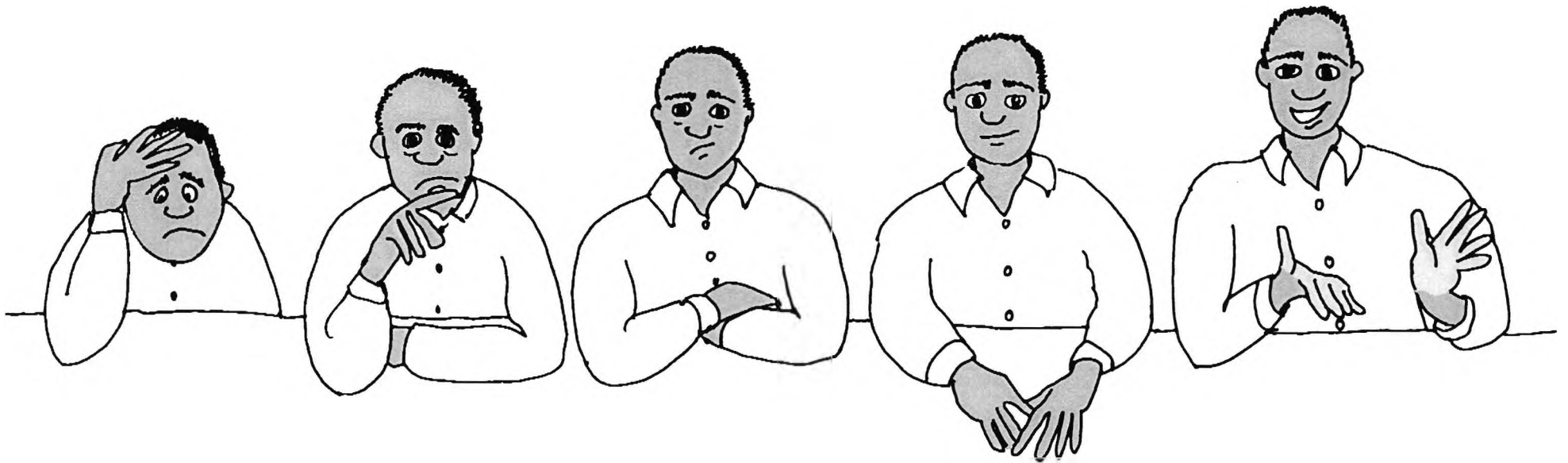


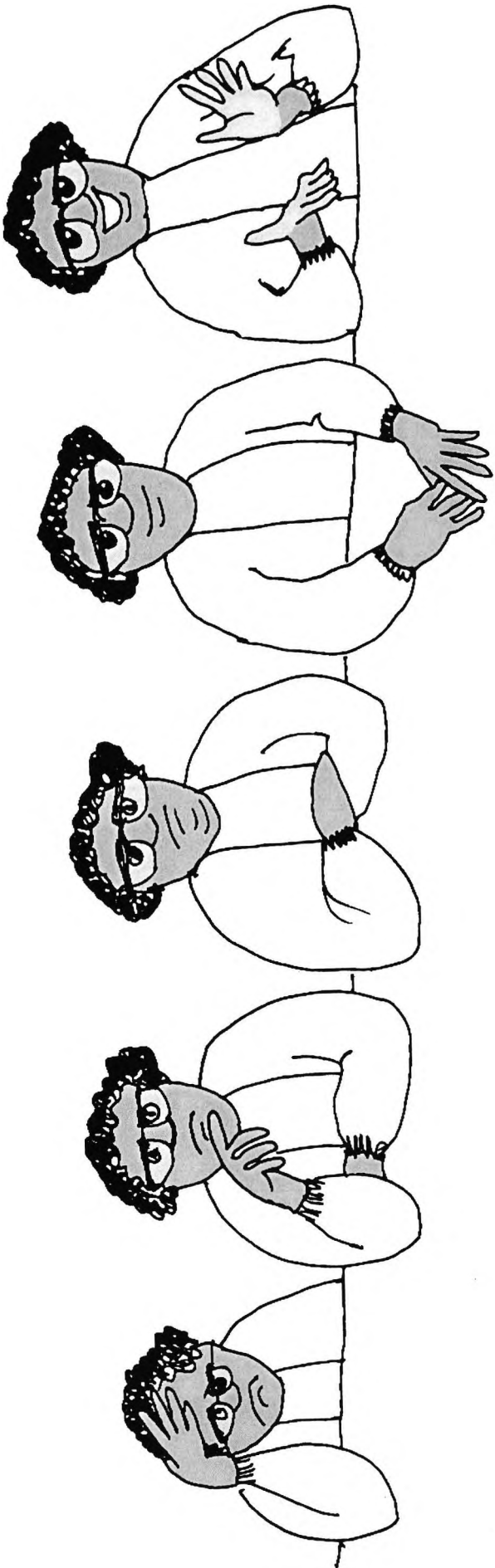


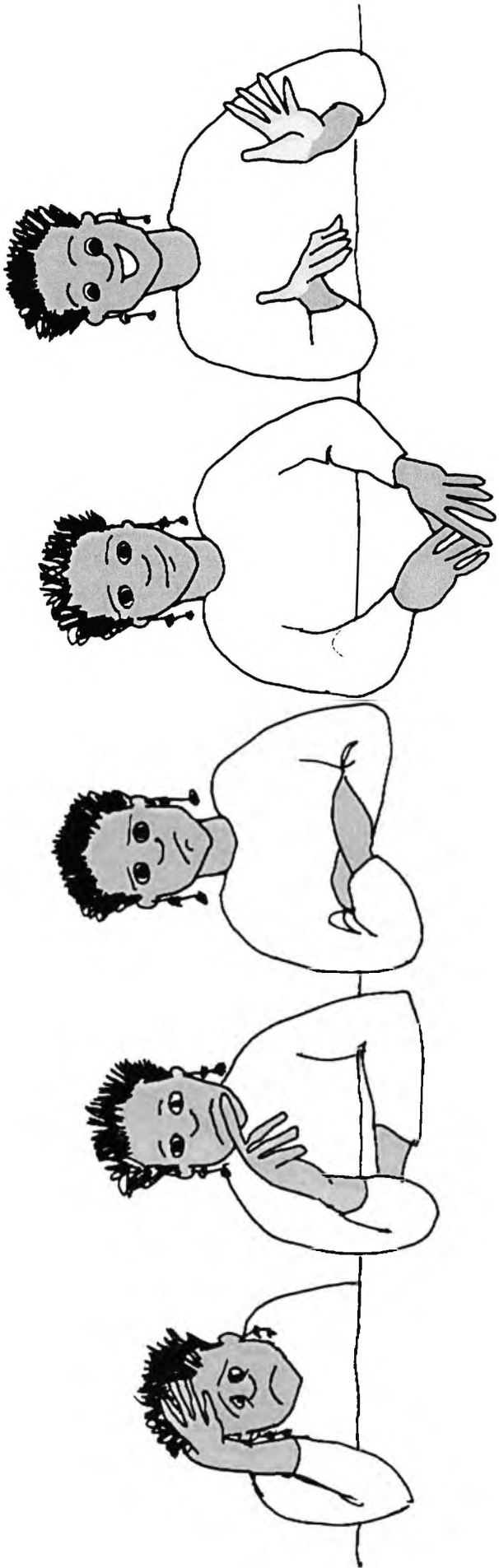


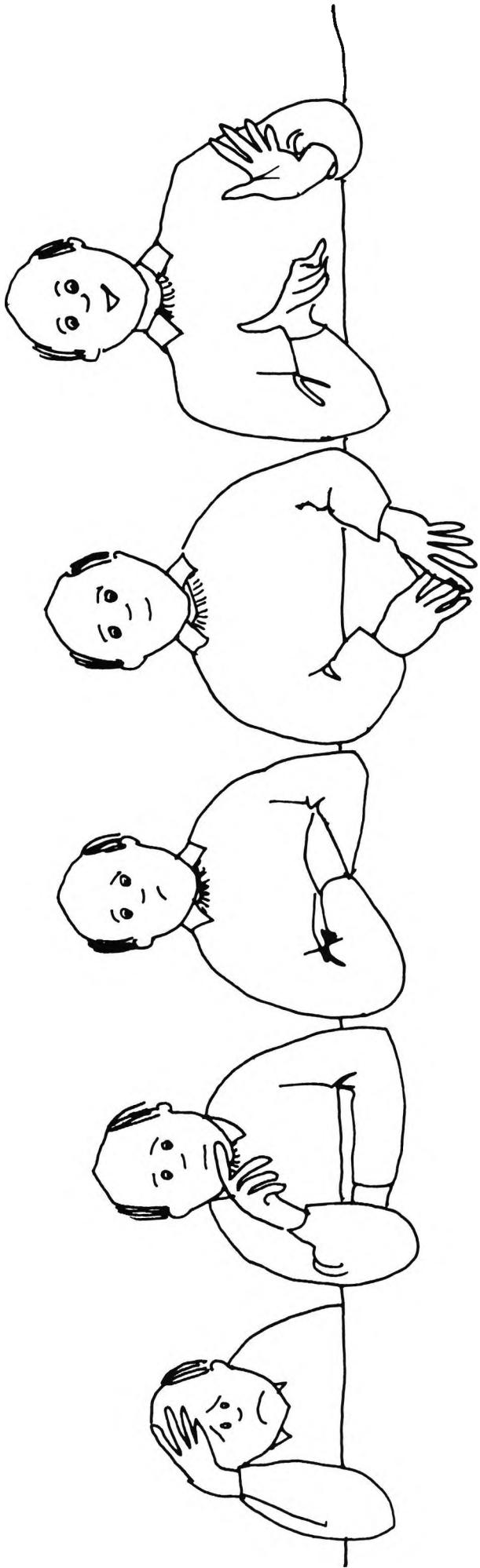


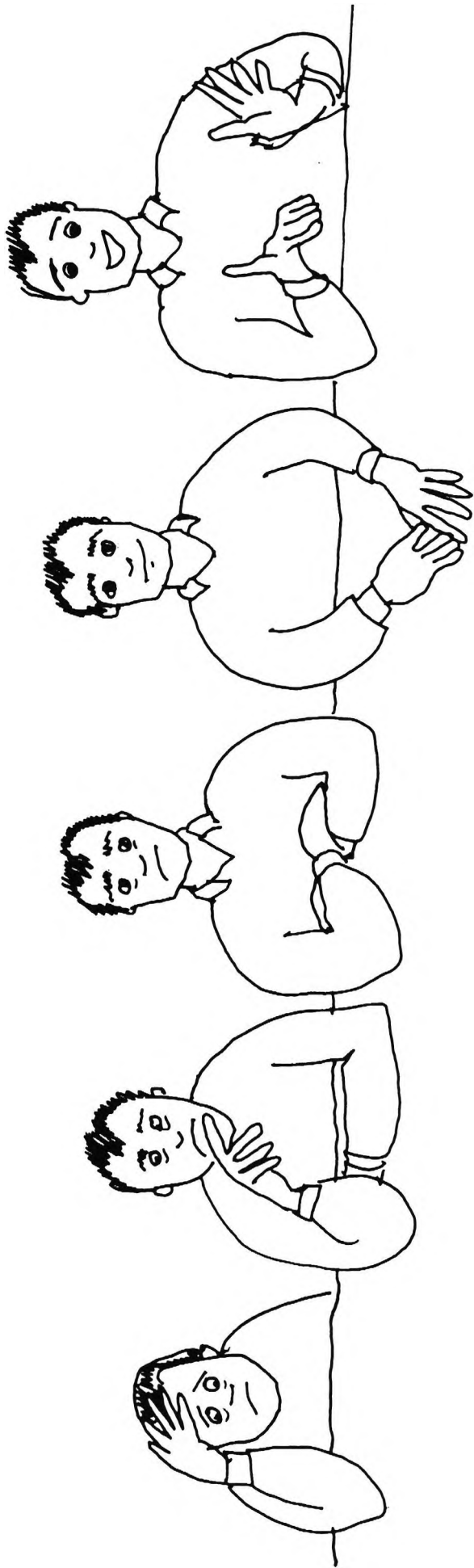


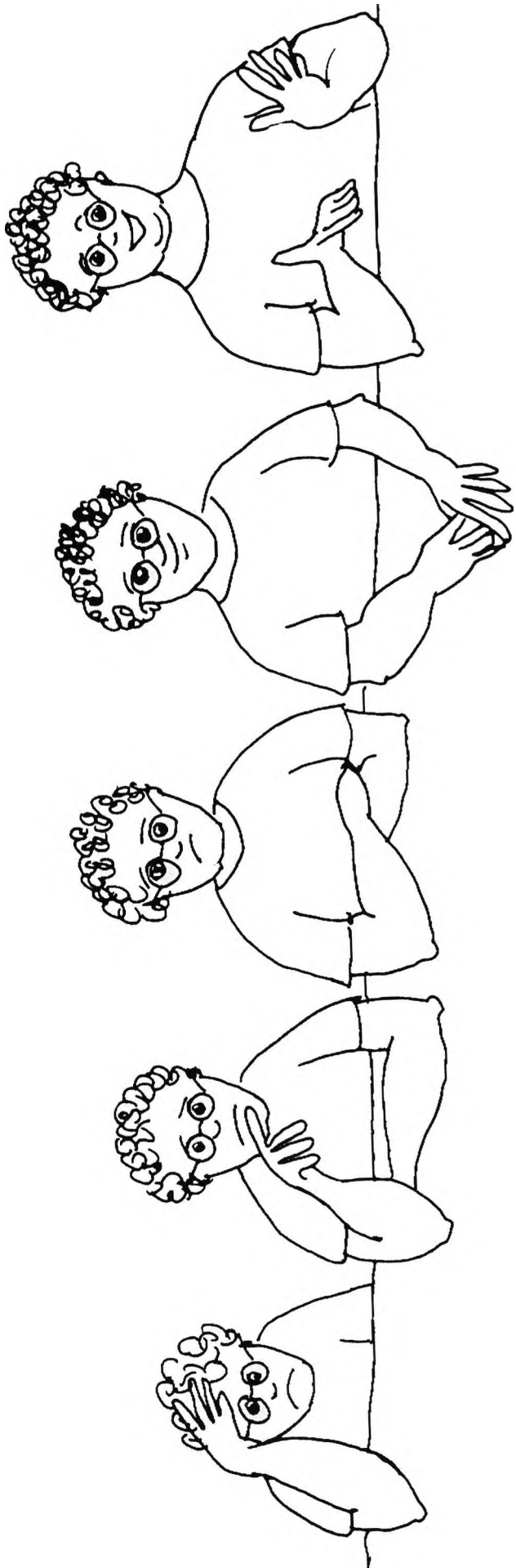


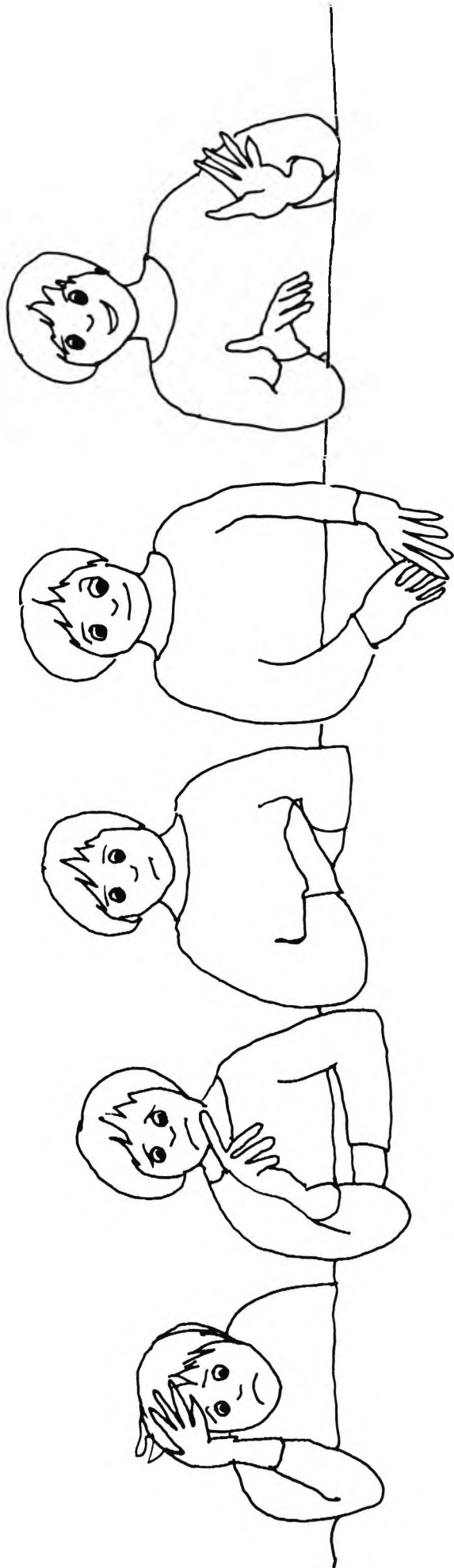




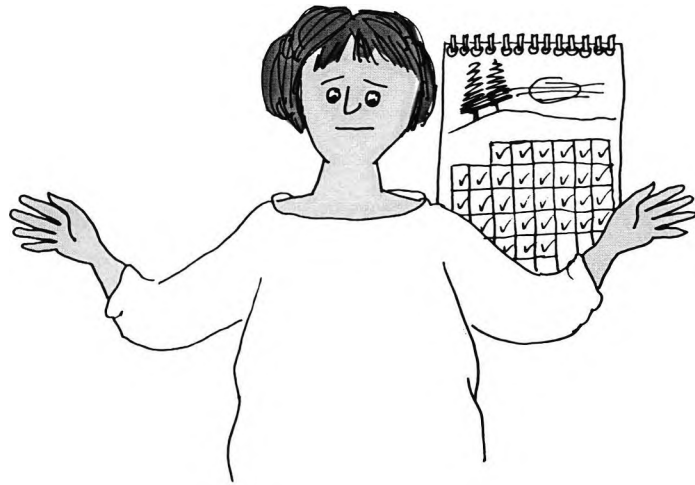








Always



Sometimes



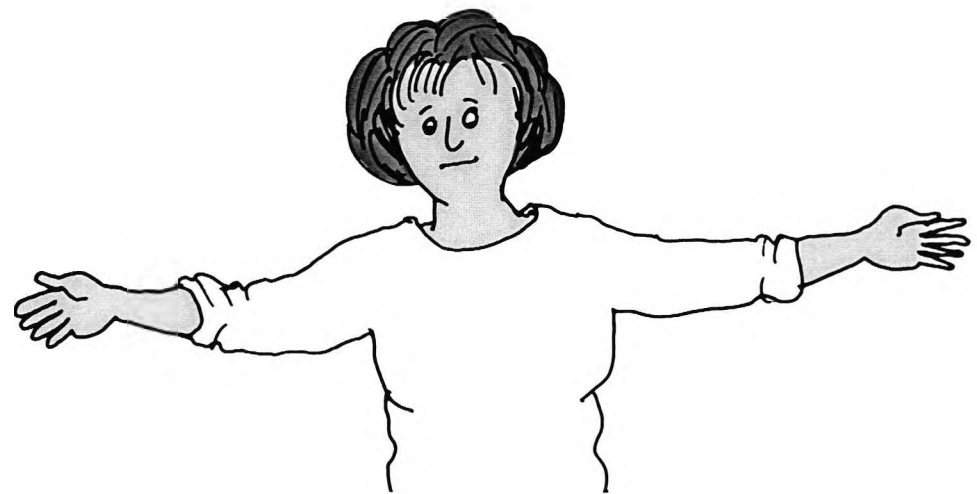
Never

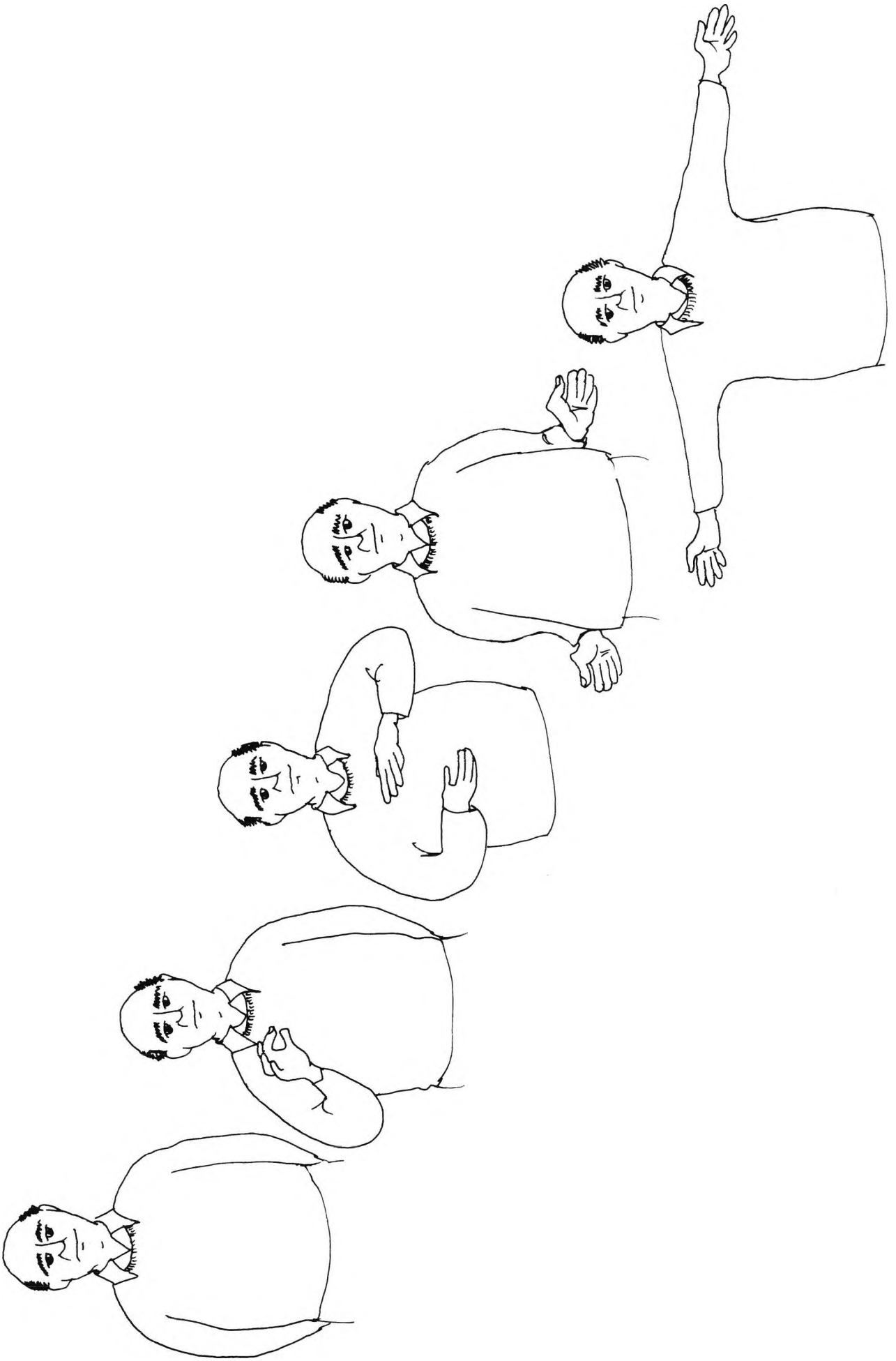


A little

or

a lot





Appendix 4.3b
The CDP – draft 2

THE COMMUNICATION DISABILITY PROFILE

Name:

Date:

NOTE: Discussion around the question is encouraged. Space is available to record verbatim responses and elaborations. Use of gesture and supported conversation is encouraged to elucidate any potential comprehension difficulties.

All the words in *italics* are to be read. Instructions to be followed are in **bold**.

"Aphasia is difficulty with talking, understanding, reading and writing.
(show picture 1).

We're going to talk about what its like for you living with aphasia.

*does it affect what you do and how you feel. **(picture 2)***

We're going to go through some questions.

The questions are all about how things have been since your stroke, during the last week.
(picture 3)

It is your view of how things are. There is no right or wrong.

I'll ask a question.

It will look at how easy it is for you to do something.

*I'll also show you a scale like this. **(show scale 1)***

You show me how easy that thing is for you.

Let's try an example.

*During the last week **(picture 4)**, how easy is it to chat to a friend **(show picture 5)***

so;

(present scale 1)

if chatting is very easy, the same as before your stroke point here
(point to far right of the scale);

if you cannot chat at all, impossible you would point here
(point to far left of the scale);

but maybe its somewhere in between (sweep hand across the scale).

So it can be any one of these points (point to all five pictures).

What do you think – how easy is chatting to a friend ... show me on the scale?

NOTE: Sweep hand across each page to ensure the aphasic person has noted the whole of the page

TALKING

Let's look at your talking (show picture 7) - finding your words and saying a sentence.

Talking: Activities

During the last week (show laminated picture), how easy is it for you to (laminated scale 1):

1. (picture 8) talk to the person closest to you? (use person's name) 0 1 2 3 4

Comments:

2. (picture 9) talk with a group of friends? 0 1 2 3 4

Comments:

3. (picture 10) talk to a stranger, someone you don't know? 0 1 2 3 4

Comments:

4. (picture 11) talk under pressure? 0 1 2 3 4

Comments:

Note: Only complete the next section if you believe non-verbal communication is an acceptable option, which is likely to be in use now or in the near future

EXPRESSING YOURSELF

"If talking is tricky, let's look at how you express yourself – get your message across in other ways, like pictures or actions (picture 12) .

Expressing yourself: Activities

During the last week, (laminated picture) how easy is it for you to (laminated scale 1):

5. (picture 13) *express yourself with the person closest to you (use person's name)*
Comments: 0 1 2 3 4

6. (picture 14) *express yourself with a group of friends*
Comments: 0 1 2 3 4

7. (picture 15) *express yourself with someone you don't know*
Comments: 0 1 2 3 4

8. (picture 16) *express yourself if you are under pressure"*
Comments: 0 1 2 3 4

UNDERSTANDING

This next section is about you understanding (picture 17).

So other people are talking. This is you following what's said.

Understanding: Activities

During the last week, (laminated picture) how easy is it for you to (laminated scale 1):

9. (picture 18) *understand the person closest to you (use person's name)*
Comments: 0 1 2 3 4

10. (picture 19) *understand a stranger, someone you don't know*
Comments: 0 1 2 3 4

11. (picture 20) *understand in a group* 0 1 2 3 4

Comments:

12. (picture 21) *understand when you're under pressure*

0 1 2 3 4

Comments:

READING

Note: Pre-morbid literacy practices will significantly influence this section and must be borne in mind when choosing whether to administer this section and with interpretation of this section.

"Can we talk about reading.(picture 22)

This is reading in your head not reading aloud

Reading: Activities

During the last week, (laminated picture), how easy is it for you to (laminated scale 1):

13. (picture 23) *read and follow one word*

0 1 2 3 4

Comments:

14. (picture 24) *read and follow a headline*

0 1 2 3 4

Comments:

15. (picture 25) *read and follow a whole story in a paper*

0 1 2 3 4

Comments:

16. (picture 26) *read and follow an official letter*

0 1 2 3 4

Comments:

WRITING

Note: Pre-morbid literacy practices will significantly influence this section and must be borne in mind when choosing whether to administer this section and with interpretation of this section.

"Lets have a look at writing – NOT holding the pen – the spelling. (picture 27)

What about finding words and spelling them?

Writing: Activities

During the last week (laminated picture) how easy is it for you to (show laminated scale 1):

17. (picture 28) write your name 0 1 2 3 4
Comments:

18. (picture 29) write other single words like a list 0 1 2 3 4
Comments:

19. (picture 30) write a letter to a friend 0 1 2 3 4
Comments:

20. (picture 31) write an official letter 0 1 2 3 4
Comments:

Participation

So if you remember, aphasia can make ALL these things tricky (picture 32).

So told me when things are easy and difficult (gesture good and bad).

21. You've told me(summarise what was easy and difficult for that person)

So, lets look at whether aphasia affects things you have to do?

Here are some things you might have to do.

(picture 33 - point to the each picture one by one).

Let's talk about them first.

Does aphasia affect:

Do not rate YET
Discuss

- Work

- Money
- Health
- Transport
- Shopping
- Business
- Other things you have to do, where aphasia gets in the way?

So overall, how are all those things you have to do?
 (Sweep hand across all the mini-pictures in bubble picture 34)

Can you show me on the scale
 (show laminated scale 1, establish a rating) RATE 0 1 2 3 4

22. (picture 35) Here are some things you might want to do.

We're going to look at things you want to do?

(Point to the each picture one by one)
 Lets talk about them first.

Does aphasia affect your:

Do not rate YET
Discuss

- Hobbies
- Clubs
- Holidays
- Going out
- Meeting friends
- Relationships
- Other things you want to do, where aphasia gets in the way?

So overall, how are all the things you want to do?
(Sweep hand across all the mini-pictures in bubble 36),

Can you show me on the scale?
(show laminated scale 1, establish a rating)

RATE 0 1 2 3 4

23. (picture 37) How's communication at home?

Discuss then rate

0 1 2 3 4

External influences

Some people have found there are things that help.

We're going to look at what helps (picture 38).

24. (pictures 39-41- choose picture with closest appropriate ethnicity)

First of all are there people who help?

WHO helps?

Do not rate

Comments:

Partner

Brother(s)/sister(s)

Son(s)/daughter(s)

Grandson(s)/granddaughter(s)/other children

Friend(s)/neighbour

Other people/health or social care workers/volunteer/warden

25. (picture 42) Are things or situations that help?

What things help?

Do not rate

Comments:

When people listen to you

If you tell people (help-cards)

Extra time

Pictures

Write things down

Someone helping

Speaking books

Dictionary computer

Other things that help that we haven't talked about? (use gesture to signal this)

Sometimes communication might be made even harder

We're going to look at what it harder (picture 43).

26. (pictures 44-46 - choose picture with closest appropriate ethnicity)

Are people who make things harder?'

Do not rate

Comments:

Partner

Brother(s)/sister(s)

Son(s)/daughter(s)

Grandson(s)/granddaughter(s)/other children

Friend(s)/neighbour(s)

Other people/health or social care workers/volunteer/warden

27. (pictures 47, 48 and 49) *What about things or situations?*

'What makes it harder?'

Do not rate

Comments:

Picture 47

If there is a glass barrier

What about queues

If you are under pressure

If you are upset/struggling

Having to use the wrong hand

Picture 48

Tired

If there's too much

Telephones

Picture 49

Point to the person in the picture depicting each barrier, as you read the list.

2 people talking at once

Speaking quickly

Looking away/not listening

Noisy or busy

Interrupting

If someone's far away

Other things that make it difficult?

Note: Only complete the next section if you believe non-verbal communication is an acceptable option, which is likely to be in use now or in the near future

EMOTIONAL CONSEQUENCES

You've told me about things that are easy and difficult for you and how that affects your life.

Those difficulties are caused by aphasia (see picture 50).

If you remember aphasia is difficulty with talking, understanding, reading, writing.

We're going to look at how living with aphasia makes you feel? (picture 51)

We're going to use a scale like this

Show laminated scale 2.

To see if you have a feeling all the time or just sometimes?

Show laminated scale 3.

And if that feel that a lot or a little?

Self image

Show picture 52.

Do any of these show how your aphasia makes you feel?

Encourage the aphasic person to choose one emotion from the page

And do you feel that all the time or just sometimes (show laminated scale 2)

And when you have that feeling do you feel that a lot or a little (show laminated scale 3).

28. Does your aphasia make you feel less confident?
when/why do you feel that?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
4	3	2	1	0

When is it better - why?

29. Do you feel you have less control?
when/why do you feel that?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
4	3	2	1	0

hen is it better - why?

30*¹. Do you feel able?
when/why do you feel that?

When is it worse - why?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
0	1	2	3	4

picture 53

Do any of these show how aphasia makes you feel?

Encourage the aphasic person to choose one emotion from the page.

Having done so – then go through each emotion one by one, obtaining a rating by using laminated scale 2 and scale 3.

31. Do you feel isolated?
when/why do you feel that?

When is it better - why?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
4	3	2	1	0

32. Do you feel embarrassed?
when/why do you feel that?

When is it better - why?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
4	3	2	1	0

33*. Do you feel valued?
when/why do you feel that?

When is it worse - why?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
0	1	2	3	4

picture 54

Do any of these show how aphasia makes you feel?

34. Do you feel angry?
when/why do you feel that?

When is it better - why?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
4	3	2	1	0

35. Do you feel frustrated?
when/why do you feel that?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
4	3	2	1	0

¹ * indicates reverse scoring

When is it better - why?

36*. Do you feel determined?
when/why do you feel that?

When are you not determined - why?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
0	1	2	3	4

picture 55

Do any of these show how aphasia makes you feel?

37. Do you feel unhappy?
when/why do you feel that?

When is it better - why?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
4	3	2	1	0

38. Do you feel worried?
when/why do you feel that?

When is it better - why?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
4	3	2	1	0

39*. Do you feel content?
when/why do you feel that?

When are you not content - why?

always	sometimes	always	sometimes	never
a lot	a lot		a little	a little
0	1	2	3	4

40. (picture 56 + laminated scale1) when you look to the future, how do things look?
Let's go back to this first scale – do you remember this one? Use laminated scale 1

Comments:

0 1 2 3 4

41. (picture 57 + laminated scale1) how do things look today?

Comments:

Use laminated scale 1

0 1 2 3 4

42. (choose from pictures 58, 59 and 60) do you have people who are important to you?

Do not rate

Discuss

43. (picture 61) what is fun for you?

**Do not rate
Discuss**

44. Is there anything else that is important to you about aphasia?
Anything you feel we haven't covered?

45. Is there anything you would like to say about your life now?

Once you have completed the profile, you can obtain a score if desired. Add the raw scores to the score-sheet.

Appendix 4.4
Feedback form 1 (to be completed after each administration)
The Communication Disability Profile

Thoughts, comments and suggestions form

Please complete after each CDP administration

Details of person with aphasia:

Age: under 40 41-50 51-60 61-70 over 70

Sex: Male Female

Ethnic background : (Please specify).....

Other relevant information about the person with aphasia?

Any comments made by the person with aphasia about the procedure?

Overall, do you think the procedure felt positive or negative for the perspective of the person with aphasia? (circle appropriate one)

Positive

Negative

Unable to comment

P.T.O.

Therapist comments and suggestions on CDP

Comments/suggestions on the **content** of the CDP

- Did the **content** seem **appropriate** for the person you were interviewing?

- If not, **why not**?

- **suggestions** for changes

Comments/suggestions on the **format** of the CDP

- was the CDP **easy to use**?

- If not **why not** (be as specific as possible please)

- Suggestions for changes

Any other comments from this administration of the CDP?

Appendix 4.5
Feedback form 2
The Communication Disability Profile

Feedback questionnaire
Please complete at end of field-test period

How many administrations of the CDP did you complete?

Were there people with aphasia, who you chose not to administer the CDP with, or you stopped having started?

If so, what stopped you?

Is there anything that could have overcome that?

What are your overall perceptions of the CDP, in terms of:

1. **Content**

(e.g. are the items relevant, have any areas been omitted?)

2. **Format and style**

(e.g. how **easy**/difficult was it **to use**, were there **sections**/items that caused **problems**, how easy was it to **score**, was it **accessible** to you and people with aphasia?)

P.T.O.

3. Relevance to **clinical practice**

(e.g. was the **information** provided useful, was the **process** useful?)

did the information **guide** your management, if so **how**, if not **why not**?)

4. Informing **practitioner**

(e.g. did anything about the process make you **reflection** on your **previous**

practice, if so **in what are your conclusions/thoughts**?)

Any other thoughts or suggestions?

THANK YOU so much for helping to field test the CDP.

Please return to me, by

Kate Swinburn
6, Brodrick Road
London SW17 7DZ

Appendix 5.1

How much does it get in the way - original draft

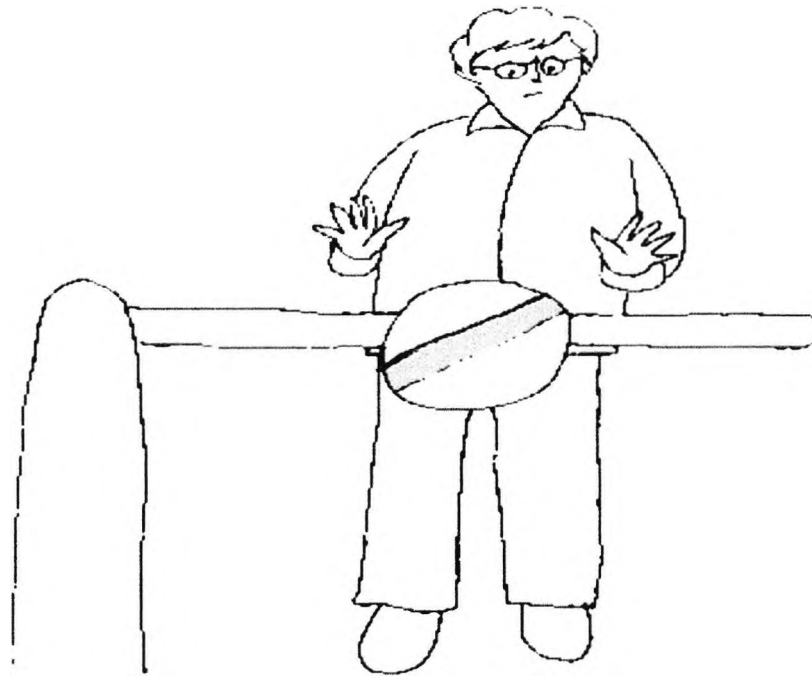
How much do these things **get in the way** of everyday life for you?



Appendix 5.2

How much does it get in the way - second draft

How is talking in everyday life?



Appendix 5.3

What makes it worse (concept)- original draft

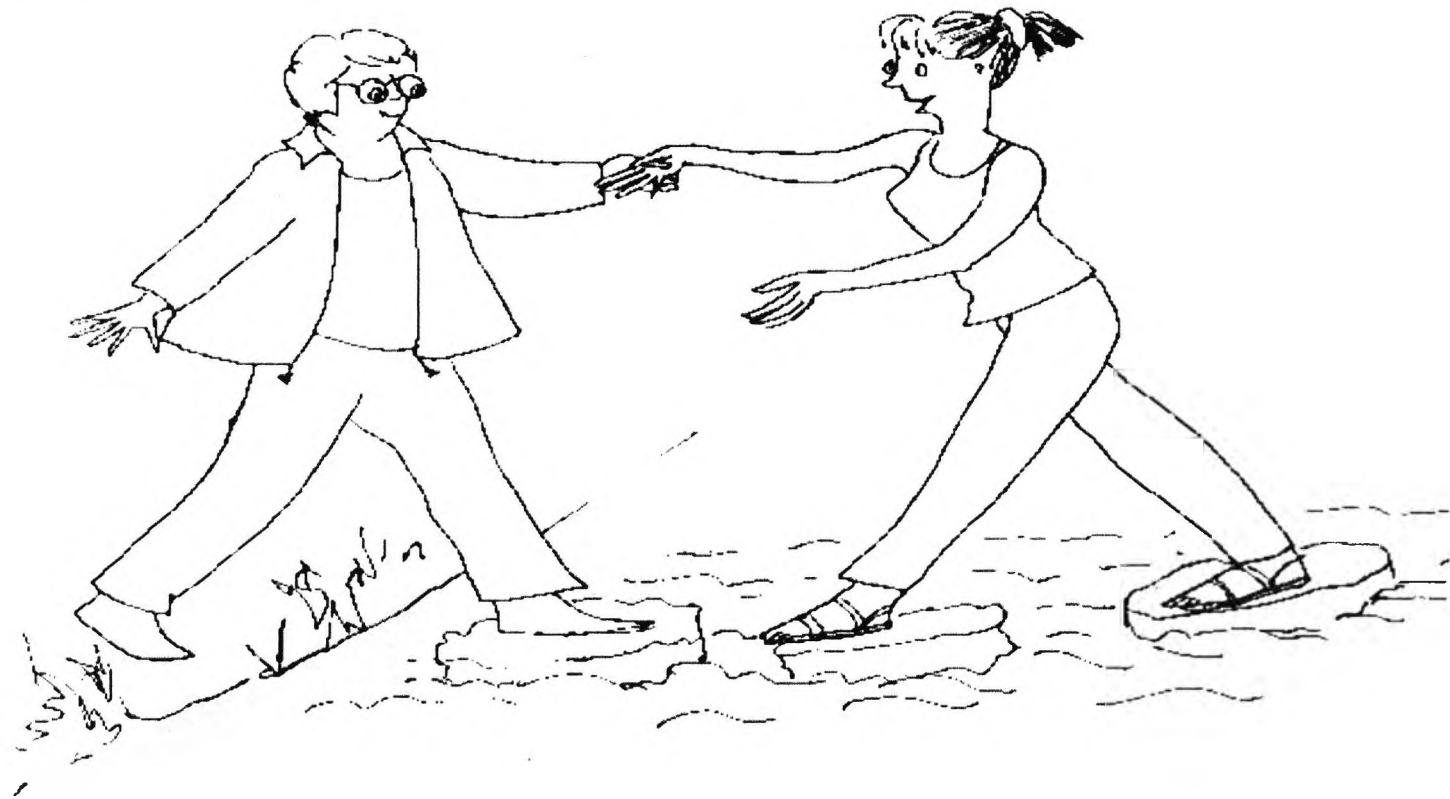
Worse



Appendix 5.4

What makes it easier (concept) - original and final draft

Easier



Appendix 5.5

Are there people who make things easier - original draft

Are there **people** who make
things easier?



Appendix 5.6
How are things you **WANT** to do
(original and final)

How are things you **want** to do?



Hobbies



Clubs



Holidays



Going out



Meeting friends



Relationships

Appendix 5.7
Things you **HAVE** to do - original and final draft

Things you **have** to do – talking



Work



Money



Health



Transport



Shopping



Business

Appendix 5.8
At HOME original and final draft



At home



Appendix 5.9
WHO helps your talking (specific) second draft

Who helps your talking?



Appendix 5.10

What THINGS help your talking (specific)- original and final draft

What **things help** your talking?



Listen to me



Help card



Extra time



Pictures



Write things down

Appendix 5.11

WHAT makes talking HARDER (concept)

What makes talking **harder**?



Appendix 5.12
WHO makes talking HARDER (specific)

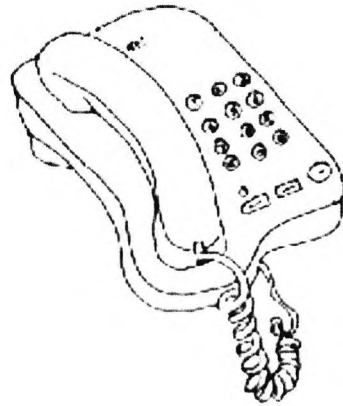
Who helps your talking?



Appendix 5.13

What makes talking HARDER picture (specific)- original draft

Are there **things** that make things **worse**



What makes talking harder?



Glass barriers



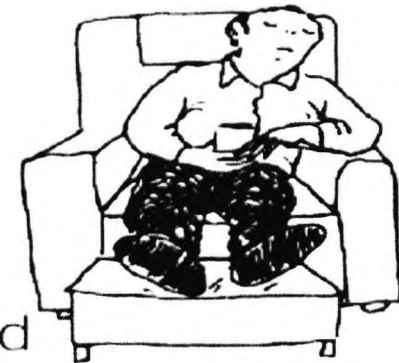
Queues



Telephones



Being upset



Being tired

Appendix 5.15

What THINGS makes talking HARDER (specific) conversational barriers

What makes talking **harder**?

Interrupted

Look away

Bored

Noisy

Far away



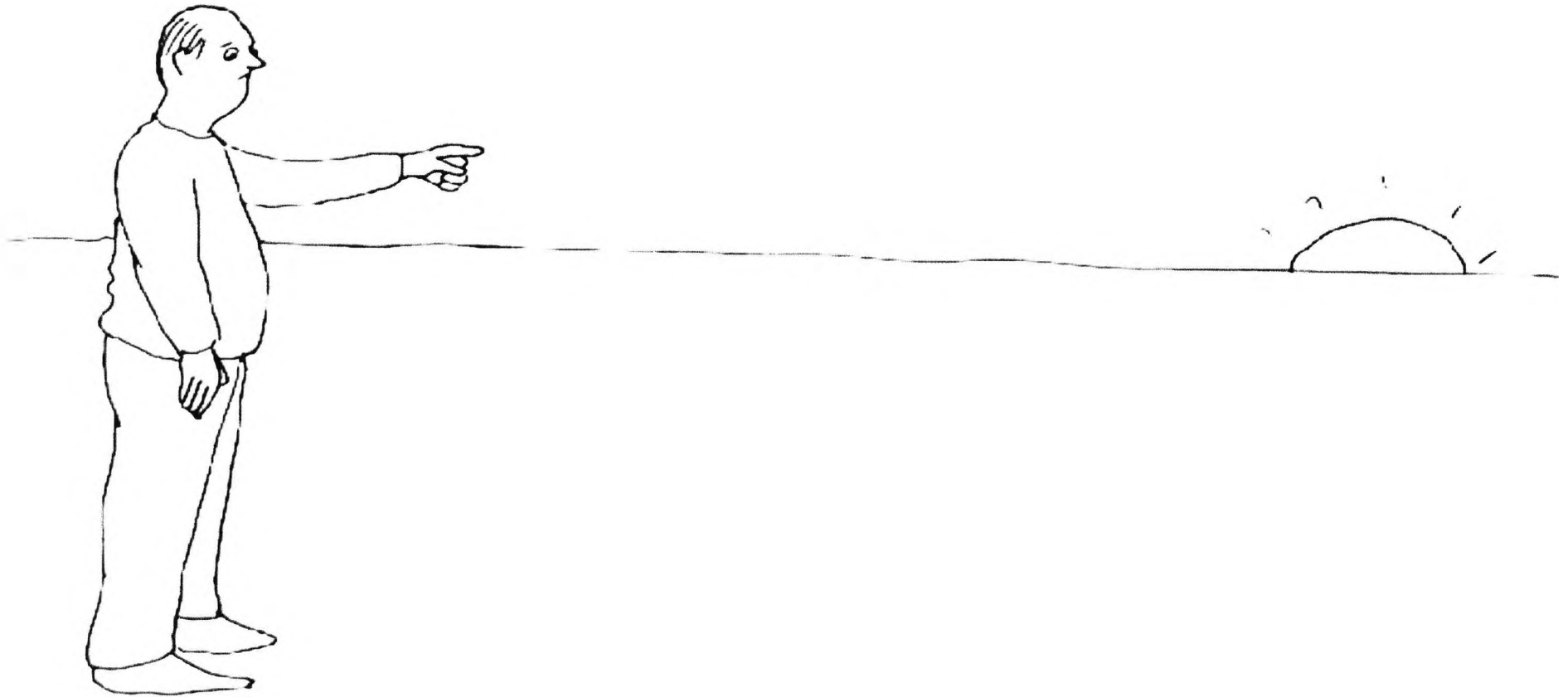
Appendix 5.16
Talking under pressure original draft

How easy is talking under pressure?



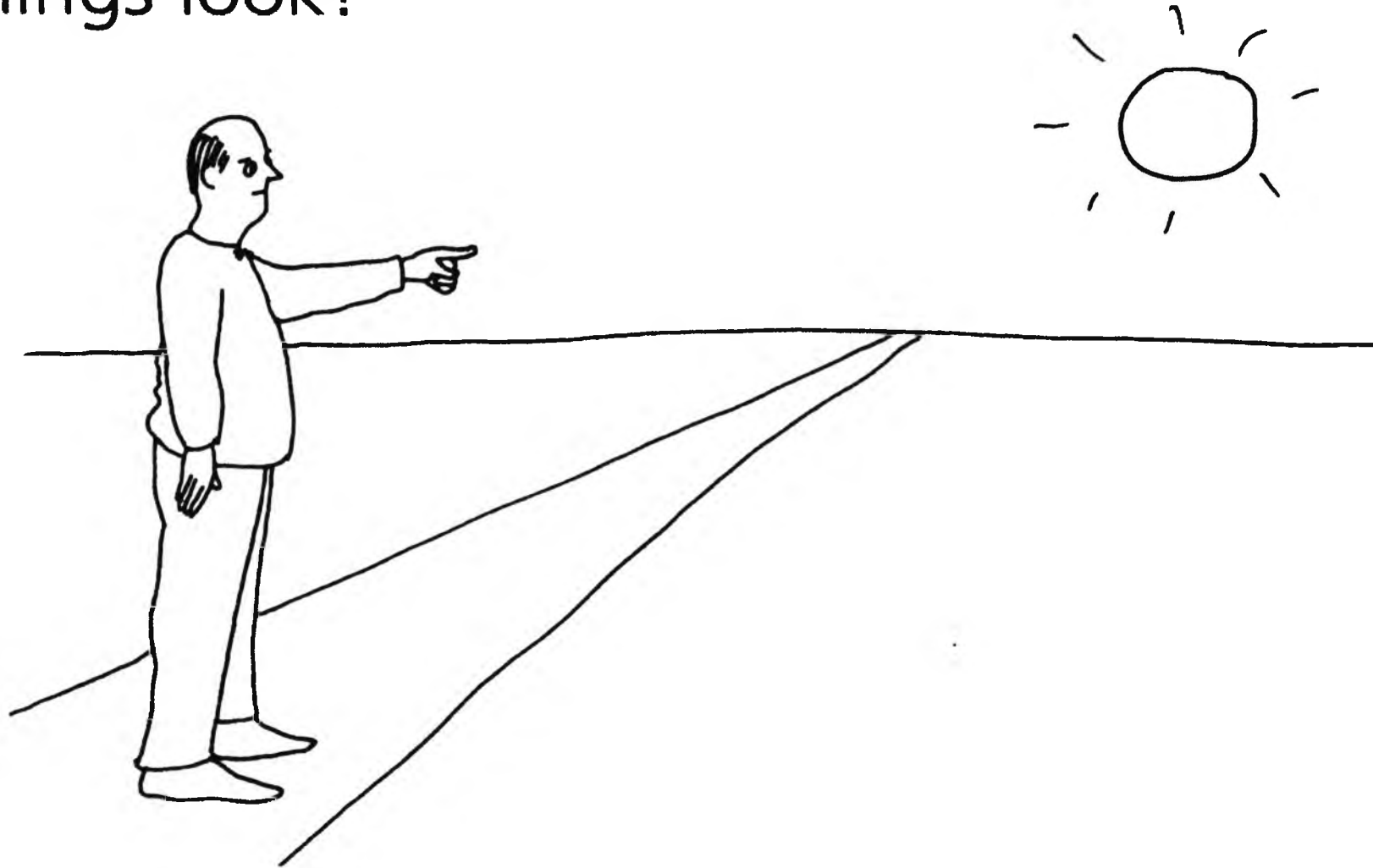
Appendix 5.17
Looking to the future - original draft

When you look to the **future**, how do things look?



Appendix 5.18
Looking to the future - final

When you look to the **future**, how do things look?



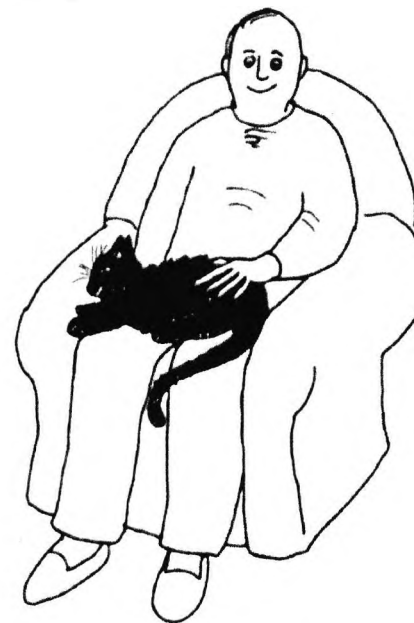
Appendix 5.19
Original 3 per page emotions picture



Unhappy



Worried



Whole

Appendix 5.20

Concepts that appear in the qualitative interviews.

<i>Domain within the CDP</i>	<i>Exemplar from the qualitative interviews</i>	<i>Existing items within CDP (draft 1) that cover this example</i>
Communication activities	Can't say children's names, husband can't understand her	Talk-person closest
Communication activities	Difficulty conversing in a group, feel limited in group, restricts talk in a group	Talk-group
Communication activities	Avoid talking to stranger	Talk-stranger
Communication activities	Speech worse under pressure (doctor/teacher), unable to ask Dr questions	Talk-pressure
Communication activities	I can understand my wife	Understand-closest
Communication activities	Can't understand what strangers say to me, avoid strangers, concentrates on children to avoid conversation at school pick-up	Understand-stranger
Communication activities	Can't focus in a group, can't understanding in a group	Understand-group
Communication activities	Can't phone	Understand-pressure
Communication activities	Can't read little words	Read-word
Communication activities	Read at the front and the back and get a rough idea	Read-headline
Communication activities	Can't read the paper, effort to read the paper	Read-article
Communication activities	Can't read official letters	Read-official
Communication activities	Can't write cheques, can write signature, unable to write name	Write-name
Communication activities	Spelling problematic, can't write a shopping list, address difficult,	Write-word
Communication activities	Writing a letter, difficulty writing sentences, can't write to friends, writing letters, able to write a	Write-friend

	card, can't write letter to friends properly	
Communication activities	Letter to bank	Write-official
Participation	Degree course, can't do dictation, can't chair meetings, loss of job, reduced hours, work mates check his writing, can't read reports	Things HAVE to do (work)
Participation	Writes list to overcome problems in bank, misperceived as being drunk when dealing with bank on phone, unable to access money due to signature changes, role change – wife now writes cheques finances, bank statement, shares, can't do cheques, can't write cheques, can't do money, writes list to overcome problems in bank	Things HAVE to do (money)
Participation	Unable to ask Dr questions	Things HAVE to do (health)
Participation	Unable to handle difficult situations like the bus, can't go where I want to, get a bus pass (avoids having to speak), reading timetable (added/agreed by advisory panel)	Things HAVE to do (transport)
Participation	Checkout at supermarket problematic, husband explains about aphasia if possibility of incorrect assumptions when shopping, perceived as being drunk in shops, have to go into shops several times to ask, role change for shopping, can't write a shopping list	Things HAVE to do (shopping)
Participation	Make notes before making business calls, wills, organise reunion, can't help with homework, can't do Christmas cards, can't do forms	Things HAVE to do (business)
Participation	Unable to handle telephone numbers	Other
Participation	Evangelising, can't keep up at classes, don't go to bowls because no-one talks to me, read history books, betting slips, crosswords, leisure activities-reading, read people's testimonies, read the bible, can't read subtitles, unable to return to PT degree course, can no longer navigate/read maps	Things WANT to do (hobbies)

Participation	Reduced involvement with church, can't go to local discussion groups, discussion group, stopped attending French club	Things WANT to do (clubs)
Participation	Holidays	Things WANT to do(holidays)
Participation	Going to pub, social life, can't go places he wants to, restricts conversation to fillers to appear 'normal', change in status in conversation (no longer speech leader, become a listener, can't be initiator, use of humour), reduced social contacts, avoids conversational opportunities, restricts conversation, approaches strangers and chats – didn't used to	Things WANT to do (going out)
Participation	Friends don't visit, keeps quiet at dinner parties, talks one to one in groups, see friends individually since stroke, loss of friends seen as a 'loser', loss of friends, use of humour now restricted, can't be spontaneous, rejection by friends, meeting friends made him aware of difficulties because had to extend conversation/less relaxed, feels contribution is not interesting because of speed of delivery Increased number of friends since stroke	Things WANT to do (meeting friends)
Participation	Can't phone friends, less contact with friends, loss of role in conversation, stay silent with others, son no longer phones, more empathic towards others, more sensitive to friends needs, read to grandchildren, less contact because can't write to friends, write to son is Australia, Christmas cards	Things WANT to do (relationships)
Participation	Diary	Things WANT to do (making plans)
Participation	Can't use the telephone	Things WANT to do (other)
Participation	Can't control grown up son, loss of power with husband when arguing, lost partner, end	At HOME

	relationship, rebuking son, wife grabs the phone from him, restricts conversation, with children to avoid frightening them by making mistakes, simplifies language with own children to keep their attention, change in mood in family since having aphasia, family's feelings of hopelessness because of aphasia, turned into a negative person, son become more abusive since aphasia, son now has power over mother, strained relationship with wife, husband now does , shopping and therefore chooses what to eat etc – wife resents change in control of domestic domain	
External influences (barrier or facilitator)	Wife, partner, partner encouraging person with aphasia to think for himself, partner offers clues, husband supplies word, help with children's homework, can't read to children, role change with wife (she now writes cheques, does paperwork – PWA happy with that), wife more involved in paperwork, dislikes switch of locus of control, unhappy about dependence due to paperwork, wife feels she is better than him because she does the paperwork, husband now does household finances, letter writing, can't write notes to remind wife to do things in morning (disabled wife), sons respect important/contrasts with other sons behaviour, one son congratulates his mother for reading aloud well, other not	People (partner)
External influences (barrier or facilitator)	Brother	People (brother/sister)
External influences (barrier or facilitator)	Daughter helps, one son good, one son not	People (son and daughter)
External influences (barrier or facilitator)	Grandchildren easy, children better	People (children)
External influences	Friends at work, old friend, neighbour, friends – rejection, friends less relaxed than family, 2	People (friend/neighbour)

(barrier or facilitator)	good friends treat me the same, friends very helpful	
External influences (barrier or facilitator)	Nurse wrote letter to the bank, speech therapy, volunteer, surveyor	People (other people/health/ social care)
External influences (barrier)	Talk over me, interrupted	Conversation (interrupting)
External influences (barrier)	Try to get away People don't listen	Conversation (look away)
External influences (barrier)	Negative attitudes They talked and not to me	Conversation (look bored/not listening)
External influences (barrier)	Too much going on gets in the way	Conversation (noisy or busy)
External influences (barrier)	Added/agreed by advisory panel	Conversation (far away)
External influences (barrier)	Added/agreed by advisory panel	Conversation (other things that make talking difficult)
External influences (barrier)	Added/agreed by advisory panel	Conversation (cover face)
External influences (barrier)	Talks quickly	Conversation (speak quickly)
External influences (barrier)	Picks out one person in a group to talk to when groups problematic Someone speaks for me	Other barriers/facilitators

External influences (facilitators)	Interested in conversation, keeping interested, interested in conversation, friendly and interested, respect, positive attitudes, positive reactions help	Listen to me
External influences (facilitators)	Tell people had a stroke, pretence at being non-aphasic, fine telling close friends about aphasia – not others, helped to tell people	Telling people (help cards)
External influences (facilitators)	Talking - extra time, patience, he was impatient, extra time for reading	Extra time
External influences (facilitators)	Added/agreed by advisory panel	Pictures
External influences (facilitators)	Someone scribing, writes things down in bank, write instead of speak	Writing things down
External influences (facilitators)	Someone helping, someone scribing at history class, volunteer helps spelling by doing crosswords, neighbour fills in betting slips	Someone helping
External influences (facilitators)	Listen to radio Listens to taped books	Speaking books
External influences (facilitators)	Dictionary	Dictionary
External influences (facilitators)	Print better than writing	Large print
External influences (facilitators)	PC (computer) – can self-correct	Computer
External influences	Talks one to one, picks out one person in a group, simplifies language, takes deep breaths,	Other facilitators

(facilitators)	rephrasing, thinks before speaking, use of first letter, repetition, talking slow and posh, rabbit on when stuck for word, others filling in words/ Someone speaks for me, writing instead of speaking, having a laugh about it, reading to self at night, re-reading, reading out loud, using a piece of paper as a guide (reading), leaving writing and coming back to it	
External influences (barriers)	Added/agreed by advisory panel	Glass barriers
External influences (barriers)	Added/agreed by advisory panel	Queues
External influences (barriers)	'phone	'phone
External influences (barriers)	Agitated, vicious circle, worse if upset, struggling makes it worse	Upset
External influences (barriers)	Tiredness Worse when tired	Tired
External influences (barriers)	Added/agreed by advisory panel	Wrong hand
External influences (barriers)	Multi-tasking	Too much
External influences (barriers)	Others filling in words Changing topic of conversation	other barriers
Emotions	Lost confidence, avoid conversations, positive attitude, not worried, more assertive since having	Less confidence

(including both positive & negative aspects of the concept)	aphasia	
Emotions	Added/agreed by advisory panel	Less control
Emotions	Added/agreed by advisory panel	Able
Emotions	Added/agreed by advisory panel	Isolated
Emotions	Added/agreed by advisory panel	Embarrassed
Emotions	Added/agreed by advisory panel	Valued
Emotions	Added/agreed by advisory panel	Angry
Emotions	Added/agreed by advisory panel	Frustrated
Emotions	Added/agreed by advisory panel	Determined
Emotions	Added/agreed by advisory panel	Unhappy
Emotions	Added/agreed by advisory panel	Worried
Emotions	Added/agreed by advisory panel	Content
Emotions	Added/agreed by advisory panel	The future?
Emotions	Added/agreed by advisory panel	Today?

Appendix 5.21
Domains raised by in-depth interviews that ARE covered by CDP.

<i>Exemplar from the qualitative interviews</i>	<i>Existing item within CDP draft 2 that cover this example</i>	<i>Domain within the CDP</i>
Can't say children's names, husband can't understand her	Talk-person closest	Communication activities
Difficulty conversing in a group, feel limited in group, restricts talk in a group	Talk-group	Communication activities
Avoid talking to stranger	Talk-stranger	Communication activities
Speech worse under pressure (doctor/teacher), unable to ask Dr questions	Talk-pressure	Communication activities
I can understand my wife	Understand-closest	Communication activities
Can't understand what strangers say to me, avoid strangers, concentrates on children to avoid conversation at school pick-up	Understand-stranger	Communication activities
Can't focus in a group, can't understanding in a group	Understand-group	Communication activities
Can't phone	Understand-pressure	Communication activities
Can't read little words	Read-word	Communication activities
Read at the front and the back and get a rough idea	Read-headline	Communication activities
Can't read the paper, effort to read the paper	Read-article	Communication activities
Can't read official letters	Read-official	Communication activities
Can't write cheques, can write signature, unable to write name	Write-name	Communication activities
Spelling problematic, can't write a shopping list, address difficult,	Write-word	Communication activities
Writing a letter, difficulty writing sentences, can't write to friends, writing letters, able to write a card, can't write letter to friends properly	Write-friend	Communication activities
Letter to bank	Write-official	Communication activities
Degree course, can't do dictation, can't chair meetings, loss of job, reduced hours, work mates check his writing, can't read reports	Things HAVE to do (work)	Participation
Writes list to overcome problems in bank, misperceived as being drunk when dealing with bank on phone, unable to access money due to signature changes, role change – wife now writes cheques finances, bank statement, shares, can't do cheques, can't write cheques, can't do money, writes list to overcome problems in bank	Things HAVE to do (money)	Participation
Unable to ask Dr questions	Things HAVE to do (health)	Participation
Unable to handle difficult situations like the bus, can't go where I want to, get a bus pass	Things HAVE to do (transport)	Participation

(avoids having to speak), reading timetable (added/agreed by advisory panel)		
Checkout at supermarket problematic, husband explains about aphasia if possibility of incorrect assumptions when shopping, perceived as being drunk in shops, have to go into shops several times to ask, role change for shopping, can't write a shopping list	Things HAVE to do (shopping)	Participation
Make notes before making business calls, wills, organise reunion, can't help with homework, can't do Christmas cards, can't do forms	Things HAVE to do (business)	Participation
Unable to handle telephone numbers	Other	Participation
Evangelising, can't keep up at classes, don't go to bowls because no-one talks to me, read history books, betting slips, crosswords, leisure activities-reading, read people's testimonies, read the bible, can't read subtitles, unable to return to PT degree course, can no longer navigate/read maps	Things WANT to do (hobbies)	Participation
Reduced involvement with church, can't go to local discussion groups, discussion group, stopped attending French club	Things WANT to do (clubs)	Participation
Holidays	Things WANT to do(holidays)	Participation
Going to pub, social life, can't go places he wants to, restricts conversation to fillers to appear 'normal', change in status in conversation (no longer speech leader, become a listener, can't be initiator, use of humour), reduced social contacts, avoids conversational opportunities, restricts conversation, approaches strangers and chats – didn't used to	Things WANT to do (going out)	Participation
Friends don't visit, keeps quiet at dinner parties, talks one to one in groups, see friends individually since stroke, loss of friends seen as a 'loser', loss of friends, use of humour now restricted, can't be spontaneous, rejection by friends, meeting friends made him aware of difficulties because had to extend conversation/less relaxed, feels contribution is not interesting because of speed of delivery Increased number of friends since stroke	Things WANT to do (meeting friends)	Participation
Can't phone friends, less contact with friends, loss of role in conversation, stay silent with others, son no longer phones, more empathic towards others, more sensitive to friends needs, read to grandchildren, less contact because can't write to friends, write to son is Australia, Christmas cards	Things WANT to do (relationships)	Participation
Diary	Things WANT to do (making plans)	Participation
Can't use the telephone	Things WANT to do (other)	Participation
Can't control grown up son, loss of power with husband when arguing, lost partner, end	At HOME	Participation

relationship, rebuking son, wife grabs the phone from him, restricts conversation, with children to avoid frightening them by making mistakes, simplifies language with own children to keep their attention, change in mood in family since having aphasia, family's feelings of hopelessness because of aphasia, turned into a negative person, son become more abusive since aphasia, son now has power over mother, strained relationship with wife, husband now does , shopping and therefore chooses what to eat etc – wife resents change in control of domestic domain		
Wife, partner, partner encouraging person with aphasia to think for himself, partner offers clues, husband supplies word, help with children's homework, can't read to children, role change with wife (she now writes cheques, does paperwork – PWA happy with that), wife more involved in paperwork, dislikes switch of locus of control, unhappy about dependence due to paperwork, wife feels she is better than him because she does the paperwork, husband now does household finances, letter writing, can't write notes to remind wife to do things in morning (disabled wife), sons respect important/contrasts with other sons behaviour, one son congratulates his mother for reading aloud well, other not	People (partner)	External influences (barrier or facilitator)
Brother	People (brother/sister)	External influences (barrier or facilitator)
Daughter helps, one son good, one son not	People (son and daughter)	External influences (barrier or facilitator)
Grandchildren easy, children better	People (children)	External influences (barrier or facilitator)
Friends at work, old friend, neighbour, friends – rejection, friends less relaxed than family, 2 good friends treat me the same, friends very helpful	People (friend/neighbour)	External influences (barrier or facilitator)
Nurse wrote letter to the bank, speech therapy, volunteer, surveyor	People (other people/health/social care)	External influences (barrier or facilitator)
Talk over me, interrupted	Conversation (interrupting)	External influences (barrier)
Try to get away People don't listen	Conversation (look away)	External influences (barrier)
Negative attitudes They talked and not to me	Conversation (look bored/not listening)	External influences (barrier)
Too much going on gets in the way	Conversation	External influences

	(noisy or busy)	(barrier)
Talks quickly	Conversation (speak quickly)	External influences (barrier)
Picks out one person in a group to talk to when groups problematic Someone speaks for me	Other barriers/facilitators	External influences (barrier)
Interested in conversation, keeping interested, interested in conversation, friendly and interested, respect, positive attitudes, positive reactions help	Listen to me	External influences (facilitators)
Tell people had a stroke, pretence at being non-aphasic, fine telling close friends about aphasia –not others, helped to tell people	Telling people (help cards)	External influences (facilitators)
Talking - extra time, patience, he was impatient, extra time for reading	Extra time	External influences (facilitators)
Someone scribing, writes things down in bank, write instead of speak	Writing things down	External influences (facilitators)
Someone helping, someone scribing at history class, volunteer helps spelling by doing crosswords, neighbour fills in betting slips	Someone helping	External influences (facilitators)
Listen to radio Listens to taped books	Speaking books	External influences (facilitators)
Dictionary	Dictionary	External influences (facilitators)
Print better than writing	Large print	External influences (facilitators)
PC (computer) – can self-correct	Computer	External influences (facilitators)
Talks one to one, picks out one person in a group, simplifies language, takes deep breaths, rephrasing, thinks before speaking, use of first letter, repetition, talking slow and posh, rabbit on when stuck for word, others filling in words/ Someone speaks for me, writing instead of speaking, having a laugh about it, reading to self at night, re-reading, reading out loud, using a piece of paper as a guide (reading), leaving writing and coming back to it	Other facilitators	External influences (facilitators)
'phone	'phone	External influences (barriers)
Agitated, vicious circle, worse if upset, struggling makes it worse	Upset	External influences (barriers)

Tiredness Worse when tired	Tired	External influences (barriers)
Added/agreed by advisory panel	Wrong hand	External influences (barriers)
Multi-tasking	Too much	External influences (barriers)
Others filling in words Changing topic of conversation	Other barriers	External influences (barriers)
Lost confidence, avoid conversations, positive attitude, not worried, more assertive since having aphasia	Less confidence	Emotions (including both positive & negative aspects of the concept)
Helpless, incapable, dependent, being trapped, need to be independent	Less control	Emotions
Can't do things, incompetent, a nutter, not being normal (?self esteem), stupid	Able	Emotions
Isolated, excluded, being ignored, unloved, rejected, neglected	Isolated	Emotions
Embarrassed, (?self esteem)	Embarrassed	Emotions
Lack of respect, being small, lower down (?self esteem)	Valued	Emotions
Angry, mad, aggressive towards family	Angry	Emotions
Frustrated	Frustrated	Emotions
Determined	Determined	Emotions
Sad, depressed, unhappy, down a bit	Unhappy	Emotions
Anxious, frightened, worried	Worried	Emotions
Pessimistic, optimistic	The future?	Emotions
Positive attitude, dissatisfied with life	Today?	Emotions

Appendix 5.22

Domains raised by in-depth interviews that are NOT covered within the CDP

<i>Exemplar from the qualitative interviews</i>
Specific communication strategy - giving alternatives
Specific communication strategy - restricting own speech
Specific communication strategy - keep quiet
Need for extra care and effort
Value of activities that have been recently taken up eg. Stroke clubs
Shocked, shock at discovering impairments
Emptiness
Confusion

What did 16 people with aphasia think of the CDP?

✓ *15/16 thought doing the CDP was a **positive experience** (one neither +ve or -ve)*



✓ *liked the **pictures***

✓ *liked the **no 'right/wrong'***

✓ ***Scales useful***

✓ *liked the fact that it looked **areas** of her life that **weren't usually addressed***

✓ *Felt it really **focussed** on **her** as a person and **respected** her point of view*

✓ *Helped to bring out the **positives** and for the person to reflect on them*

✓ *Very **thought-provoking** –think in **structured** way about impact of aphasia in different settings (tumour)*

but



- *Emotional scale – more confusing*
- *found it exhausting*
- *Wanted to go into more depth in participation section (things you have to do, things you want to do, at home)*
- *Did not like the lightning strike*
- *‘worried’ and ‘content’ the opposite ends of the same emotion?*
- *how you rate would depend on where you were*
- *how you rate would depend on your mood*
- *some situations were variable e.g talking with a group of friends could be easier but sometimes not*

- *Not prepared to be pigeon-holed, especially in the emotions section*
- *wanted to rate **between the pictures***

What did 7 Speech & Language Therapists
think of the CDP?



- ✓ *Content good and relevant*
- ✓ *Strong positive reaction to some of the pictures and questions*
- ✓ *Easy to use*
- ✓ *Score-sheet simple*
- ✓ *Gave structure as a forum for discussing emotional issues*
- ✓ *Gave me specific ideas re; advice to family based on HIS experiences not SLTs*
- ✓ *The CDP enabled him to be more assertive in expressing his views*
- ✓ *I've enjoyed doing it*

- ✓ haven't come across **anything** which covers such a **lot of ground** (from the aphasic person's perspective) so **neatly**.
- ✓ It's **different**, and **highly useable**.
- ✓ **Identified** several issues that were **not** previously **recognised** by the SLT
- ✓ **confident** that **simple** things really do make a **big difference**
- ✓ what you see as a **SLT** to be the problem, may **not** be what is **important** for this **person**
- ✓ **highlight** with someone with **mild** aphasia the **huge** impact on **activities**
- ✓ Made me very **keen** to do more education/**teaching** in **hospitals**, nursing homes, day centre
- ✓ Makes you think about the **need** to **inform** the **general public** more about aphasia

but



- *opens up several other areas that SLT not able to deal with?*
- *Can be quite time consuming*
- *difficult to divide effect of aphasia from other problems: weakness, fatigue*
- *Too many pictures, this got easier*
- *Emotional scales took time and practice*
- *Participation section not appropriate in hospital setting*
- *table space tricky – too many pictures*
- *Couldn't understand the 'able' picture*
- *things you have to do – client wanted to talk about each one specifically*

Example of how pilot suggestions for change were taken to advisory group

10th July – decisions

➤ *Participation section – things you HAVE to do, WANT to do, at HOME*

- **rate each area*
- **? appropriate for hospital setting*

➤ *Emotional section*

- **one emotion per page?*
- **two-stage rating or one?*
- **mood*
"is it a good or a bad day today?"
- **change 'able' picture?*
- **'worried' and 'content' the same idea?*
- **at present can only rate the absence of negative emotions – any ideas?*

➤ *smaller version – what do you think?*

The Communication Disability Summary Score sheet

Name :

Date:

Q	<u>Domains</u>	<u>Raw scores</u> <u>(circle)</u>	<u>Section totals</u>	<u>Percentage totals</u>
1	Talk-person closest	0 1 2 3 4		
2	Talk-group	0 1 2 3 4		
3	Talk-stranger	0 1 2 3 4		
4	Talk-pressure	0 1 2 3 4		
	<i>Talk total</i>		<i>/16</i>	
5	Express-person closest	0 1 2 3 4		
6	Express-group	0 1 2 3 4		
7	Express-stranger	0 1 2 3 4		
8	Express-pressure	0 1 2 3 4		
	<i>Express total</i>		<i>/16</i>	
9	Understand-person closest	0 1 2 3 4		
10	Understand- stranger	0 1 2 3 4		
11	Understand- group	0 1 2 3 4		
12	Understand-pressure	0 1 2 3 4		
	<i>Understand total</i>		<i>/16</i>	
13	Reading-word	0 1 2 3 4		
14	Reading-headline	0 1 2 3 4		
15	Reading-story	0 1 2 3 4		
16	Reading-official	0 1 2 3 4		
	<i>Reading total</i>		<i>/16</i>	
17	Writing-name	0 1 2 3 4		
18	Writing-list	0 1 2 3 4		
19	Writing-friend	0 1 2 3 4		
20	Writing-official	0 1 2 3 4		
	<i>Writing total</i>		<i>/16</i>	
	<i>Activities total:</i> <i>(with express yourself)</i> <i>(without express yourself)</i>		<i>(-express) /64</i> <i>(+express) /80</i>	Activities %
	<u>Life style/</u> <u>Participation:</u>			
	have to:	0 1 2 3 4		
21	Money	0 1 2 3 4		
22	Health	0 1 2 3 4		
23	Transport	0 1 2 3 4		
24	Shopping	0 1 2 3 4		
25	Business	0 1 2 3 4		
26	Work	0 1 2 3 4		
	want to:	0 1 2 3 4		
27	Hobbies	0 1 2 3 4		

The Communication Disability Profile summary score sheet

28	Clubs	0 1 2 3 4			
29	Holidays	0 1 2 3 4			
30	Going out	0 1 2 3 4			
31	Meeting friends	0 1 2 3 4			
32	Relationships	0 1 2 3 4			
33	At home	0 1 2 3 4			
	Participation		/48	Participation	%
	Facilitators:				
	Barriers:				
28	Angry	0 1 2 3 4			
29	Frustrated	0 1 2 3 4			
30	<i>Determined</i>	*0 1 2 3 4			
31	Unhappy	0 1 2 3 4			
32	Worried	0 1 2 3 4			
33	<i>Content</i>	*0 1 2 3 4			
34	Less confident	0 1 2 3 4			
35	Less control	0 1 2 3 4			
36	<i>Able</i>	*0 1 2 3 4			
37	Lonely	0 1 2 3 4			
38	Embarrassed	0 1 2 3 4			
39	<i>Valued</i>	*0 1 2 3 4			
40	Future	0 1 2 3 4			
41	Today	0 1 2 3 4			
42	Enjoy?				
	Emotions total		/56	Emotions	%

The Communication Disability Profile summary score sheet

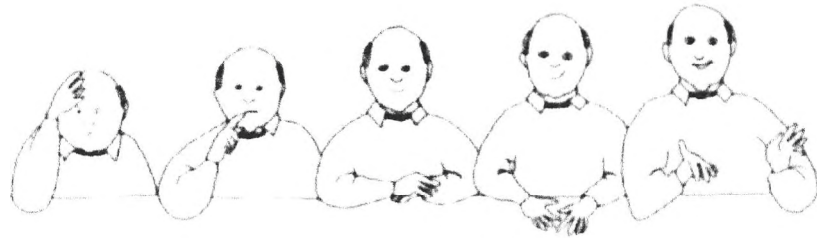
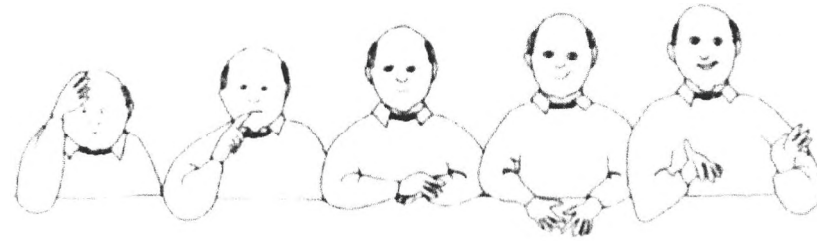
Grand totals:				
Activities:		Participation:	Emotions:	
/64	%	/48	/56	
/80	%	%	%	

Key people:

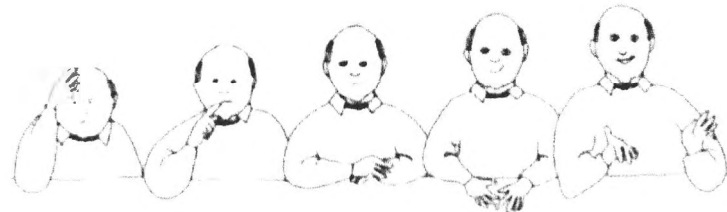
Key issues:

Possible action:

Appendix 5.27
Options for one-stage rating stage (condensed)



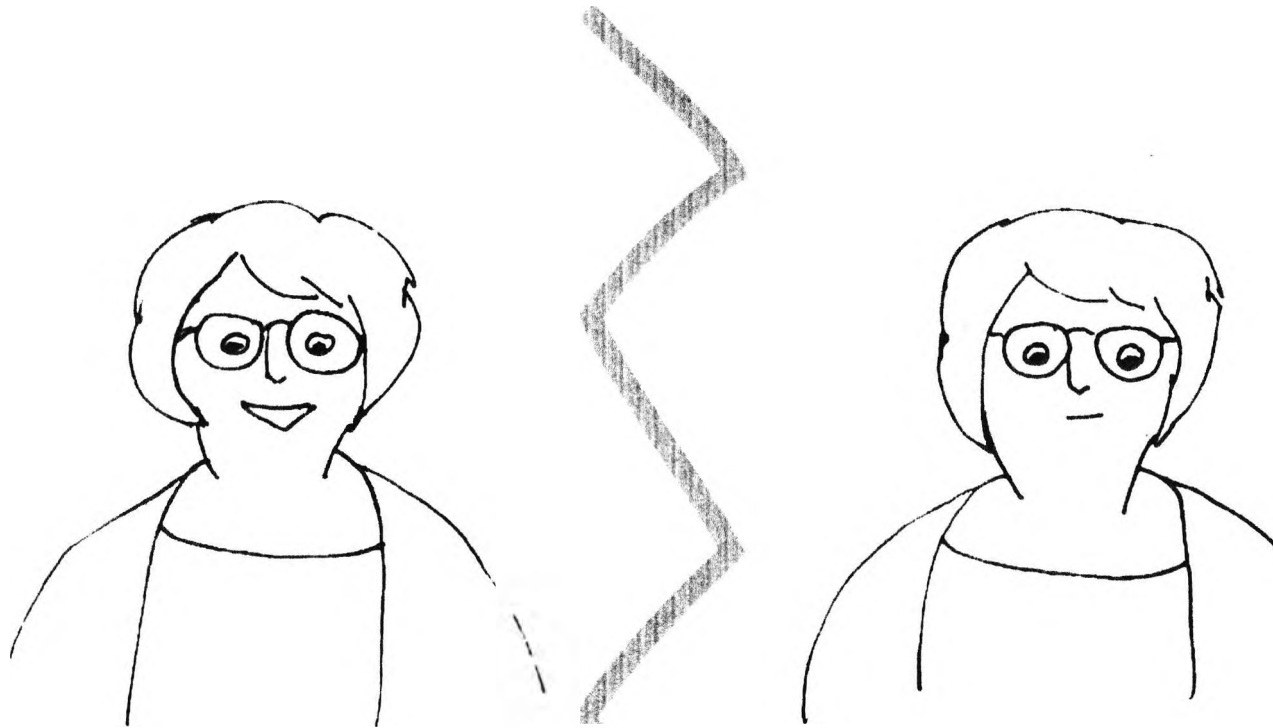
4 3 2 1 0



×× × — ✓ ✓✓

Appendix 5.28
Before and after stroke - original draft

Since your **stroke**...



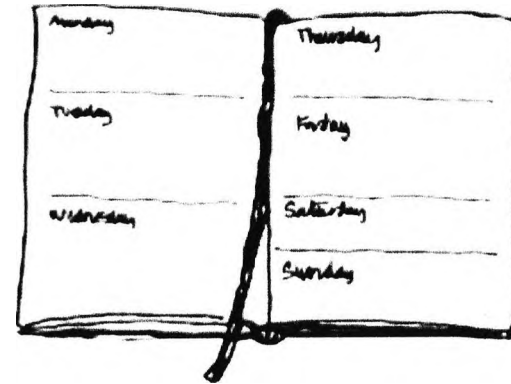
Appendix 5.29
Condensed 'since your stroke' - final draft

Since your stroke... during the **last week**



Appendix 5.30
During the last week - original draft

...during the **last week**...



Appendix 6.1
Appointment letter to John

Kate Swinburn
Home address given

02.10.2001

Dear John,

We have **two** meetings in the **next two weeks**.

1. **Tuesday 9th October**
11-1.30
Connect
2. **Tuesday 16th October**
11 - 2.30
Start at Connect for an hour or so.
We will then **move out to TAZ**.

I believe this is a nice local **restaurant!!**

See you then

Appendix 6.2

Email to Sue with conclusions and next appointment times

Conclusions for Sue

The following emotions came out as the winners (with the following wording):

Valued

Able

Determined

Whole

Rejected 'spontaneous' and 'strong minded'. Strong minded was rejected because it was felt that though strong minded people may want to rate this after their stroke – they may be others who were NOT strong minded BEFORE their stroke who would be a bit alienated by it – therefore 'determined' was chosen as being more of an emotion rather than a personality trait

The group agreed to rate the social participation section in the way that we discussed i.e. to discuss each area of things you have to do, and then rate overall, then discuss areas of life that you want to do that are affected by aphasia.

I did have a thought after this – at the moment we are proposing to rate:

1. how is talking in every day life?
2. how are things you want to do?
3. how are things you have to do?
4. how is talking at home?

Do you think we need the first one of these, now?

We discussed all the new pictures – there are still some problems particularly with the abstract ones but basically we're nearly there I think

We discussed the quote about subjective well being and whether it changes with time – you remember we discussed that on the 'phone.

Harry felt that 6 months was about right but that that was based on the expectation of him revering his speech fully – that's what he had been told by the therapists.

John felt that 6 years on he had still not recovered his sense of well-being

SOOOOOOOOOOOOO!

Anyway next meeting booked for **October 16th** (Tuesday I'm afraid but I thought if you had notice it would be OK – I hope so). Meet at **11** then I want to **take everyone out to lunch afterwards to say thanks**. So put it in your diary – and let me know any suggestions for places to eat around Connect

Appendix 6.3
Issues for consideration letter for John

Kate Swinburn
Home address given

22.06.01

Dear John,

Welcome home!

I hope you had a **good holiday**.

We **missed you** at the aphasia **advisory group**.

Our next meeting is on:

Tuesday 10th July

12.00 until 2.30

at **Connect**.

I have some **questions** for you.

Look at the next sheet – which words do you **like best**?

Can you tick the ones you think are EASIEST to understand?

If it's too hard – don't worry – I'll bring it on the 10th to discuss.

Hope to see you on 10th

Each line **means the same** but the **words are different**.

Can you tick the words you think are the **best**?

1.

How is talking **day to day**?

How is talking in your **daily life**

How is talking in your **everyday life**

2.

What people help your talking?

Who helps your talking?

3.

What makes talking **harder**?

What makes talking **worse**?

4.

Understand (what people say)?

Follow (what people say)?

If it's too hard – don't worry – I'll bring it on the 10th to discuss.

If you can do it – please send it to me at home

(Home address given)

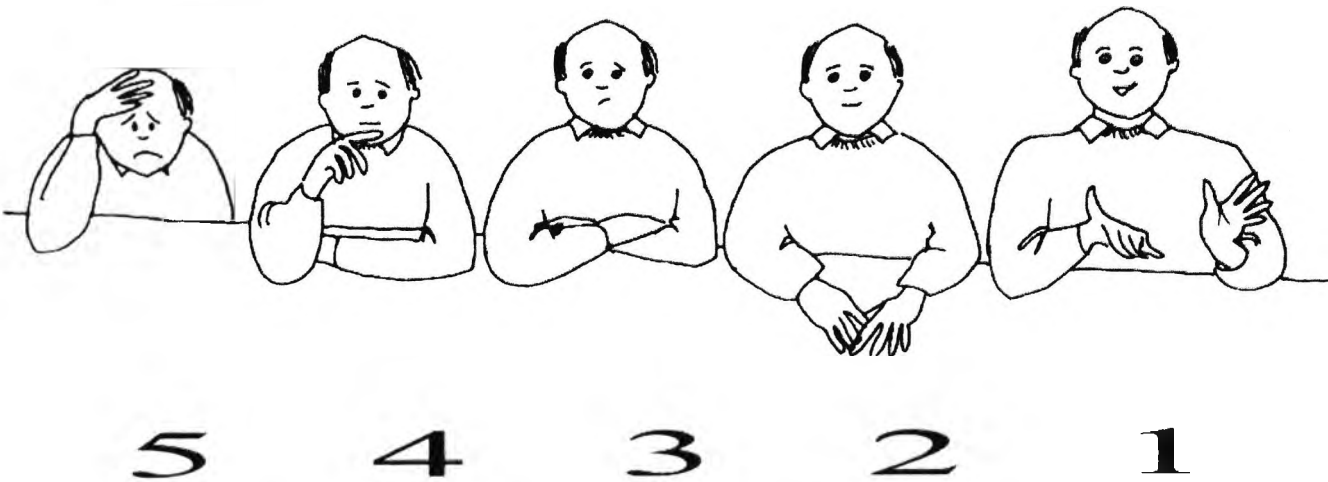
Thank you!!!!!!

Appendix 6.4

Rating scale 1 - version 1

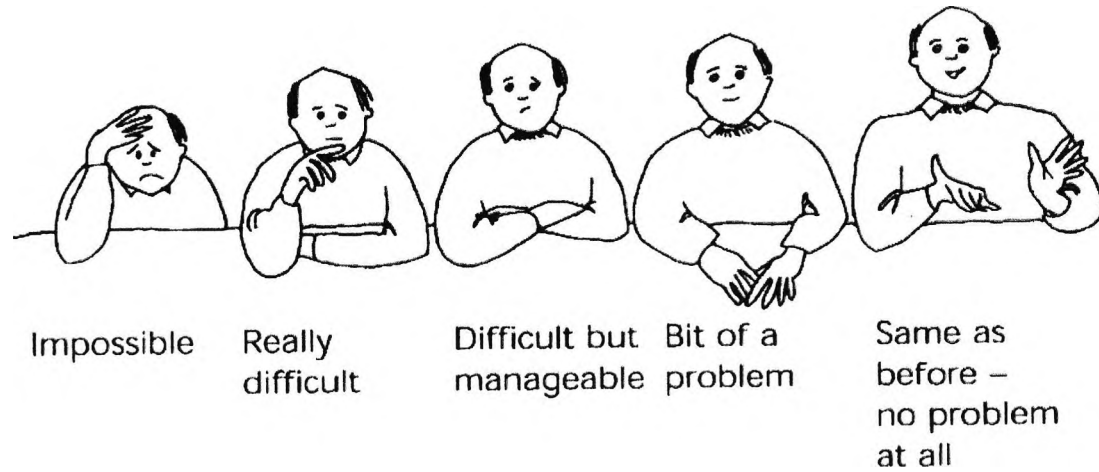


Appendix 6.5
Rating scale 1 version 2



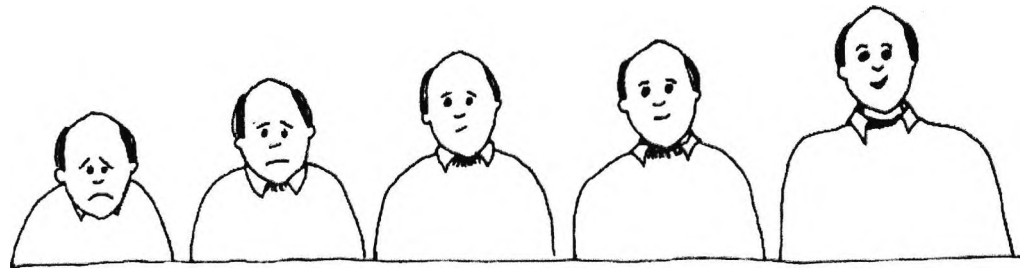
Appendix 6.6
Rating scale 1 version 3

How easy is it for you...?



Appendix 6.7 Rating scale 1 version 4

How easy is it for you...?



Impossible

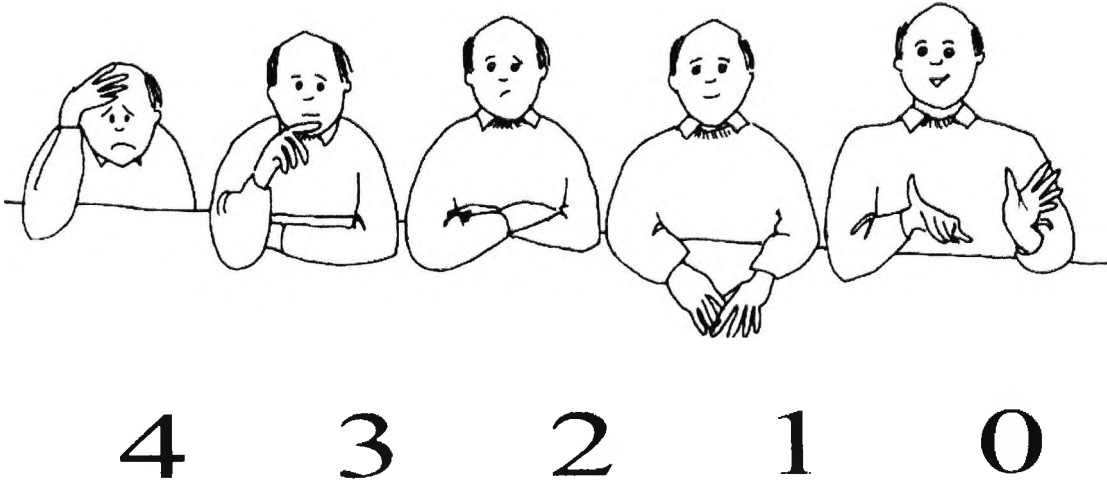
Really
difficult

Difficult but
manageable

Bit of a
problem

Same as
before –
no problem

Appendix 6.8
Rating scale 1 version 5



Appendix 6.9

Consent form from another SLT project

Subject Information and Consent Form

You are being invited to participate in a research project conducted by a graduate student in the

department of Communication Disorders and Speech Science.

This project has been designed to study factors that contribute to quality of life for persons with aphasia. The effect that aphasia has upon the life experience of individuals differs greatly and does not appear to be solely predicted by the severity of language impairment. The purpose of this investigation is identify the degree to which an aphasic individual's social environment impacts outcome.

If you agree to participate in this project, you will be asked to attend two sessions. In session one, the investigator will interview you and your significant other for approximately 1 1/2 hours. In session two, you will be given an aphasia test that will take approximately 1 1/2 hours. These two sessions will be scheduled at times convenient for you over the course of four weeks. Sessions will take place either at the clinic in which you received(d) treatment or in your home.

In the interview session will be asked a series of questions having to do with the types and frequency of supportive assistance you have received in the last month. For example, you might be asked, "How many times in the last month has someone helped you get around town?" or "How many times in the last month has someone offered you advice?" or "How many times in the last month has someone let you know that they enjoyed being with you?" Your significant other will be asked to accompany you during the interview session to help you respond to questions if talking or understanding language is difficult for you. The aphasia test will be like those you received as part of your treatment. You will be asked to complete tasks involving listening, reading, speaking and writing.

There is no risk to you as a participant in this project except that some of the aphasia questions may be difficult or frustrating for you and some interview questions may touch upon sensitive subjects. If you are upset by any of the activities or you become fatigued, you may take a break, or you can tell us that you want to stop. You also have the right to refuse to answer any questions for any reason.

While there are no anticipated direct personal benefits to your participation in this project, you may experience a sense of satisfaction in knowing that you have contributed to our effort to better understand aphasia. If you would like, your test results from this study can be shared with you and/or your therapist if you are currently in a therapy program.

Your participation in this project is voluntary and you may stop all further participation in the project at any time. Just let us know that you want to quit, and we will stop testing or questioning.

If you participate in this study, you also need to give us separate written permission to look at your medical and speech-language pathology records.

All sessions will be audio and video recorded to allow later scoring verification. However, your individual privacy will be maintained in all published and written data resulting from this study. All data, medical record information, audio video recordings will be referred to by a subject number. The only record of subject identifying information will be kept in a

locked file in the office of the principle investigator. All test records, medical records and recordings will be destroyed when they are no longer being used for research purposes.

If you or your family have any questions regarding your rights as a subject, or concerns regarding this project or any dissatisfaction with any aspect of this study, you may contact _____ or the _____.

You or your family may also ask the Executive Secretary for a copy of the University's statement to the Federal Government entitled "Assurance of Compliance, in the Health and Human Services (HHS) Regulations."

A copy of the Informed Consent form will be provided to you at the time you sign it. I understand the above information and voluntarily consent to participate in the research project entitled, _____.

Subject Signature _____ date _____

Print Subject Name _____

Legal Guardian Signature _____ date _____

Print Legal Guardian Name _____

If a legal guardian is signing this form, the signature of the legal guardian assures that the legal guardian has witnessed the verbal explanation of the contents of the consent form in the subject's presence and the legal guardian agrees that the subject understands the nature of the work and wishes to participate in the study.

INFORMATION SHEET



Kate Swinburn
(Speech and Language Therapist)
Richmond Rehabilitation Unit,
Evelyn Rd. Richmond TW2 9TF SURREY
Phone: 0171-228-8400

This is a **project** about **how** your **talking problems** affect your **life**.

It is **NOT** speech therapy.

The project is looking at **how** speech therapists look at your **talking difficulties**.

An **assessment** has been **written**

It asks **lots of questions**.

It looks at **how** your talking **gets in the way** of day to day life.

It has **questions** about **how you feel** about your talking difficulties.

You can **answer** the questions **just by pointing** if you want.

The tool is called a **Rating Scale**.

You will be asked what you think of the rating scales.

Your views are really important.

Your thoughts about it will help to make the rating scale better.

This will be the **first time** views of **people with talking problems** have been **included** in developing a tool.

If you would like to help - **here's what will happen:**

- **Kate Swinburn (a speech therapist)** will come to see you
- She will **do the rating scales** with you

Appendix 6.11
Information sheet used in this research project (page 2)

later on ...

- **6 weeks later** you will come to **join other people** with talking problems.
- You will be **picked up** and **taken home** by **taxi**.
- The group will run at **City Dysphasic Group, Goswell Place**, near the **Angel**.
- **Susie Parr** (a **different speech therapist**) will run the group.
- You will **chat with everyone** about the **rating scales**.
- The **group** will take about **2 hours**.

If you **don't like it**, you can **STOP**.

If you **change your mind**, you **don't have to COME**.

No one will ask any questions.

Your **speech therapy** will **not change** if you stop.

If you **want to take part**:

- **talk to** (name of the relevant speech therapist)

she will **make all the arrangements**)

OR

ring **Kate Swinburn** on **0171-228-8400**
say "I'm phoning about the rating scales project")

This project has been **looked at** by.....**Ethics Committee** (they **check the project is air and good**).

They **say it can go ahead**.

Appendix 6.12
Consent form used for this project (page 1)


CONSENT FORM


Kate Swinburn,
Speech and Language Therapist,
Richmond Rehabilitation Unit,
Evelyn Rd, Richmond.

Telephone: 0171-228 8400





The project has been explained.

YES 

NO 

I understand what I have to do.

YES 

NO 

I spoke to about the project.

I can STOP at any time.



Appendix 6.13 Consent form used in this project (page 2)

It won't affect my speech therapy.

There is **NO DANGER**



no danger

Everything is **confidential**.

No one will know what I said.



Do you **agree** to take part in the project?



YES



NO



Signed:

Date:

Name in **CAPITALS**:

Signature of Kate Swinburn: