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

by

Catharine Anna Swinburn

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REFERENCES

Acker J., Barry K. & Essesveld J. (1983) 'Objectivity and truth: problems in doing feminist research' *Women's Studies International Forum,* vol. 6, no. 4, pp423-435

Addington Hall J. & Mc Carthy (1995) Dying from cancer: results of a national population-based investigation. *Palliative Medicine. vol.* 9, pp295-305

Addington-Hall J. & Kalra L. (2001) Who should measure quality of life? *British Medical Journal* vol. 322, pp1417-1420

Ahlsio B., Britton M., Murray V. & Theorell T. (1984) Disablement and quality of life after stroke *Stroke* vol. 15, no. 5 pp 886-890

Aitken R.C.D. (1969) Measurement of feelings using visual analogue mood scales. *Proceedings of the Royal Society of Medicine.* vol. 62, pp989-993

Allison P., Locker D. & Feine J. (1997) Quality of life: a dynamic construct. *Social Science Medicine* vol. 45, no. 2, pp221-230

Anderson R. (1988) The quality of life of stroke patients and their carers. In *Living with Chronic Illness: The experiences of patients and their families.* Edited by R. Anderson and M. Bury. London Unwin-Hyman

Angeleri F., Angeleri V.A., Foschi N., Giagninto S. & Nolfe G. (1993) The influence of depression, social activity, and family stress on functional outcome after stroke *Stroke* vol. 24, no 10, pp1478–1483

Asberg M., Montgomery S., Perris C., Schalling D. & Sedvall G. (1978) The Comprehensive Psychopathological Scale *Acta Psychiatrica Scandanavica* Supplement 271. pp136-152

American Speech-Language Hearing Association *Functional Assessment of Communication Skills for Adults* (1997) (ASHA FACS),

Bach S. (1991) *Life paints its own span: on the significance of spontaneous pictures by severely ill children* Zurich: Daimon Verql.

Badley E.M. (1995) The genesis of handicap: definition, models of disablement and role of external factors. *Disability and Rehabilitation* vol. 17, no.2, pp53-62

Barker R. (1990) Development of a questionnaire to assess patient's satisfaction with consultations in general practice *British Journal of General Practice* vol. 40, pp487-490

Barnes C. (1996) Disability and the Myth of the independent researcher. *Disability & Society* vol. 11, no. 1 pp107-110

Barnes C. (1992) Qualitative research: valuable or irrelevant? *Disability, Handicap & Society,* vol.7, no.2, 115-124

Barnes C. & Mercer G. (1997) *Doing Disability Research* (eds) Leeds: The Disability Press.

Beck A.T., Ward C.H., Mendelson M., Mock J., & Erbaugh J. (1961). An inventory for measuring depression, Archives of General Psychiatry, vol.4, pp561-567.

Bergner M. (1993) 'Developing testing and using the sickness impact profile' in S.R. Walker & R. M. Rosser (eds) *Quality of Life Assessment: Key issues in the 1990 (2^{nd} ed)* Dordrecht: Kluwer Academic

Béthoux F., Calmels P. & Gautheron V. (1999) Changes in the quality of life of hemiplegic stroke patient with time *American Journal of Physical Medicine and Rehabilitation* vol. 78, no. 1

Bhopal R. (2001) Racism in medicine *British Medical Journal* vol.322, pp1503-4

Block R.J. & Yuker H.E. (1979) Attitudes towards disability are the key *Rehabilitation Digest* vol. 10, pp2-3

Blomert L., Kean M.-L., Koster C. & Schokker J. (1994) Amsterdam-Nijmegen Everyday Language Test: construction, reliability and validity. *Aphasiology*, vol. 8, no.4, pp381-407

Boazman S. (1999) Inside Aphasia chapter in *Disability Discourse.* Eds Corker M & French S OUP, Buckingham

Booth T. & Booth W. (1994) *Parenting under pressure* Buckingham, Open university Press.

Boulton G. & Ahmedzai S. (1997) Project will assess effects of patients writing about their terminal illness on self perceived quality of life. *British Medical Journal* vol.314, p1485

Bowd, A.D. (1988).*Client satisfaction and normalization of residential services for retarded persons.* Annual convention, American Psychological Association, Atlanta.

Bowling A. (1995) What things are important in people's lives. A survey of the public's judgments to inform scales of health related quality of life. *Social Science Medicine.* vol.41, no.10 pp1447-1462

Bowling A. (1997a) Measuring Health: A review of quality of life measurement scales *Open University Press.* Buckingham. Philadelphia.

Bowling A. (1997b) Research Methods in Health: Investigating Health and Health Services *Open University Press.* Buckingham. Philadelphia.

Bowling A. (1998) Measuring Disease: A review of disease-specific quality of life measurement scales. *Open University Press.* Buckingham. Philadelphia.

Bradburn N.M. (1969) *The Structure of Psychological Well-being.* Chicago, Il. Aldine

Bricher G. (2000) Disabled People, Health professionals and the social model of disability: can there be a research relationship? *Disability and Society* vol. 15, no. 5, pp 781-793

Brod M., Stewart A.L., Sands L. & Walton P. (1999) Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DqoL) *The Gerontologist* vol. 39 no. 1 pp25-35

Brott T., et al. (1989) Measurements of acute cerebral infarction: a clinical examination scale. *Stroke* vol.20, pp864-870,

Brownlea A. (1987) Participation,: Myths, realities and prognosis *Social Science Medicine* vol. 25, no.6, pp605-614

Brumfitt S. (1993a) Losing your sense of self: what aphasia can do *Aphasiology,* vol. 7, no 6 pp569-591

Brumfitt S. (1993b) The primacy of self. *Aphasiology,* vol. 7, no. 6, 56/89-591

Brumfitt S. (1998) The measurement of psychological well-being in the person with Aphasia *International Journal of Language & Communication Disorders* vol. 3, supplement pp116-120

Brumfitt S. (1999) *The Social Psychology of Communication Impairment* Whurr publications London

Brumfitt S. & Sheeran P. (1999a). *VASES: Visual Analogue Self Esteen Scales.* Winslow Press. Chesterfield. UK

Brumfitt S. & Sheeran P. (1999b) The development and validation of the Visual Analogue Self-Esteem Scale (VASES) *British Journal of Clinical Psychology.* vol. 38, pp387-400

Bury M. (1991) The sociology of chronic illness: a review of research and prospects *Sociology of Health and Illness*, vol.13, no.4, pp451-468

Bury M. (1996) Disability and the Myth of the independent researcher. *Disability & Society* vol. 11, no. 1 pp111-113

Byock I.R. (1999) Conceptual models and the outcomes of caring *Journal of Pain and Symptom Management* vol.17, no.2 pp83-92

Cairns J. (1996) Measuring health outcomes *British Medical Journal* vol.313, pp6

Campbell J. & Oliver M. (1996) *Disability Politics; understanding our past: changing our future* London, Routledge.

Cameron A. (2001) Speaking out *Royal College of Speech and Language Therapists Bulletin* Issue 586

Cardol M., de Haan R. J., van den Bos P., deJong B. A. & de Groot I. J. M. (1999) The development of a handicap questionnaire: the impact of participation and autonomy *Clinical Rehabilitation* vol. 13, pp411-419

Carr A. J., Gibson B. & Robinson P. G. (2001) Measuring quality of life; Is quality of life determined by expectations or experience? *British Medical Journal* vol.322, pp1240-1243

Carr A. J. & Higginson I. J. (2001) Measuring quality of life: are quality of life measures patient centred?

British Medical Journal vol. 322, pp1357-1360

Carrick R., Mitchell A. & Lloyd K. (2001) User involvement in research: power and compromise. *Journal of Community & Applied Psychology.* vol.11, pp217-225

Cassidy S. (2000) The use of self-advocacy in gaining the views of clients with learning difficulties *Assignment – ongoing work of health care students* vol. 6, no. 3 pp30-38

Chalmers I. (1995) What do I want from health research and researchers when I am a patient? *British Medical Journal* vol. 310, pp1315-1318

Charmaz L (1995) The body, identity and self: adapting to impairment. *The Sociological Quarterly* vol. 36, no. 4 pp657-680

Chambers L.W., Sackett D., Goldsmith C et al (1976) Development and application of an index of social function *Health Service Review* vol.11, pp430-41

Chang A. E. & Macknezie A. E. (1998) State self esteem following stroke *Stroke* vol.29, pp2325-2328

Chapman J. & Forshaw N. (2002) Making services accessible *Royal College of Speech and Language Therapist Bulletin* May. pp7-8

Charlton J. (1998) *Nothing about us without us: disability oppression and empowerment.* Berkeley: University of California Press.

Cheetham J. (1992) *Evaluating Social Work Effectiveness* Milton Keynes. Open University Press

Clarke P., Black S.E., Badley E.M., Laurence J.M. & Williams J.I. (1999) Handicap in stroke survivors *Disability and Rehabilitation* vol. 21, no 3 113-123

Clear M. (1999) The 'Normal' and the monstrous in Disability Research *Disability and Society* vol. 14, no.4, pp435-448

Code C. & Müller D. (1992) The Code- Müller Protocols Far Communications Ltd. Great Britain

Coles J. (2001) The social model of disability: what does it mean for practice in services for people with learning difficulties? *Disability & Society* vol. 16, no. 4, pp501-510

Compton W. C. (2000) Meaningfulness as a mediator of subjective well-being *Psychological reports* vol.87, pp156-160

Connect (2001) *The Way We Work.* Connect – the communication disability network handbook.

Conrad P. (1990) Qualitative research on chronic illness: commentary on method and concept development. *Social Science Medicine* 30, no. 11 pp1257-1263

Corker M. & French S. (1999) Disability Discourse Open University Press, Buckingham. UK

Cornwell J. (1984) *Hard Earned Lives: Accounts of Health and Illness in East London.* London. Tavistock.

Coutler A. (1997) Partnership with patients: the pros and cons of shared decision-making *Journal of Health Service Research Policy* vol. 2, no.2, pp112-121

Crockford C. & Lesser R. (1994) Assessing functional communication in aphasia: clinical utility and time demands of three methods *European Journal of disorders of Communication*, vol. 29, pp165-182

Cruice M., Worrall L., Hickson L., Hirsch F. & Holland A (2000a) Quality of life measurement for people with aphasia: performance on and usability of quality of life assessments *Asia Pacific Journal of Speech, Language and Hearing* Vol. 5, pp85-91

Cruice M., Worrall L. & Hickson L. (2000b) Quality-of-life measurement in speech pathology and audiology *Asia Pacific Journal of Speech, Language and Hearing* Vol. 5, pp1-20

Cummins R. A. (1997) Self-rated quality of life scales for people with an intellectual disability: a review *J of Applied Research in Intellectual Disability* vol. 10, no 3 pp199-216

Damico J. S., Simmons-Mackie N., Oelschlaeger M., Elman R. & Armstrong E. (1999) Qualitative methods in aphasia research: basic issues *Aphasiology* vol. 13, no. 9-11 p651-665

Davis K. (1993) The crafting of good clients. In Swain J, Finkelstein V, French S & Oliver M (1993) *Disabling Barriers - Enabling Environments* Sage publications

De Haan, M. S., Aaronson N., Limburg M., Langton-Hewer R., & van Crevel H. (1993) Measuring quality of life in Stroke *Stroke* vol 24, no 2 pp.320-7.

De Haan R. J., Limburg M., Van Der Meulen J. & Bossuyt P. (1993) A comparison of five stroke scales with measures of disability, handicap and quality of life. *Stroke* vol. 24, pp1178-1181

Department of Health (2000) *The NHS Plan, a Plan for Reform* HMSO: London.

DeSanto L.W., Olsen K.D., Perry W.C., Rohe D.E & Keith R.L. (1995) Quality of life after surgical treatment of cancer of the larynx *Annuals of Otolaryngology, Rhinology and Laryngology* Vol.. 104, pp743-749

Dewart H. & Summers S. (1996) *Pragmatics Profile of Everyday Communication Skills in Adults.* NFER-Nelson. Swindon. England.

Diprose R. (1993) Nietzsche and the pathos of difference, in P. Patton (ed.) *Nietzsche, Feminism and Political Thought.* Syndney: Allen and Unwin

Disability, Handicap & Society (1992) Special Edition: *Researching Disability.* 7 (2)

Drewett A. (1997) Evaluation and Consultation *Evaluation* vol.. 3, no. 2, pp 189-204

Duchan J. F. (2001) Impairment and social views of speech-language pathology: clinical practices re-examined *Advances in Speech-Language Pathology* vol. 3, no. 1 pp37-45

Eastwood J. (1988) Qualitative research: an additional research methodology for speech pathology? *British Journal of Disorders of Communication*, vol.23, pp171-184

Edgerton R.B. (1996) A longitudinal-ethnographic research perspective on quality of life. In R.L. Schalock (Ed.) *Quality of life Volume 1: Conceptualization and measurement* (pp83-91). Washington DC: American Association of Mental Retardation

Edwards C., & Staniszewska S (2000) Accessing the users perspective *Health and Social Care in the Community* vol. 8, no. 6 pp417-424

Eiser C., Mohay H. & Morse R. (2000) The measurement of quality of life in young children *Child: Care, Health & Development* vol. 26 no 5 pp401-414

Elman R. J., Ogar J. & Elman S. H. (2000) Aphasia: Awareness, advocacy and activism *Aphasiology,* vol. 14, no 5/6 pp 455-459

Enderby P. (1992) Outcome measures in speech therapy: impairment, disability, handicap and distress *Health Trends,* vol.24, no.2, 61-4

Enderby P. (1997) *Therapy Outcome Measures* Singular Publishing Group.

Enderby, P. & Davies, P. (1989) Communication disorders: Planning a service to meet the needs. *British Journal of Disorders of Communication* vol.24, pp301-31

Enderby P., Wood V. A., Wade D. T. & Langton Hewer R. (1987) The Frenchay Aphasia Screening Test: A Short, Simple Test for Aphasia Appropriate for Non-Specialists *International Rehabilitation Medicine*, vol.8, pp116-170

Epstein A.M., Hall J.A., Tognetti J., Son L.H. & Conant L (1989) Using proxies to evaluate Quality of Life. *Medical Care.* Vol. 27, no.3, Supplement pp91-S98

Erling A. (1999) Methodological considerations in the assessment of health-related quality of life in children *Acta Paediatrica supplement* vol. 428 pp106-7

EuroQol Group. (1990) EuroQol - a new facility for the measurement of health-related quality of life. *Health Policy* vol. 16 no.3 pp199-208.

Fatimilehin I. A. & Coleman P.G. (1999). You've got to have a Chinese chef to cook Chinese food!! Issues of power and control in mental health services. In *Evaluation and Social Work Practice* I. Shaw & J Lishman (eds) Sage, London

Felce D. (1997) Defining and applying the concept of quality of life *Journal of Intellectual Disability Research* vol. 41, part 2, pp126-135

Ferrans C., & Powers M. (1985) Quality of life index: Development and psychometric properties *Advanced Nursing Science* vol.8, pp15-24

Finkelstein V. (1985) Unpublished paper given at the World Health Organization Meeting, 24-28 June Netherlands.

Finkelstein V. (1991) Disability: an administrative challenge (the health and welfare heritage)? In Oliver (eds) *Social Work: Disabled people and disabling environments* Jessica Kingsley, London.

Finkelstein V. (1999) Doing Disability Research (extended book review) *Disability & Society* vol. 14, pp859-867

Foucault M. (1972) *The Archeology of Knowledge* New York: Pantheon.

French S. (1993a) Disability, impairment or something in between? In Swain J, Finkelstein V, French S & Oliver M (1993) *Disabling Barriers - Enabling Environments* Sage publications

French S. (1993b) Experiences of disabled health and caring professionals In Swain J, Finkelstein V, French S & Oliver M (1993) *Disabling Barriers - Enabling Environments* Sage publications

French S. (1994a) Disabled people and professional practice Chapter 8 in *On Equal Terms: Working with Disabled People* (eds French) Butterworth-Heinemann, Oxford

French S. (1994b) Dimensions of disability and impairment Chapter 2 in *On Equal Terms: Working with Disabled People* (eds French) Butterworth-Heinemann, Oxford

French S. (1994c) Researching Disability Chapter 10 in *On Equal Terms: Working with Disabled People* (eds French) Butterworth-Heinemann, Oxford.

French S. (1994a) The disabled role Chapter 4 in *On Equal Terms: Working with Disabled People* (eds French) Butterworth-Heinemann, Oxford.

Fries J.F., Spitz P., Kraines et al (1980) Measurement of patient outcome in arthritis *Arthritis and Rheumatology* vol.23, pp137-45

Garrett K.L. (1999) Measuring outcomes of group therapy Chapter in R.J. Elman (eds) *Group treatment of neurogenic disorders: the expert clinician's approach.* Butterworth-Heinemann. Woburn.

Gladis M. G., Gosch E. A., Nicole M. D. & Crits-Christophe P. (1999) Quality of life: Expanding the scope of Clinical Significance *Journal of Consulting & Clinical Psychology* vol. 67, no 3 320-331

Goffman E. (1978) *The Presentation of Self in Everyday Life* Penguin

Goldberg D. (1978) *The General Health Questionnaire* NFER-Nelson Publishing Co ltd.

Goodacre H. & Lockwood S. (1999) Involving patients in clinical research *British Medical Journal* vol. 319, pp724-5

Goodacre H. & Smith R. (1995) The rights of patients in research *British Medical Journal* vol.310, pp1277-8

Goodglass H. & Kaplan E. (1972) *The assessment of Aphasia and related disorders* (revised 1983 and 2000) Lea and Febinger, Philadelphia P A. Henry Kimpton Publishers. London

Gordon J. K. (1997) Measuring outcomes in aphasia: bridging the gap between theory and practice or burning the bridges *Aphasiology* vol. 11, no. 9 pp845-854

Garnde E., Todd C., Barclay S., Farquhar M. (1999) Does hospital at home for palliative care facilitate death at home? Randomised controlled trial *British Medical Journal vol.* 319 pp1472-1475

Grant G. (2001) User involvement, empowerment and research. *Journal of Learning Disabilities* vol. 5, no.2, pp91-95

Gradwell L. (1999) *Review of Disability; Controversial Debates and Psychosocial Perspectives* by Deborah Marks *Community Care* 28/10 to 30/11, p36

Gray D.B., Hendershot G.E. (2000) The ICIDH-2: Developments for a new Era of Outcomes Research *Archives of Physical Medicine and Rehabilitation* vol. 81, suppl. 2, December ppS10-S14

Haase J E, Heiney S P , Ruccione K S & Stutzer C (1999) Research triangulation to derive meaning-based quality of life theory: adolescent resilience model and instrument development *International Journal of Cancer* Supplement vol.12, pp125-131

Hackett M., Duncan J., Anderson C., & Broad J. (2000) Health-related quality of life among long-term survivors of stroke - Results from the Auckland Stroke Study, 1991-1992. *Stroke* vol.31 no.2, pp440-447.

Hall R., Horrocks J., Clamp S. et al (1987) Observer variation in assessment of results of surgery for peptic ulcers. *British Medical Journal* i: pp117-23

Hamilton M. (1960) A rating scale for depression. *Journal of Neurology, Neurosurgery and Psychiatry,* vol.23, pp56-62

Hanley B., Truesday A., King A., Elbourne D. & Chalmers I. (2001) Involving consumers in designing, conducting and interpreting randomized controlled trials: questionnaire study *British Medical Journal* vol. 322, pp519-23

Hanita M. (2000) Self report measures of patient utility: should we trust them? *Journal of Clinical Epidemiology* vol.53, pp469-476

Harrison S. & Mort M. (1998) Which champions, which people? Public and user involvement in health care as a technology of legitimation *Social Policy & Administration* vol. 32, no. 1, pp60-70

Hart C. & Chesson R. (1998) Children as consumers *British Medical Journal* vol. 316, pp1600-1603

Hatton C. (1998) Who's quality of life is it anyway? Some problems with the emerging Quality of life consensus *Mental Retardation* vol. 36, no 23, pp104-115

Hermann H. (1999) Reconciliation and consumer outcomes in mental health services. *Journal of Mental Health* vol. 8, no.2, pp113-116

Herrman M. & Wallesch C.W. (1989) Psychosocial changes and Psychosocial adjustment with chronic and severe non-fluent aphasia *Aphasiology* vol. 3, no. 6, pp513-526

Hetu R., Riverin L., Lalande N., Getty L. & St-Cry C. (1988), Qualitative analysis of the handicap associated with occupational hearing loss *British Journal of Audiology* vol. 22, pp251-264

Hickey E. M. & Bourgeois M.S. (2000) Health-related QoL (HR-QOL) in nursing home residents with dementia: stability and relationships amongst measures. *Aphasiology* vol. 14, no 516, pp669-679

Higginson I. J. (1999) Evidence based practice *British Medical Journal* vol. 319, pp462-463

Higginson I. J. & Carr A. J. (2001) Measuring quality of life: using quality of life measured in the clinical setting. *British Medical Journal* vol. 322, pp1297-1300

Hilari K (2002) Assessing Health-related Quality of life in people with aphasia. PhD thesis. City Univeristy. London

Hilari K., Wiggins R., Roy P., Byng S., Smith S (in press) Predictors of health-related quality of life (HRQL) in people with chronic aphasia

Hogan A. (1999) Carving out a place to act: acquired impairment and contested identity. Chapter 9 in *Disability Discourse* Eds Corker M & French S OUP, Buckingham

Holland A., Frattali C .& Fromm D. (1999) *Communication Activities of Daily Life (CADL-2)* The Psychological Corporation.

Hughes B. & Paterson K. (1997) The social model of disability and the disappearing body: towards a sociology of impairment *Disability and Society*, vol. 12, no. 3 pp325-340

Hugman R. (1991) *Power and the Caring Professions* Basingstoke: Macmillan

Hunt S.M. (1986) Measuring health in clinical care and clinical trials in G. Teeling Smith (ed.) *Measuring health: a practical approach* Chicester: John Wiley

Hunt S.M. (1997) The problem with quality of life *Quality of Life Research* vol. 6, pp205-12

Ignatieff M. (1989) Citizenship and Moral Narcism *Political Quarterly*

Ireland C. & Wotton G. (1996) Time to talk: counseling for people with dysphasia *Disability and Rehabilitation* vol. 18, no. 11, pp585-591

Jacobsen L., Wilkinson C., Pill R., & Hackett P. (1996) Communication between teenagers and British general practitioners: a preliminary study of the teenage perspective. *Ambulatory Child Health* vol. 1, no. 4, pp291-301

Jakubowska D. & Crossley P. (1999) Developing skills in consulting with the public *British Medical Journal Classified* September p2-3

Jenkinson C., Strandling J. & Peterson S. (1998) How should we evaluate health status? A comparison of three methods in patients presenting with obstructive sleep apnoea *Quality of Life Research* vol.7, pp95-100

Jenney M. E. M. & Campbell S. (1997) Measuring Quality of life *Archives of Disorders of Childhood* vol. 77, pp347-350

Jordan L .& Kaiser W. (1996) *Aphasia – a social approach.* London Chapman & Hall

Jørgensen H. S., Reith J., Nakayama H., Kammersgaard L. P., Raaschou O. & Olsen T. S. (1999), What determines good recovery in patients with the most severe strokes *Stroke* vol.30, pp2008-2012

Kagan A. (1995) Revealing the competence of aphasic adults through conversation: a challenge to health professionals. *Topics in Stroke Rehabilitation* vol. 2 no. 1 pp15-28

Kagan A., Winckel J. & Schumway E. (1996) *Pictographic Communication Resources Manual.* North York Centre, Ontario.

Kahn R. & Cannell C. (1957) *The dynamics of interviewing.* New York, John Wiley.

Kaplan E, Goodglass H & Weintraub, S (1976). *The Boston Naming Test.* Boston: Veteran's Administration.

Katschnig H. (1997) How useful is the concept of quality of life in psychiatry? *Current Opinion in Psychiatry* vol. 10, pp337-345

Katz S., Ford A.B., Moskowitz W. et al (1963) Studies of illness in the aged: the index of ADL – a standardized measure of biological and psychosocial function. *Journal of American Medical Association.* vol. 185, pp914-19

Kay J., Lesser R. & Coltheart M. (1997). *The Psycholinguistic Assessment of Language Processing in Aphasia.* Psychology Press. Hove.

Kearney C.A. & McKnight T.J. (1997) preference, choice and persons with disabilities: a synopsis of assessments, interventions and future directions *Clinical Psychological Review* vo.l 17, no.2, pp217-238

Kerruish A. (1995) Basic Human Values: The Ethos for Methodology *Journal of Community & Applied Social Psychology* vol. 5, pp121-143

Kertesz A (1982) *The Western Aphasia Battery* Grune and Stratton. New York

King P. (1992) *Talking pictures: triggered pictures to help children talk about themselves.* London: British Association for Adoption and Fostering.

Kitchin R. (2000) The researched opinions on researched: disabled people and disabled research *Disability & Society* vol 15, no 1 pp25-47

Kitzinger J. (1995) Introducing focus groups *British Medical Journal* vol.311, pp299-302

Kleinman A. (1988) The Illness narratives: suffering, healing and the human condition Basic books USA

Laman H. & Lankhorst G. J. (1994).Subjective weighting of disability: an approach to quality of life assessment in rehabilitation *Disability and Rehabilitation* vol 16, no. 4 pp198-204

LaPointe L. L. & Horner J. (1979) *Reading Comprehension Battery for Aphasia* . C C Publications Inc. Oregon.

Le Dorze G. & Brassard C. (1995) A description of the consequences of aphasia on aphasic persons and their relatives and friends, based on the WHO model of chronic diseases *Aphasiology* vol.9 no.3, pp239-255

Laslett B. & Ropoport R. (1975) Collaborative interviewing and interactive research *Journal of Marriage and the Family* vol. 37, pp968-977

Lawrence L. & Christie D. (1979) Quality of life after stroke: a three year follow up *Age and Aging* vol.8, pp167-172

Lawton M.P. (1975) Philadelphia Geriatric Centre Morale Scale: a revision. *Journal of Gerontology* vol.30, pp85-89

Le Dorze G. & Brassard C. (1995) A description of the consequences of aphasia on aphasic persons and their relatives and friends, based on the World Health Organisation model of chronic diseases *Aphasiology* vol. 9, no 3, pp239-255

Leplège A. & Hunt S. (1997) The problem with quality of life in medicine. *Journal of the American Medical Association* vol. 278, pp47-50

Liberati A. (1997) Consumer participation in research and health care *British Medical Journal* vol. 315, p499

Likert R.A. (1952) A technique for the development of attitude scales. *Educational and Psychological Measurement.* Vol. 12, pp313-15

Lindley R. I., Waddell F., Livingstone M., Sandercock P., Dennis M. S., Slattery J., Smith B. & Warlow C. (1994) Can simple questions assess outcome after stroke? *Cerebrovascular Disease* vol.4, pp314-324

Lipowski Z. J. (1969) Psychological aspects of disease. *Annuals of Internal Medicine* vol 71, pp1197-1206

Little P, Everitt H, Willaimson I, Warner G, Moore M, Gould C, Ferrier K & Payne S (2001a.) Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *British Medical Journal* vol. 323 pp908-911.

Llewellyn A & Hogan K. (2000) The Use and Abuse of Models of Disability *Disability and Society* vol. 15 no. 1 pp157-165

Lofgren B., Gustafson Y. & Nyberg L. (1999) Psychological well-being 3 years after severe stroke *Stroke* vol.30, pp567-572

Lomas J., Pickard L., Bester S., Elbard H., Finlayson A., & Zoghaib C. (1989) The communicative effectiveness index: development and psychometric evaluation of a functional communication measure for adult aphasia *Speech and Hearing Disorders* vol 54, pp113-124

Lyon J.G., Cariski D., Keisler L., Rosenbeck J., Levine R., Kumpala J., Ryff C., Coyne S., & Blanc M. (1997) Communication partners: enhancing participation in life and communication for adults with aphasia in natural settings. *Aphasiology* vol. 117, pp693-708

Lyon J.G. (1999) A commentary on qualitative research in aphasia *Aphasiology* vol. 13, no.s 9-11 pp689-690

Macaulay A., Commanda L., Freeman W., Gibson N., McCabe M. & Robbins C. et al (1999) Participatory research maximizes community and lay involvement : North American Primary Care Research Group. *British Medical Journal* vol.319, pp774-778

Mac Duff C. (2000) Respondent generated quality of life measures: useful tools for nursing or more fool's gold? *Journal of Advanced Nursing* vol. 32 (2) pp375-382

Mac Duff C. & Russell E. (1998) The problem of measuring change in individual quality of life health-related quality of life by postal questionnaire: use of the patient generated index in a disabled population. *Quality of Life Research* vol.7, pp761-769

Maclean N., Pound P., Wolfe C. & Rudd A. (2000) Qualitative analysis if stroke patients motivation for rehabilitation *British Medical Journal* vol 321 no.28 pp1051-1054

Mahoney F. & Barthel D. (1965) Functional Evaluation: the Bartel Index *Maryland State Medical Journal* vol.

14, pp61-5

Manochiopinig S., Sheard C. & Reed V. A. (1992), Pragmatic assessment in adult aphasia: a clinical review *Aphasiology* vol. 2, no. 6 pp519-533

Marshall C. & Rossman G. B. (1989) Designing qualitative research Sage publications

Mason P. (1992) The representation of disabled people in policy and planning decisions. *Contact* (Journal of the Royal Association for Disability and Rehabilitation) vol. 72, pp44-5

Mays N. & Pope C. (1995a) Rigour and qualitative research *British Medical Journal*, 311, 109-12

McGee H. M .(1996) Ethics and the assessment of quality of life *The Irish Journal of Psychology* vol.17, no.2, pp156-177

McHorney C.A. (1999) Health Status Assessment Methods for Adults: Past accomplishments and future challenges *Annual Review of Public Health* vol. 20, pp309-335

McHorney C.A. (1996) Measuring health status in the elderly with the SF-36 Health Survey: Practical and methodological issues. *The Gerontologist* vol. 36, no. 5, pp571-583.

McKenna P. & Warrington E. J. (1983) *"Graded Naming Test"* NFER-Nelson

McWinney I.R., Bass M.J. & Donner A (1994) Evaluation of a palliative care service: problems and pitfalls *British Medical Journal* vol. 309, pp1340-1352

Meyers A.R. & Andresen E.M. (2000) Enabling our instruments: Accommodation, Universal Design, and Access to Participation in Research *Archives of Physical Medicine and Rehabilitation* Vol. 81, suppl 2 ppS5-S 9

Mohay H. (1997) Interviewing children and adolescents. In : *Medical Consultation Skills: Behavioural and Interpersonal Dimensions of Health Care* (eds. M. Saunders, C. Mitchell & G. Bryne), pp131-150. Addison-Wesley, Melbourne.

Moore M., Beazley S. & Maelzer J. (1998) *Researching Disability Issues* Open University Press

Morris J. (1991) *Pride Against Prejudice: transforming Attitudes to Disability.* The Women's Press. London

Morris J. (1992) Personal and Political: a feminist perspective on researching physical disability *Disability, Handicap & Society* vol. 7, no 2, 157-166

Morris J. (1993) Gender and disability, In Swain J, Finkelstein V, French S & Oliver M (1993) *Disabling Barriers - Enabling Environments* Sage publications

Mozley C. G., Hexley P., Sutcliffe C., Bagley H., Burns A., Challis D. & Cardingley L. (1999) 'Not knowing where I am doesn't mean I don't know what I like': cognitive impairment and quality of life responses in elderly people *International Journal of Geriatrics Psychiatry.* vol. 14, pp776-783

Muldoon M. F., Barger S. D., Flory J. D. & Manuck S. B. (1998) What are quality of life measures measuring *British Medical Journal* vol.316, pp542-545

Müller D., Code C. & Mugford J. (1983) Predicting psychosocial adjustment in aphasia *British Journal of Communication Disorders* vol. 18, no.1, pp23-9

Nelson E. C., Landgraf J. M., Hays R. D., Wasson J. H. & Kirk J. W. (1990) The Functional Status of Patients: How can it be measured in physician's offices? *Medical Care* Dec, vol. 28, no 12

Nelson E. C., Wasson J. Kirk J., Keller A., Clark D., Dietrich A., Stewart A. & Zubkoff (1987) Assessment of functional routine in clinical practice; Description of the COOP chart method and preliminary findings. *Journal of Chronic Disability* vol. 40, suppl. 1, pp55S-63S

Nettleton S. (1995) *The sociology of Health and Illness* Polity Press, Cambridge UK

Nickels L.A. & Howard D. (1995) Aphasic naming: what matters? *Neuropsychologia*, vol. 33, pp1281-1303.

Nieme M.-L., Laaksonen R., Kotila M. & Waltimo O. (1988) Quality of life four years after stroke *Stroke* vol. 19, no, 9, pp1101-1106

Northway R. (2000) Ending Participatory Research? *Journal of Learning Disabilities* vol. 4, no.1, pp27-36

Notting Hill Housing Trust (1994) *Supported housing tenant's survey 1994.* London, Notting Hill Housing Trust.

Nunnally J. (1970) *Introduction to psychological measurement.* McGraw-Hill, New York

Oblowitz N., Green L. & Heynes DeV. (1991) A Self Concept Scale for the hearing impaired. *The Volta Review* vol. 93 pp19-29

O' Boyle C., McGee H, Hickey A. et al (1992) Individual quality of life in patients undergoing hip replacement. *Lancet.* Vol. 339, pp1088-91

O'Hanlon D.H., Harkin M., Karat D., Sergeant T., Hayes N. & Griffin S.M. (1995) Quality of life assessments in patients undergoing treatment for oesophageal carcinoma. *British Journal of Surgery* vol. 82, pp1682-5

Oliver M. (1990) *The politics of disablement.* Macmillan, London.

Oliver M. (1992) Changing the social relations of research production? *Disability, Handicap and Society* vol. 7, no.2 101-114

Oliver M. (1996) Understanding Disability: From theory to practice MacMillan Press Basingstoke

Oliver S. (1995) How can health service users contribute to the NHS research and development programme? *British Medical Journal* vol.310, pp1318-20

Oxenham D., Sheard C. & Adams R. (1995) Comparison of clinician and spouse perceptions of the handicap of aphasia: everybody understands understanding. *Aphasiology*, vol. 9, no. 5, pp477-493

Parr S. (1994) Coping with aphasia: conversations with 20 aphasic people *Aphasiology* vol. 8, no. 5, pp457-466

Parr S. (1995) Everyday reading and writing in aphasia: role change and the influence of pre-morbid literacy practice. *Aphasiology,* vol. 9, no. 3, pp223-238

Parr S., Byng S., Gilpin S. with Ireland C. (1997) *Talking about aphasia* Open University Press

Parr S., Pound C. & Marshall J. (1995) A handful of power for aphasic people *College of Speech and Language Therapists Bulletin* May

Paterson C. (1996) Measuring outcomes in primary care: a patient generated measure, MYMOP, compared with the SF-36 health survey *British Medical Journal* vol. 312 pp1016-1020

Patterson K. & Hughes B. (1999) Disability Studies and phenomenology: the carnal politics of everyday life *Disability and Society,* vol. 14, no.5, p597-610

Patton M.Q. (1990) *Qualitative Evaluation and Research Methods* London: Sage

Pedersen P. M., Vinter K., & Olsen T. S. (2001) The Communicative Effectiveness Index: Psychometric properties of a Danish adaptation *Aphasiology* vol. 15, no 8 pp787-802

Penn C Milner K, Fridjon P. (1992) The Communicative Effectiveness Index: its use with South African Stroke Patients. *Journal of Communication Disorders* vol. 39, pp74-82

Penn C. (1998) Clinician-researcher dilemmas: Comment on supported conversation for adults with aphasia. Clinical Forum. *Aphasiology* vol. 12, pp839-843

Petheram B. & Parr S. (1998) Diversity in aphasiology: crisis or increasing competence? *Aphasiology* vol. 12, no. 6, pp435-487

Phillips M. J. (1990) Damaged goods: oral narratives of the experience of disability in American culture *Social Science Medicine* vol.30, no.8, pp849-857

Pickard S., Johnson J., Penn A. et al. (1999) Replicability of SF-36 summary scores by the SF-12 in stroke patients. *Stroke* vol. 30 no.6, pp1213-1217

Pilgrim D. & Waldron L. (1998) User involvement in mental health service development: How far can it go? *Journal of Mental Health* vol. 7, no. 1, pp95-104

Pollock C., Freemantle N., Sheldon T., Song F. & Mason J. M. (1993) Methodological difficulties in rehabilitation research. *Clinical Rehabilitation*, vol.7, pp63-72

Porch B.E. (1967) *Porch Index of Communicative Abilities: Administration and development (vol 1.).* Palo Alto, Calif.: Consulting Psychologists Press.

Pope C. & Mays N. (1995) Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health service research *British Medical Journal,* vol.311 pp42-5

Pound C. (1996) Pound steady as City banks on change *Royal College of Speech and Language Therapists Bulletin* 532. pp12-13

Pound C., Parr., Lindsay J., & Woolf C. (2000) Beyond Aphasia: Therapy from living with communication disability. Winslow Press. Buckingham

Pound C. (2000) FCTP: Functional Communication Therapy Planner. Book review Aphasiology vol. 11 pp1146-7

Priestley M. (1997) Whose research? A personal audit. Chapter in C. Barnes & G. Mercer *Doing Disability Research* The Disability Press. Leeds.

Rapley M. & Antaki C. (1996) A conversational analysis of the 'acquiescence' of people with learning difficulties. *Journal of Community an Applied Social Psychology* vol.6, pp371-391

Rhodes P., Nocon., Wright J. & Harrison S. (2001) Involving patients in research: setting up a service users' advisory group. *Journal of Management in Medicine* vol. 15, no.2, pp167-171

Richards T. (1998) Partnership with Patients *British Medical Journal* vol. 316, pp85-6

Riddell S., Wilkinson H. & Baron S. (1998) From emancipatory research to focus groups: people with learning difficulties and the research process, in P. Clough & L Barton (Eds) *Articulating the difficulty: research voices in inclusive education* (London, Paul Chapman Publishing)

Ross K.E. & Wertz R.T (2002) Relationships between language-based disability and quality of life in chronically aphasic adults. *Aphasiology* vol. 16, no. 8, pp791-800

Rothwell P.M., McDowell Z., Wong C.K. & Dorman P.J. (1997) Doctors and patients don't agree: cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis *British Medical Journal* vol. 314, p1580

Rowan J. (1981) A dialectical paradigm for research. In Reason P & Rowan J (Eds) *Human Inquiry; a sourcebook of a new paradigm research* (Chichester, John Wiley)

Ruhl C.M., Gleich L.L., & Gluckman J.L.(1997) Survival, function and quality of life after total glossectomy *The Laryngoscope vol 107,* pp1316-21

Ruta D.A. & Garratt A.M. (1996) Reliability of such instruments needs to be proved letter in *British Medical Journal* vol.313, pp626-627

Ruta D.A., Garratt A.M., Leng M., Russell I.T & Mac Donald L. (1994) A new approach to the management of Quality of Life: the patient generated index. *Medical Care*. vol 32, no. 11 pp1109-1126

Sacchett C. & Marshall J. (1992) Functional assessment of communication: implications for the rehabilitation of aphasic people: reply to Carol Frattali *Aphasiology*, vol.6, no.1, pp95-100

Salisbury C. & Bosanquet N. (2000) Assessing palliative care is difficult. *British Medical Journal* vol. 320 p942

Sarno J.E., Sarno M.T. & Levita E. (1973) the Functional Life Scale *Archives of Physical and Rehabilitation Medicine* vol.54, pp214-220

Sarno M. T. (1963) *The Functional Communication Profile*: New York University Press

Sarno M. T. (1997) Quality of life in aphasia in the first post-stroke year *Aphasiology*, vol 1, no 7, 665-679

Scandinavian Stroke Group (1985) Multi-centre trail of haemodilution in ischaemic stroke: background and study protocol. *Stroke:* vol. 16, pp885-890

Schegloff (1990) *Born Talking: Episode IV* [video series written & presented by Jonathon Miller. Produced by John McGreevy Productions and Primedia Productions Ltd. In association with the BBC and TV Ontario]

Schlaff C. (1993) From dependency to self-advocacy: Redefining disability *The American Journal of Occupational Therapy* vol. 47, number 10 p 943-948

Scullion P. (1995) Disability research and health care professionals: some issues for debate *British Journal of Therapy and Rehabilitation* vol.2, no.6., pp318-322

Schwartz R. G. (1983) Development and validation of the Geriatric Evaluation of Relative's Rating Instrument (GERRI). *Psychology Reports* 53; 479-488

Schuell H (1965) *Minnesota Test for Differential Diagnosis of Aphasia* SuperDuper Inc. Greenville, South Carolina.

Senior P. A. & Bhopal R. (1994) Ethnicity as a variable in epidemiological research *BMJ* vol. 309 pp327-330

Shepherd D. (2002) Effect of patient centredness and positive approach Letter in *British Medical Journal* vol. 324, p543

Shewan C.M. & Cameron H. (1984) Communication and related problems as perceived by the aphasic individuals and their spouses *Journal of Communication Disorders*, vol. 17, pp175-187

Siegal M., Eiser C. & Patty J. (1990) A re-examination of children's perceptions of contagion. *Psychology and Health* vol. 4, pp156-166

Simmons-Mackie N. & Damico J. S. (1996) Accounting for handicaps in aphasia: communicative assessment from an authentic social perspective *Disability and rehabilitation,* vol.18, no. 11, pp40-549

Simmons-Mackie N. & Damico J. S. (1999) Qualitative methods in aphasia research: ethnography *Aphasiology* vol. 13, no. 9-11, pp681-687

Simmons-Mackie N (2000) Social Approaches to the management of aphasia in Worral & Frattali *Functional Communication*

Skinner C., Wirz S., Thompson I. & Davidson J. (1984) *Edinburgh Functional Communication Profile.* Winslow Press. Chesterfield. UK

Slevin M.L., Plant H., Lynch D., Drinkwater J. & Gregory W.M. (1988) Who should measure quality of life, the doctor or the patient? *British Journal of Cancer* vol. 57, 109-112

Smyth R. L. (2001) Research with children *British Medical Journal* vol. 322, pp1377-1378

Sprangers M.& Aaronson N.(1992) The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: a review *Journal of Clinical Epidemiology* vol. 45, no.7, pp743-760

Starkstien S. & Robinson R. G. (1988) Aphasia and depression *Aphasiology*, vol.2, no.1, pp1-20

Stewart A. L. & Napoles-Springer A. (2000) Health-related quality of life assessments in diverse population groups in the US *Medical Care* vol 38, no.9 supp II pt II pp102 – II124

Stewart M. (2001) Towards a global definition of patient centred care *British Medical Journal* vol. 322, pp444-5

Stineman M., Escare J., Goin J. et al (1994) A case mix classification system for medical rehabilitation . *Medical Care* vol. 32. pp366-79

Streiner D. L.& Norman G. R. (1995) *Health Measurement Scales: a practical guide to their development and use.* Oxford Medical Publications. Oxford

Stuart O. (1993) Double oppression: an appropriate starting-point? In Swain J., Finkelstein V., French S. & Oliver M. (1993) *Disabling Barriers - Enabling Environments* Sage publications

Sutcliffe L. M. & Lincoln N. B. (1998) The assessment of depression in aphasic stroke patients: the development of the stroke Aphasic Depression Questionnaire *Clinical rehabilitation* vol. 12, pp06-513

Swain J, Finkelstien V, French S & Oliver M (1993) *Disabling barriers - Enabling environments* Sage publications.

Swain J. & French S. (2000) Towards an affirmation Model of Disability *Disability & Society* vol. 15, no. 4, pp569-582

Swinburn K., Porter G. & Howard D (in press) *The Comprehensive Aphasia Test* Psychology Press. Hove

Tallon D. & Chard J. (2000) Consumer involvment in research is essential *British Medical Journal* vol. 320, p380

Teno J.M., McKniff K. & Lynn J. (2000) Measuring Quality of Medical Care for Dying Persons and Their Families: Preliminary Suggestions for Accountability. In *Annual Review of Gerontology & Geriatrics.* vol 20. pp97-119.Edited by Lawton P. Springer Publishing Company, New York,

Thelander M.J., Hoen B. & Worsely J. (1994) York-Durham Aphasia Centre: Report on the Evaluation of Effectiveness of a Community Program for Aphasic Adults. Toronto: Coopershill Consulting.

Thompson C. K. (1998) Treating Sentence Production in agrammatic aphasia chapter in *Approaches to the Treatment of Aphasia* N. Helm-Estabrooks & A Holland (eds) Singular Publishing Group, Inc. San Diego.

Tyne A. (1994) Taking responsibility and giving power *Disability and Society,* vol.9, no.2, pp249-254

Van der Gaag, A., Smith L., Mowles, C., Davis, S., Moss, B. (2002) *'An evaluation of Connect therapy and support services'* Presentation given at user involvement study day

Wade D (1992) *Measurement in Neurological Rehabilitation* Oxford: Oxford University Press

Währborg P. (1991a) The assessment of emotional and psychosocial disorders in aphasic individuals and their families Chapter 5 in *Assessment and management of emotional and psychosocial reactions to brain damage and aphasia* Far Communications Ltd. Great Britain

Walmsley J. (2001) Normalisation, emancipatory research and inclusive research in learning disability *Disability & Society* vol. 16, no 2, p187-205

Ware J.E. (1993) Measuring Patients views: The optimum outcome measure. *British Medical Journal.* vol. 306, pp1429-30

Webb C.R., Wrigley J.M., Yoels W.C., Fine P.R. (1995) Explaining quality-of-life for persons with traumatic brain injuries 2 years after injury. *Arch Phys Med Rehabil*, vol. 76, pp1113-9

Whurr R. (1996), *The Aphasia Test,* Whurr Publishers, London

Williams B. (1994) Patient Satisfaction: A valid concept? *Social Science and Medicine* vol. 1, no. 4, pp509-16

Williams J. I. (1998) Time, space and motion: the unanswered challenges in measuring Quality of life *Canadian Journal of nursing research,* vol. 30, no.2, pp119-124

Williams J. I. (1999) The unanswered challenges in measuring Quality of life *Canadian J of Nursing Research*, vol. 30, no.4 pp295-298

Williams J. I. (2000) Ready, set, stop. Reflections on assessing quality of life and the WHOQOL-100 US version *Journal of Clinical Epidemiology* vol. 53, pp13-17

Williams L. S., Weinberger M., Harris L. & Biller J. (1999a) Measuring the quality of life in a way that is meaningful to stroke patients *Neurology* vol. 53 pp1835-1850

Wood-Dauphinee S., Opzoomer M.A., Williams J.I., Marchand B. & Spitzer W. O. (1988) Assessment of global function: the Reintegration into Normal Life Index *Archives of Physical Rehabilitation Medicine* 69; 583-590

Woolley M (1993) Acquiring hearing loss: acquired oppression In *Disabling Barriers: Enabling environments* (1993) eds Swain J, Finkelstein V, French S & Oliver M Sage publications

Worrall L. (1999) Functional communication therapy planner. Oxon, UK: Winslow Press.

Worrall L. (2001). The social approach: another new fashion in speech-language pathology? *Advances in Speech-Language Pathology* vol.3 no.1 pp51–54.

Worrall L. & Cruice M. (2000) Book review VASES: Visual Analogue Self-Esteem Scale. *Aphasiology* vol. 1, pp1153-4

Worrall, L. & Frattali, C. (Eds) (2000) Neurogenic Communication Disorders: A Functional Approach. Thieme: NY.

World Health Organization (1980) International Classification of Impairments, Disabilities & Handicaps World Health Organization. Geneva

World Health Organization (1994) Quality of life assessment: an annotated bibliography, Geneva World Health Organization publications.

World Health Organization group (1998a) The World Health Organization quality of life group (WHOQOL): Development and general psychometric properties. *Social Science Medicine* vol. 46, no 12 p1569-1585

World Health Organization group (1998b) Development of the World Health Organization WHOQOL-BREF quality of life assessment: *Psychological Medicine* vol. 28, pp551-588

World Health Organisation (2000) International classification of functioning, disability and health World Health Organization. Geneva

Wu A. W. & Rubin H. R. (1992) Measuring health status and quality of life in HIV and aids *Psychology and Health* vol. 6, pp251-264

Young J. & Storer J (2002) Speaking the same language Royal College of Speech and Language Therapists *Bulletin* issue 603. pp11-12

Zarb G. (1992) On the road to Damascus: first steps towards changing the relations of disability research production. *Disability, Handicap & Society*, vol.7, no.2, pp125-138

Zarb G. (1993) The dual experience of ageing with a disability Chapter in Swain J, Finkelstien V, French S & Oliver M (1993) *Disabling barriers - Enabling environments* Sage publications

Zarit S.H., Reever K.E. & Bach-Peterson J. (1980) Relatives of the Impaired Elderly; correlates of feelings of burden. *Gerontologist* Vol. 20, pp649-655

Zigmund A.& Snaith R. (1983) The Hospital Anxiety and Depression Scale *Acta Psychiatrica Scandanavia*, 67,361-370

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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-Nijmegan 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 Esteen 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**
Stage 1 Indirect user involvement Phase 1	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
Phase 2	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
Phase 3	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	
Stage 2	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 *comprehension* 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 *talking* 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 *read*.
Q 13-16	Common literacy-based activities, which vary in the amount and complexity of the text to be *written*.
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 DQ 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

<u>Changes between the DQ drafts 3 & 4</u>

(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 *who* 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 *who* 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 *reading* 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 *who* 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, (*reiterate an example of where they have difficulty*) 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 Profile[1] (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).

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[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 *TALKING (etc.)* 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 *frustrated, sad, angry?*	
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 added	Q37		Do you have people who are important to you?	Reduce the negativity of the tool.
Acceptability	Un-rated item added	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 *picture***	**Advisory panel comments relating to *wording***	**Advisory panel comments relating to *concept***	**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**)

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				
	1anxiety 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 group of friends?	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 stranger, someone you don't know?	Reordered on advice of panel, & in line with endorsement frequencies
Acceptability.	Reworded item.	Talk **if you** are stressed?	Talk under pressure?	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 *each* modality (talking, reading etc.) on participation.
Acceptability. Accessibility.	Items moved to form a new section. Section expanded as detailed below (○)	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 *each* modality (talking, reading etc.)
Acceptability	New section introduced.		Express yourself with the person closest to you	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 group of friends	See above

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

Acceptability. Accessibility.	Expanded external influences section – new item.		What THINGS helps?	See above
Acceptability. Accessibility.	Expanded external influences section – new item.		WHO makes it harder?'	See above
Acceptability. Accessibility.	Expanded external influences section – new item.		WHAT makes it harder?	See above
Accessibility.	Changes to manner of presentation. Reworded on advice from panel.		Do any of these show living with aphasia makes you feel?	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 less confident?	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 less in control?	Stress that control relates to life situations NOT communication ability.
Acceptability Accessibility	New concept on advice from panel.		Do you feel able?	Positive expression of construct of competence. Worded on advice from panel.
Acceptability. Accessibility.	Original concept reintroduced. Reworded on advice from panel.		Does living with aphasia make you isolated?	
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 embarrassed?	Focus on emotional consequence of misperceived competence.
	New concept introduced and worded on advice from panel.		Do you feel valued?	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 angry?	Reduce causal link between impairment and disability.
Accessibility. Acceptability.		Does your communication make you **frustrated?**	Does living with aphasia make you frustrated?	Reduce causal link between impairment and disability.
Accessibility. Acceptability.	New concept introduced and worded on advice from panel.		Do you feel determined?	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 unhappy?	
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 worried? (asked once only)	Concept confined to single question only.
Acceptability.	New concept introduced and worded on advice from panel.		Do you feel content?	Positive expression of construct of contentment
Acceptability.	New concept introduced and worded on advice from panel.		What is fun for you?	Enabling expression of positive aspects of current life
Acceptability	New concept introduced and worded on advice from panel.		Is there anything else that is important 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 anything you would like to say about your life 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**
PEOPLE that HELP or HINDER – talking/understanding	
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
THINGS that HELP– talking/understanding	
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
THINGS that HINDER - talking /understanding	
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
Things that HELP - reading/writing	
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
Things that HINDER- reading/writing	
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 ***
Less control	Interviews	Helpless, incapable, dependent, being trapped
Less confidence	Interviews/DQ	Lost confidence
Embarrassed	Interviews/?DQ	Embarrassed, (?self esteem)
Isolated	Interviews/DQ	Isolated, excluded, being ignored, unloved, rejected, neglected
Angry	Interviews/DQ	Angry, mad
Frustrated	Interviews/DQ	Frustrated
Sadness	Interviews/DQ	Sad, depressed, unhappy, down a bit
Anxiety	Interviews/DQ	Anxious, frightened, worried
Able	Interviews/?DQ	Can't do things, incompetent, a nutter, not being normal (?self esteem), stupid
Valued	Interviews/?DQ	Lack of respect, being small, lower down (?self esteem)
Determined	Interviews	Determined
Contented	Advisory panel	Sense of loss, being whole
Independent	Advisory panel	
Uptight	Interviews	Uptight
Shocked	Interviews	Shocked
Tired	Interviews	Tired, exhausted, knackered
Proud	Interviews	Proud
Hopeless	Interviews/DQ	Hopeless
Unfair	Interviews/DQ	Unfair
Optimistic	Interviews/DQ	Pessimistic, optimistic
Satisfied with life	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)**
CONTENT and overall perception:	Content was relevant Found it very helpful Thought it was useful Identified with the emotions illustrated She seemed to enjoy it, in that she was engaged and keen to respond Very thought-provoking – enabled her to discuss concerns re: future, think in structured way about impact of aphasia in different settings (tumour) She liked the fact that it addressed areas of her life that weren't usually addressed Felt it really focussed on her as a person and overtly respected her point of view Put (us) on the right track Commented that some situations were not appropriate to him (didn't ever do the shopping or go to the bank) Some sections were positive using encouragement and feedback e.g. domains 1-20 Others were negative e.g. barriers; emotional consequences, lifestyle/particaption (dependent on

	mood - patient's whole performance in therapy changes, depends on whether feeling positive or negative. Overall a mixed picture. Thought was helpful to talk about emotions Both liked the emphasis on THEIR perspective and that it was respectful of them Brought up fact that he did not think his partner always understood the difficulties he experienced (useful) * some situations were variable e.g. talking with a group of friends could be easier but sometimes not
FORMAT: - general	Felt pictures were useful – easy to identify with Seemed easy to do Happy to comply but because of expressive difficulties unable to comment about procedure but seemed to find it helpful Both liked the pictures Both liked the no 'right/wrong' aspect Liked the pictures –very helpful Scales useful Commented that some situations the rating varied *Emotional scale – more confusing *Not prepared to be pigeon-holed, especially in the emotions section * emotions scale complicated – took time to accept it 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 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).
- length:	Good * found it exhausting (this person had an untreatable brain tumour) Not too long

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: - Appropriate (those *ed rated the content as appropriate but added comments that suggested limitations) - NOT appropriate	20 3
FORMAT: - Easy to use (those asterisked rated the format as easy to use but added comments that suggest limitations) - 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

	shingles Chose not to do with people who had aggressive high grade tumours currently undergoing treatment In-patients – too soon after CVA e.g. poor attention, distress 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.
CONTENT: - general	Some situations he avoids or has never done Generally very good Participation section was really important section for him Content good and relevant as shown by strong reaction to some of the pictures and questions Content was appropriate Content relevant with the opportunity for him to elaborate *Opens up several other issues for client that SLT not necessarily able to deal with Pictures were very appropriate – identified well with them and also the 'what helps'. Felt pictures were useful – easy to identify with Felt all content relevant Felt participation section was over too quickly and was rather generalised 'worried' and 'content' queried by both participants One client commented that single word and headline reading varied - sometime she could and sometimes she couldn't Mostly apart from emotional factors; patient insight heightened by the negative changes Items were relevant but perhaps need to choose/omit some if patient becomes anxious The items were relevant to all situations that an aphasic person may experience post stroke
- aphasia separate from other areas:	Looking to the future brought up general issues i.e. the uncertainty she was feeling about future strokes. Still participating actively in daily life however emotional issues have greatest impact *Found it difficult to explain looking only at aphasia and not mobility problems in case of impact on participation.

	* 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) Some areas not relevant because housebound and physical impairment having more impact on daily life.
FORMAT: - general	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.
- Structure:	*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 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
- Length:	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

	Very lengthy to do in one session – might be tempted to skip the discussion which we felt was very very useful (inoperable tumour) Took 1 and ½ hours – one session (inoperable tumour) Exhausting but liked the fact that it enabled him to give HIS perspective – he surprised his wife (positive) (brain tumour) Do sections only of the CDP rather than in entirety Both clients had mild expressive aphasia and it took 2-3 sessions to complete Took time to elicit the scores – undertaken over 2-3 sessions – shorter format would be helpful
- Script/scoresheet:	Further instructions would have been good for scoring Once mastered the script relatively straightforward Easy to use though verbatim text could be improved with boxes, upper case etc. * 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 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 Scoring was OK once patient was focused
- Accessible:	Felt would be able to use with all abilities Emotional scales took time and practice – definitely needed repetition and gesture *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) Unable to convey difference between talking and expressing your self (memory problems) Couldn't understand the 'able' picture Accessible but a bit fiddly with using different pages.
- Acceptable:	Less 'flow' in barriers section – not all situations applied

	*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) Wanted to be placed between scale points
- General comments:	*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) People with memory problems = recapping on previous sessions very difficult if done over no. of sessions
RELEVANT TO CLINICAL PRACTICE?	I think you have devised a very useful and well thought out instrument. The comments are mere suggestions 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 It enabled us to discuss some issues more and highlight others e.g. confidence was a bigger issue than I had realised. Nice comparison between their in-patient stage…there can be quite a shift and that's implied but you can reflect that 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 It has lead on to further discussion and moving away from impairment towards living with aphasia It was a gentleman I know quite well but there were still a few surprises Both felt it was directly relevant to their daily lives/living with aphasia Highlighted issues within their support/family network and their individual coping skills 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 Information useful, provided additional information that helped in subsequent sessions Definitely guided management as I knew what the main concerns were and could use that in treatment

	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)
INFORMING PRACTITIONER?	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

	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**

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 have 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 than 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 - 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%
Disability associated with comprehension	**.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**	**items**
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

LIST OF APPENDICES

(All appear sequentially)

CHAPTER 2

CHAPTER 4

CHAPTER 5

CHAPTER 6

Appendix 2.1

The Comprehensive Aphasia Test

Table of contents

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 (5) < -	------------------------- > (1)	No None

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 √

Appendix 2.4

Example of a DQ help-sheet introduced (page 1)

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

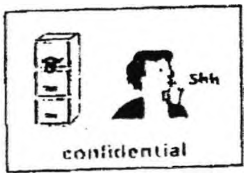
It **won't affect** my **speech therapy**.

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. *talk to **the person closest to you (use person's name)*** **Rating:**
Comments **0 1 2 3 4**

2. *talk to **someone you don't know*** **Rating:**
Comments **0 1 2 3 4**

3. *talk to **3 or 4 family or friends*** **Rating:**
Comments **0 1 2 3 4**

4. *talk **if you are stressed**"* **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?* **Rating:**
Comments **0 1 2 3 4**

7.(*S) *does that **worry you** ?* **Rating:**
Comments **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)*** **Rating:**
Comments **0 1 2 3 4**

9. *understand **someone you don't know*** **Rating:**
Comments **0 1 2 3 4**

10. *understand **3 or 4 family or friends*** **Rating:**
Comments **0 1 2 3 4**

11. *understand **when you're under pressure*** **Rating:**
Comments **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?* **Rating:**
Comments **0 1 2 3 4**

14.(*S) *does that **worry you?*** **Rating:**
Comments **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* **Rating:**
Comments **0 1 2 3 4**

16. *read and follow **a newspaper headline*** **Rating:**
Comments **0 1 2 3 4**

17. *read and follow **piece in a paper*** **Rating:**
Comments **0 1 2 3 4**

18. *read and follow **an official letter*** **Rating:**
Comments **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?* **Rating:**
Comments **0 1 2 3 4**

21(*S) *does that **worry you** ?* **Rating:**
Comments **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*** **Rating:**
Comments **0 1 2 3 4**

23. *spell **other single words** like a shopping list* **Rating:**
Comments **0 1 2 3 4**

24. *write a **letter to a friend*** **Rating:**
Comments **0 1 2 3 4**

25. *write an **official letter*** **Rating:**
Comments **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?* **Rating:**
Comments **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?"
  - physically
  - communication
  - reading & writing
  - speech
  - understanding,
  - 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:

- other people's reactions
  - in hospital,
  - when discharged
- 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:

- friends
- family
- social life
- hobbies
- work
- how you felt about yourself
- other people's reactions
- emotions
- ?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

- family
- friends
- environment
- attitudes
- mood
- therapy
- anything about you as a person that helped
- anything in the past
- specific things that you do when you can’t find a word/follow what
- 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?”

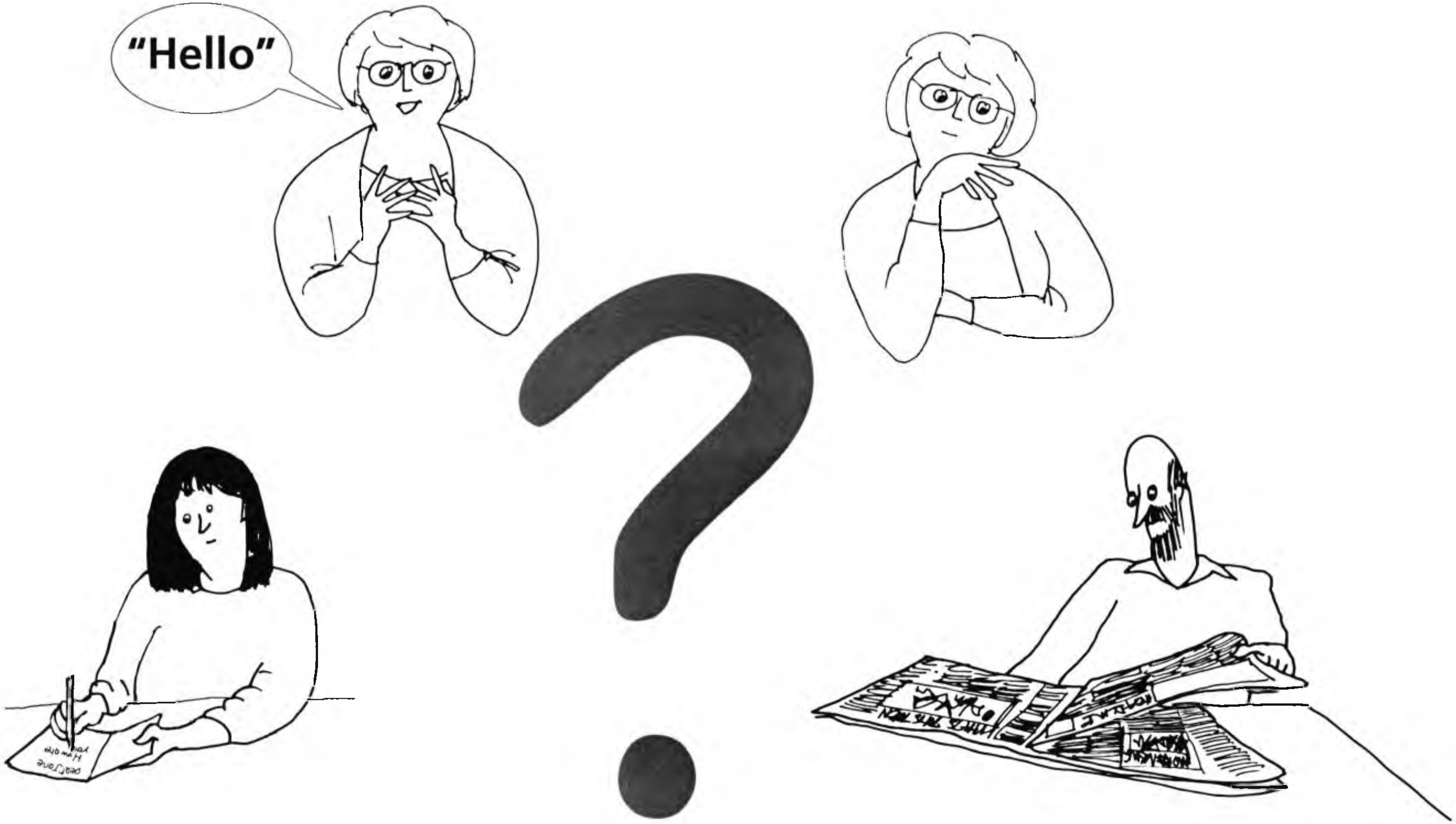
Thank yous

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

Communication Disability Profile

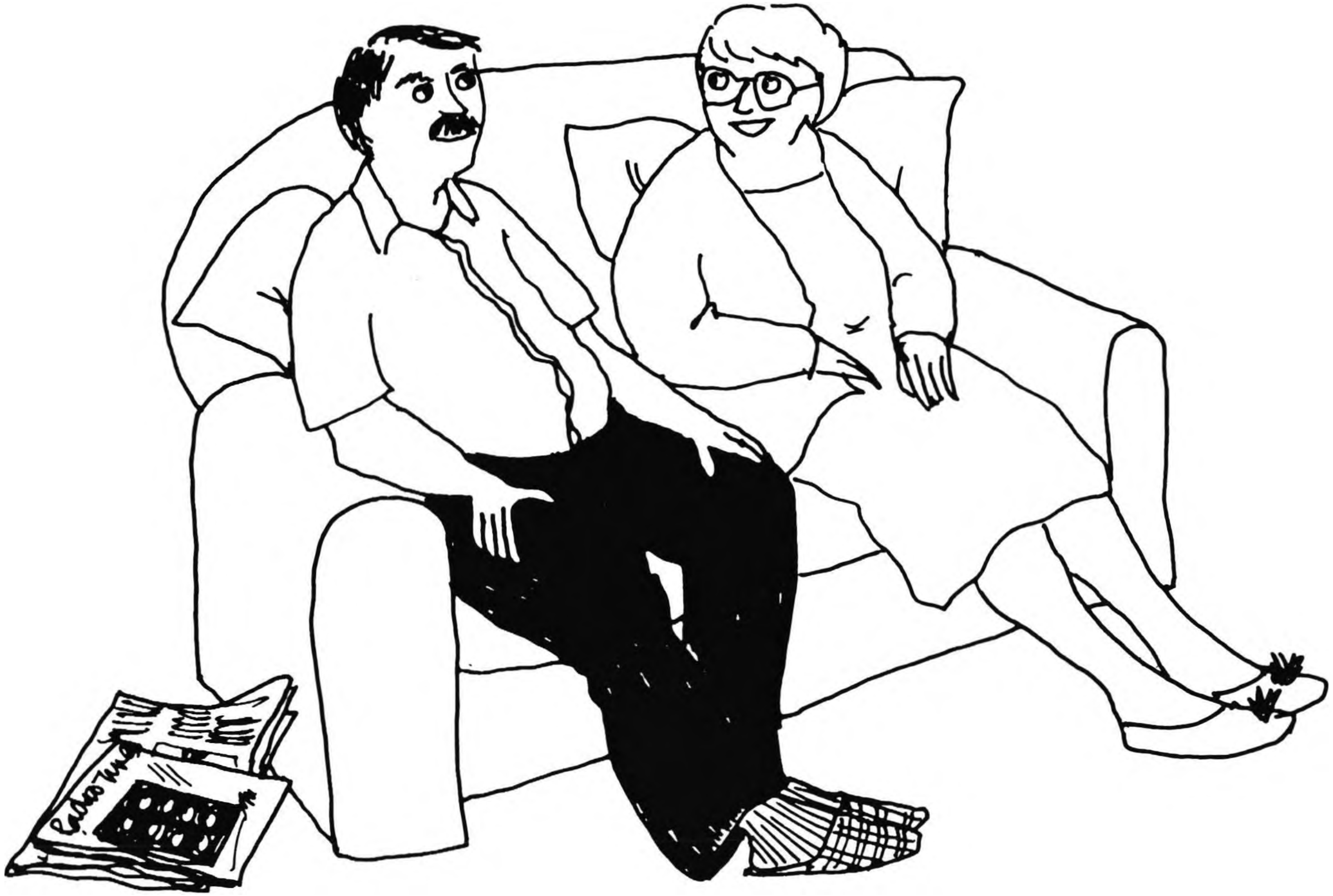
Conceived and written by **Kate Swinburn** with **Sally Byng**
Designed and drawn by **Caroline Firenza**

Aphasia



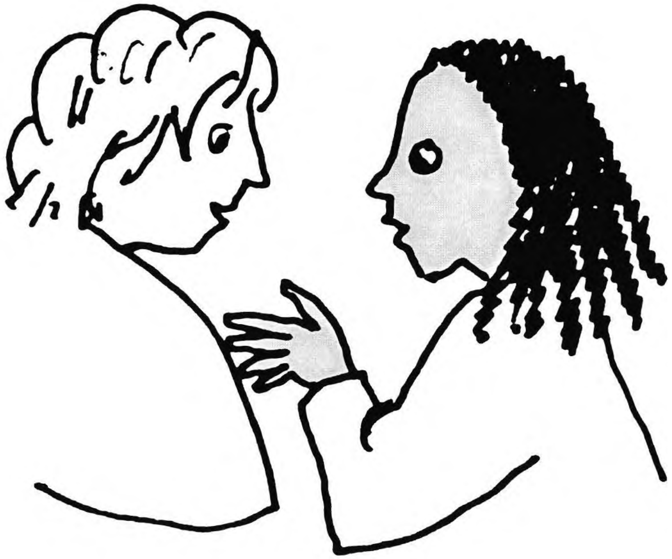
What you **do**

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

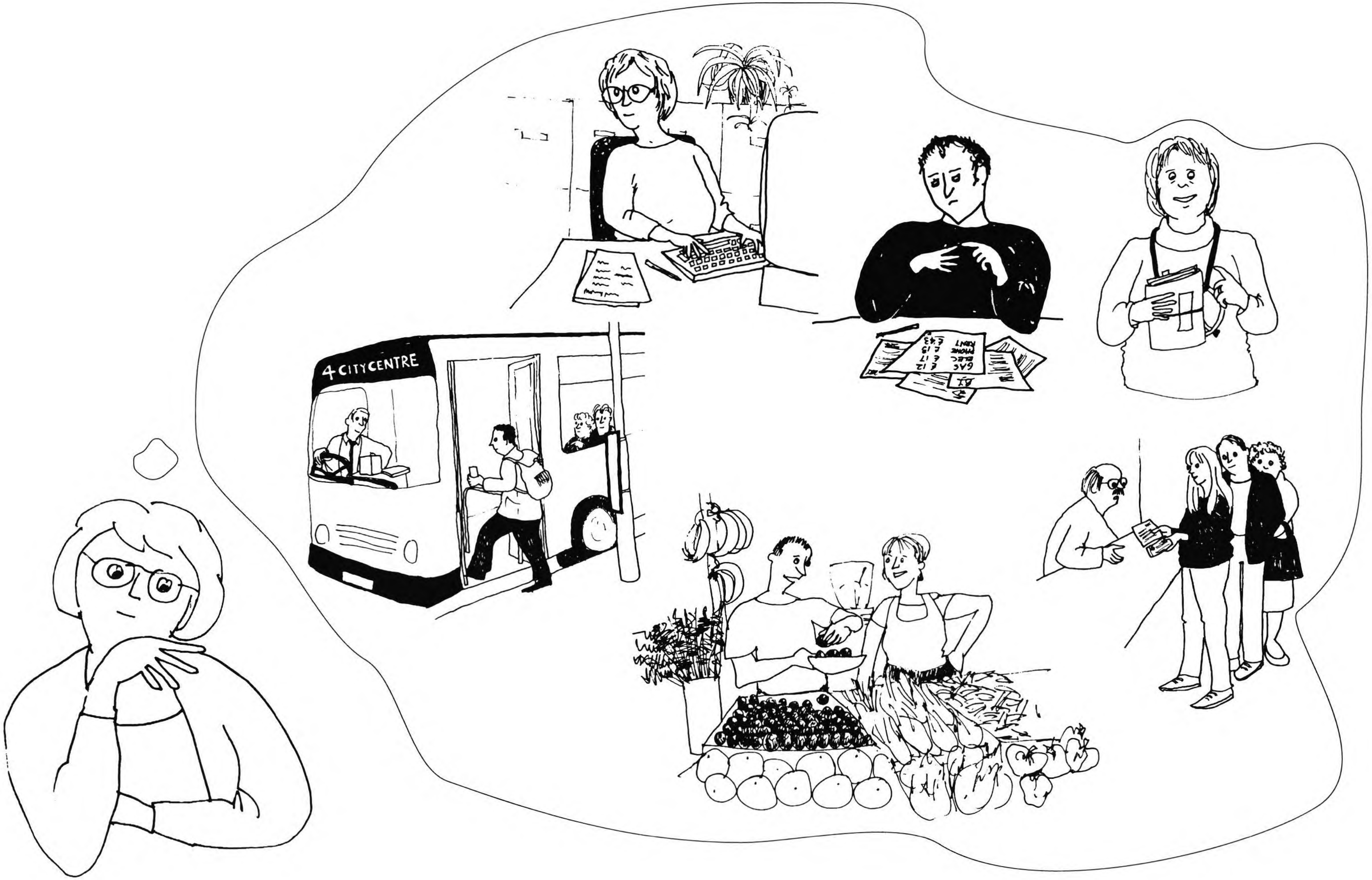
Health

Transport

Shopping

Business

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

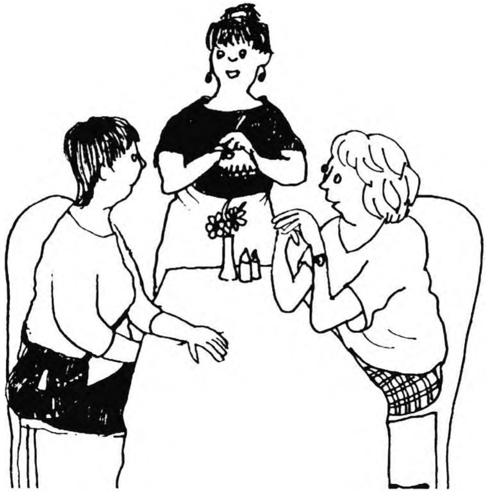


How are things you **want** to do?

Hobbies

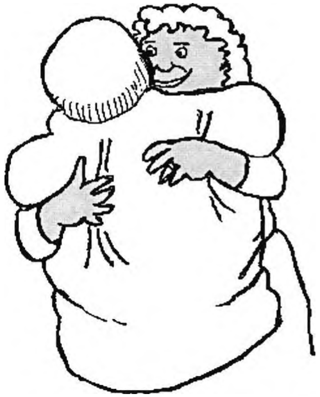
Clubs

Holidays



Going out

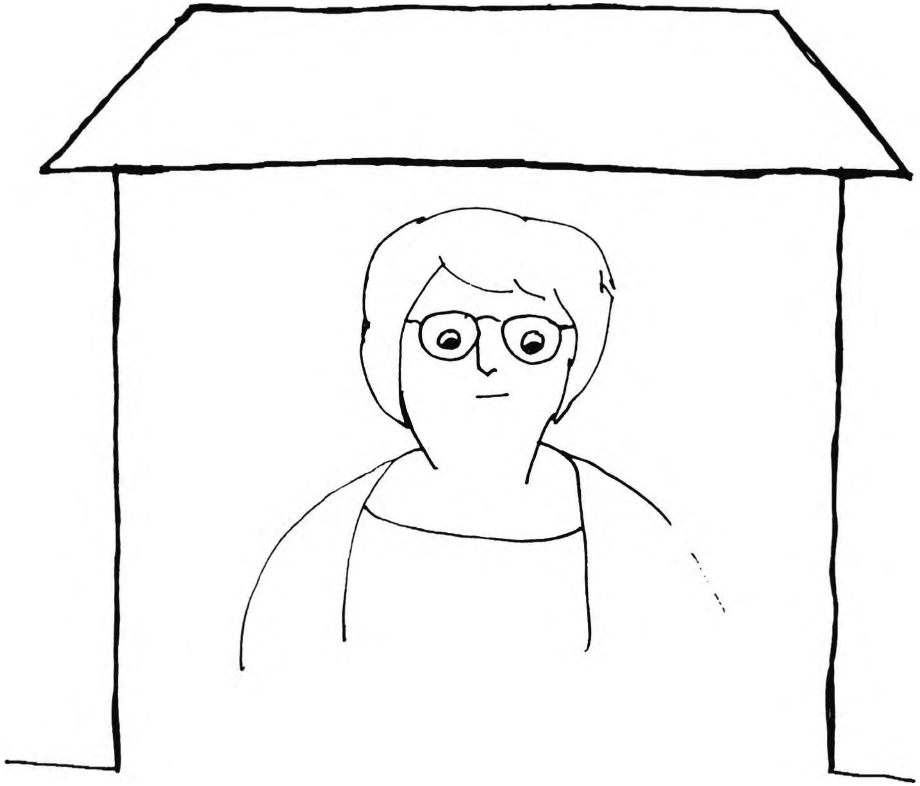
Meeting friends



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

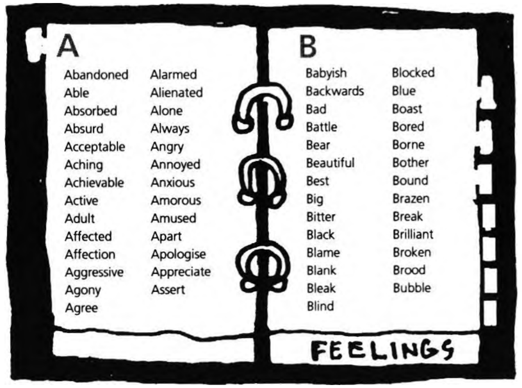
Pictures

Write things down

What **things help** you?

Someone helping

Dictionary



Speaking books

Computer

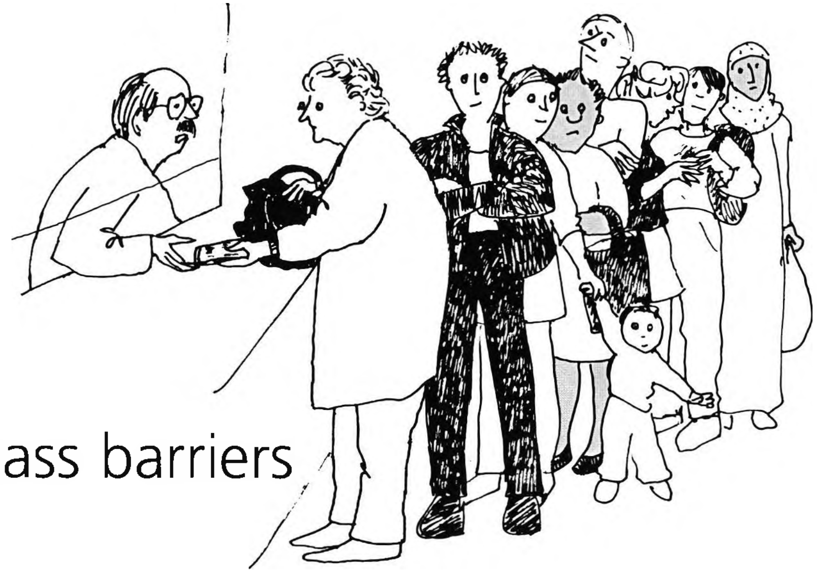
What makes it **harder**?

Who makes it **harder**?

Who makes it **harder**?

Who makes it **harder**?

What makes it **harder**?



Glass barriers

Queues

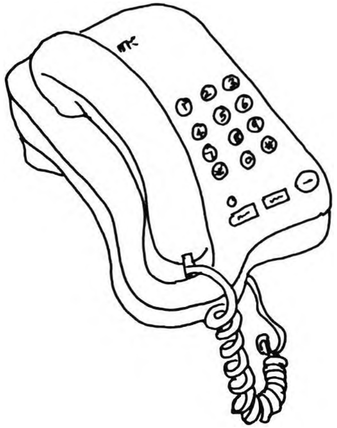
Being under pressure

Being upset

The wrong hand

What makes it **harder**?

Too much



Telephones

Being tired

What makes it **harder**?

Two people talking at once

Speaking quickly

Look away

Noisy/busy

Interrupting

Far away

Aphasia

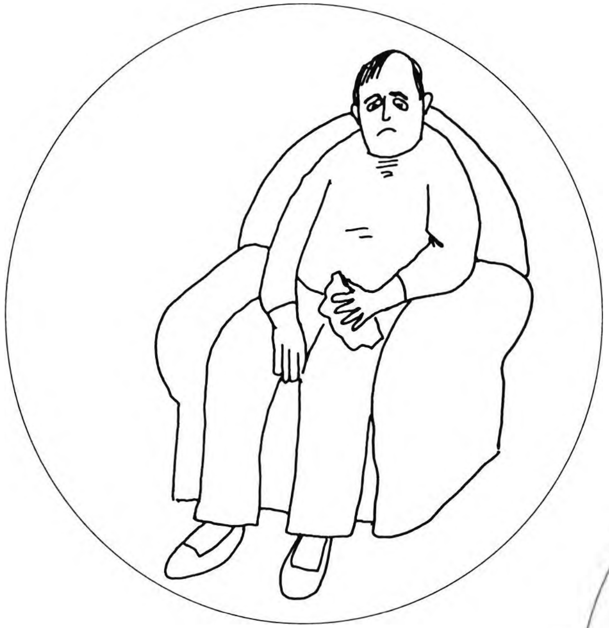
How does that make you **feel**?

Frustrated

Angry

Determined

Unhappy



Content

Worried

Less confident

Less control

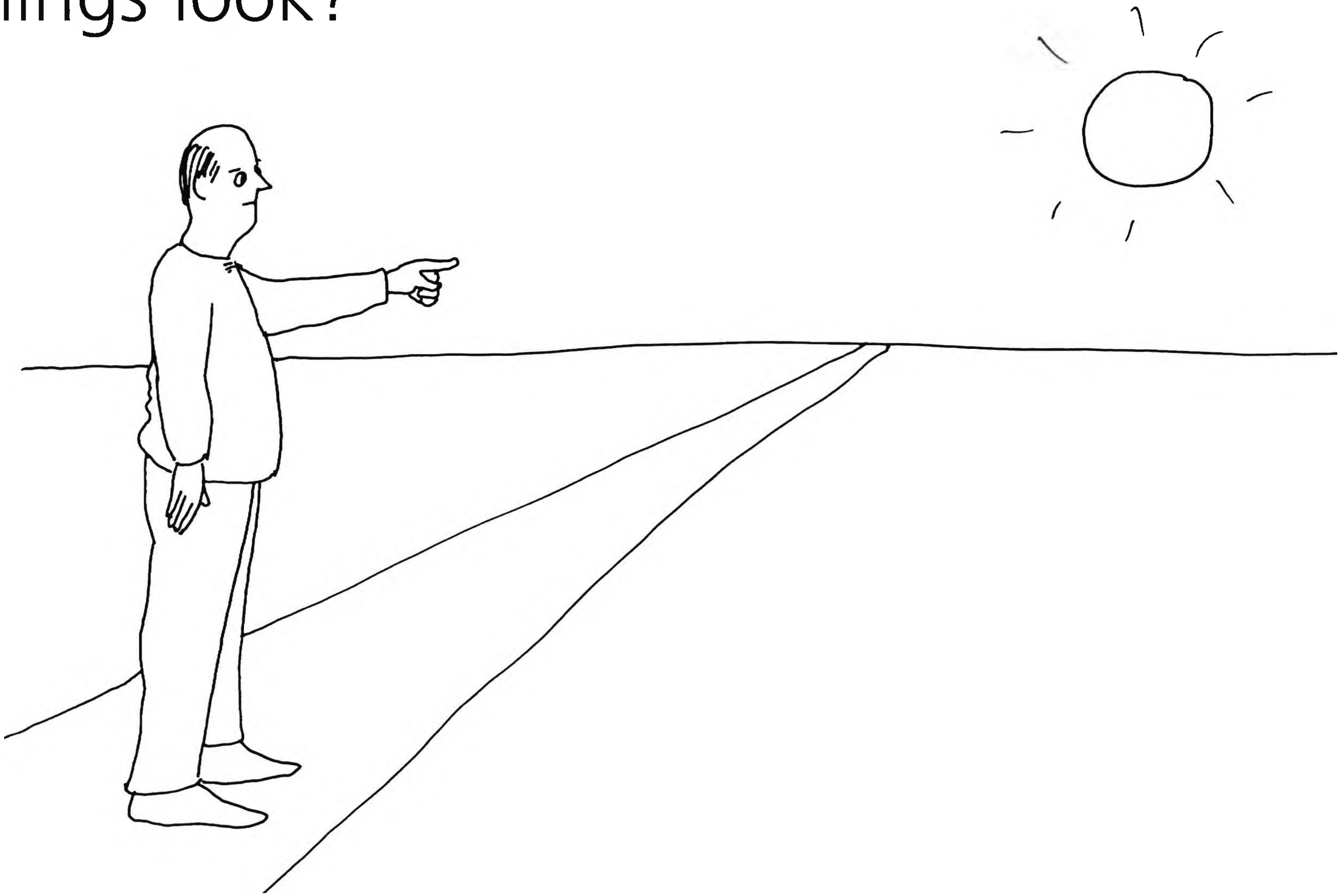
Able

Isolated

Valued

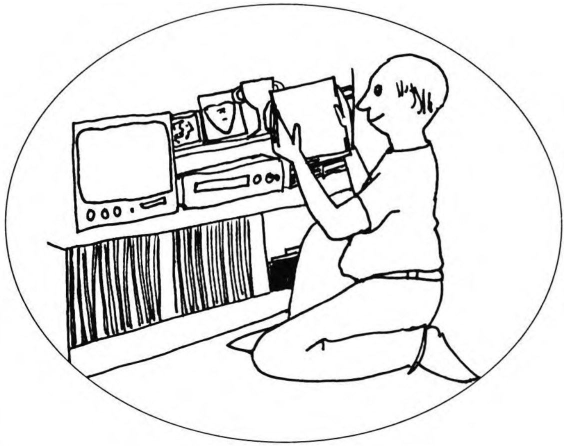
Embarrassed

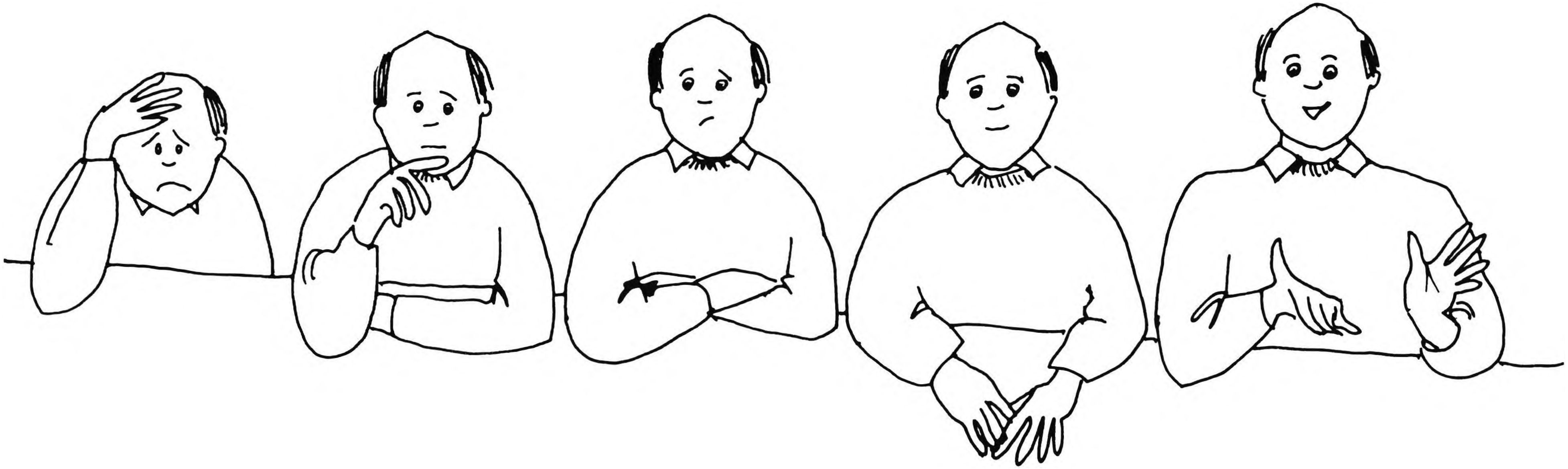
When you look to the **future**, how do things look?

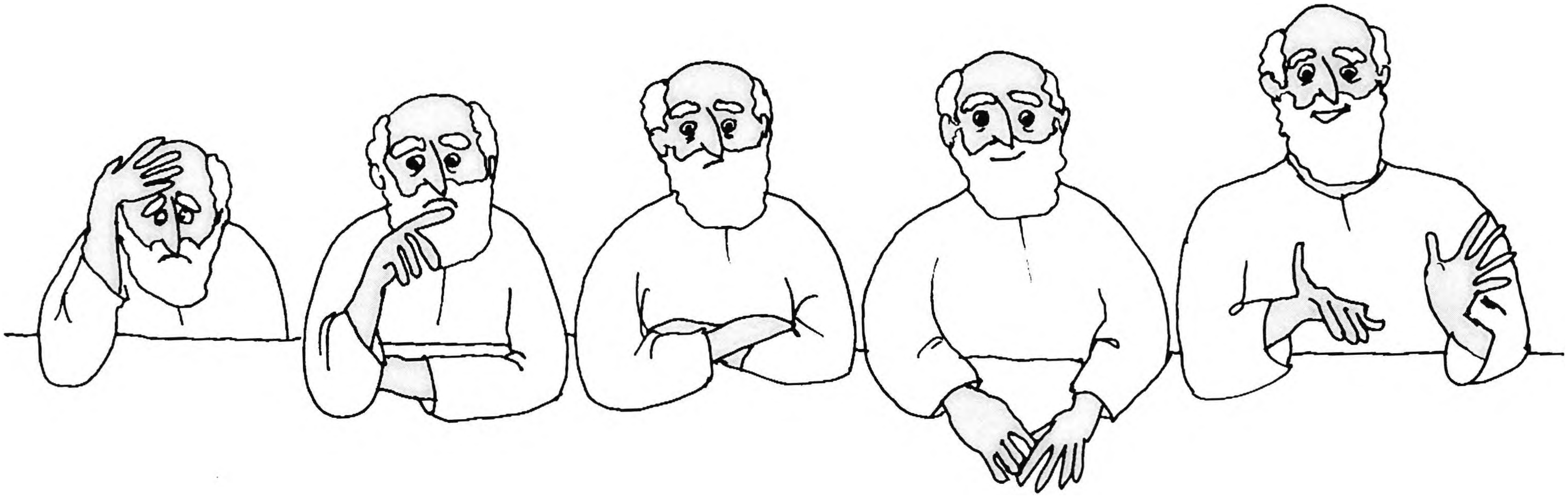


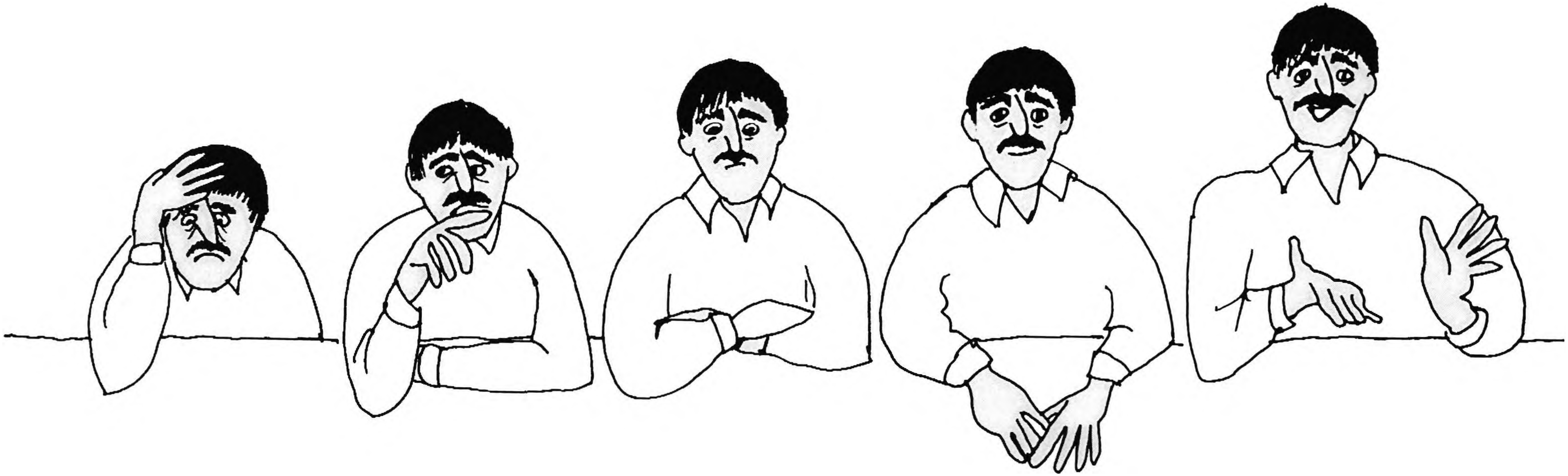
How do things look **today**?

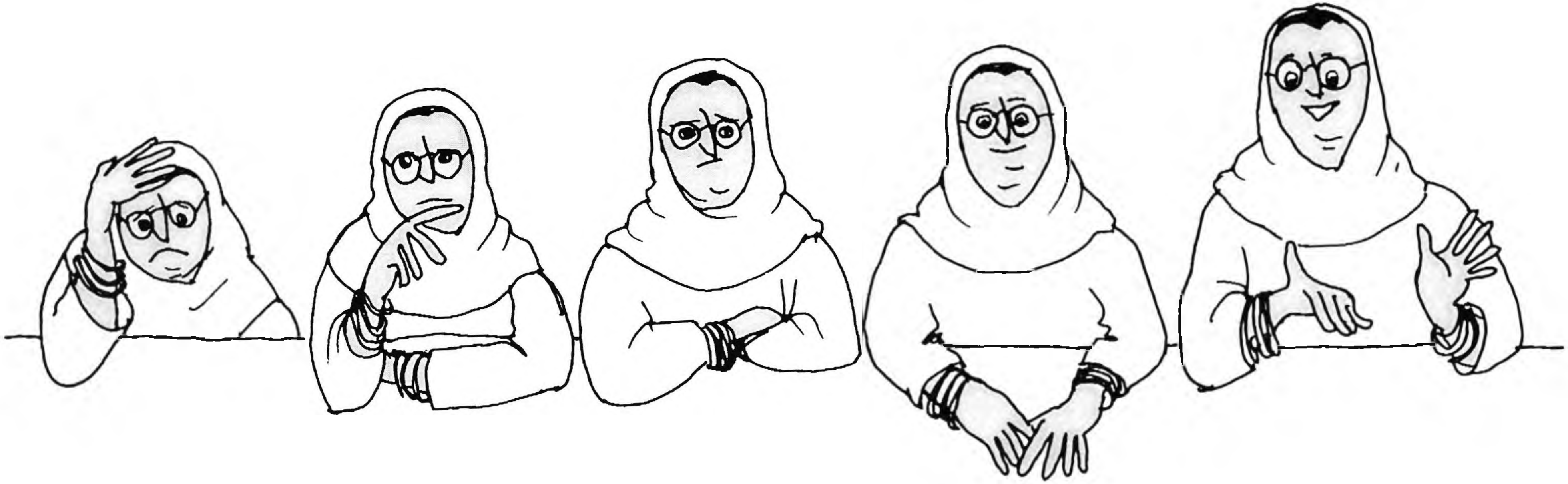
What is **fun** for you?

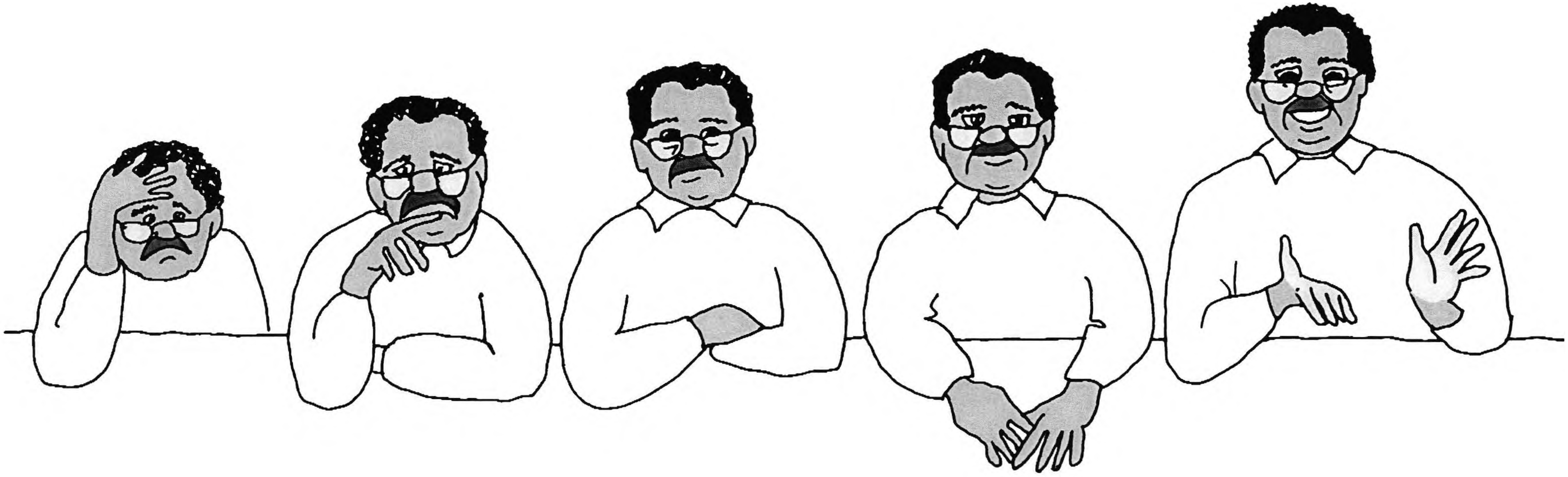


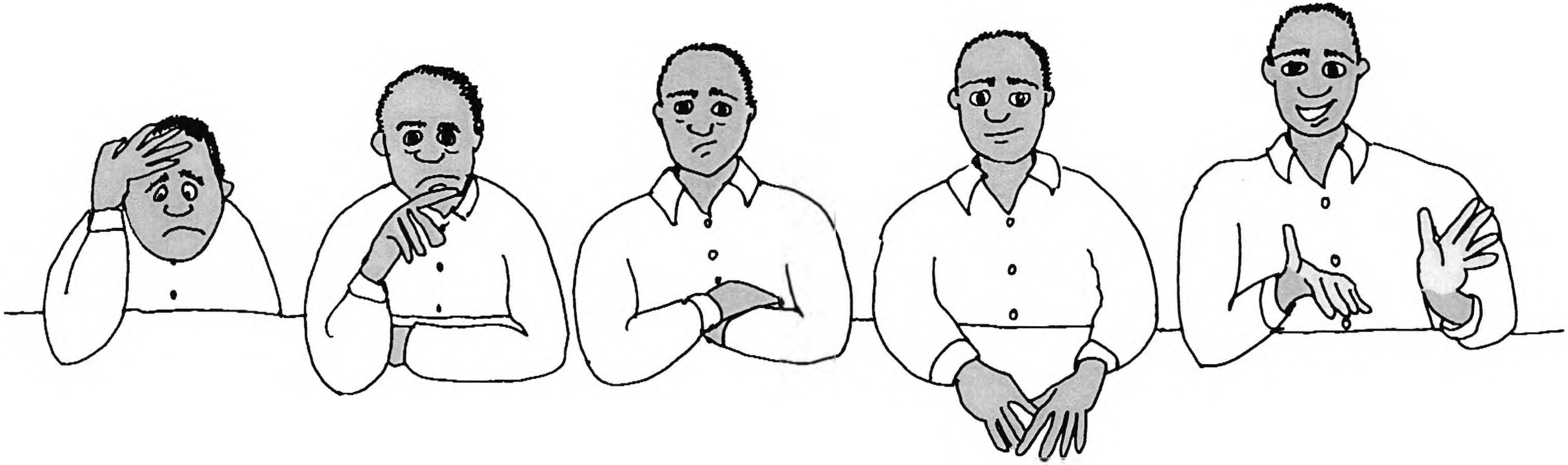


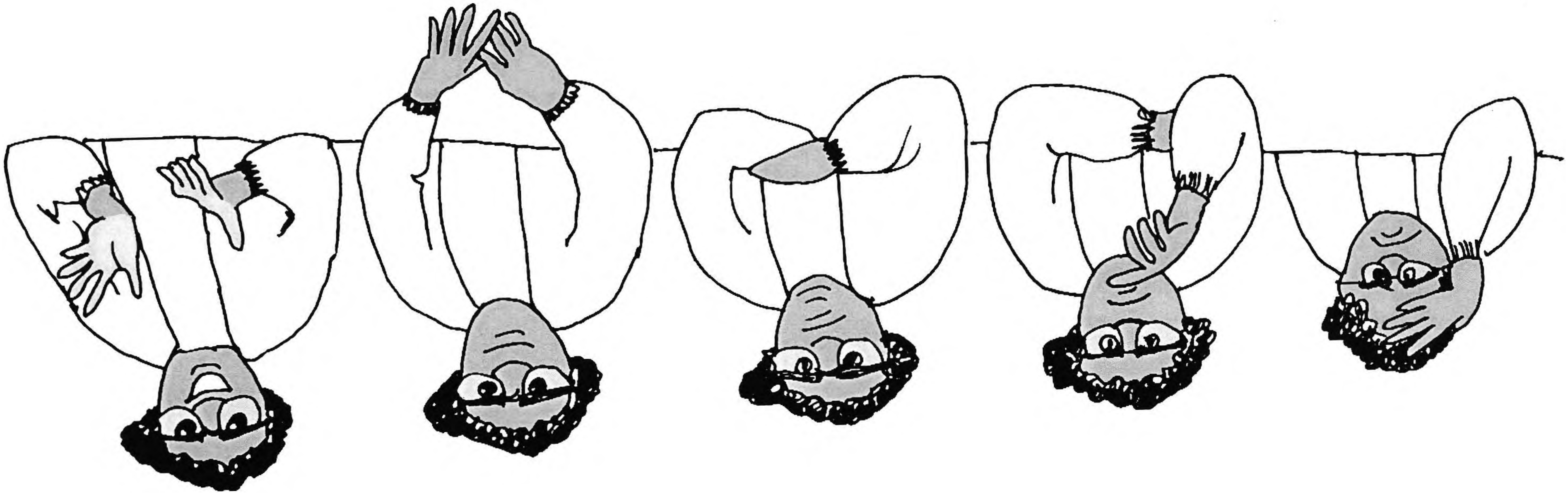


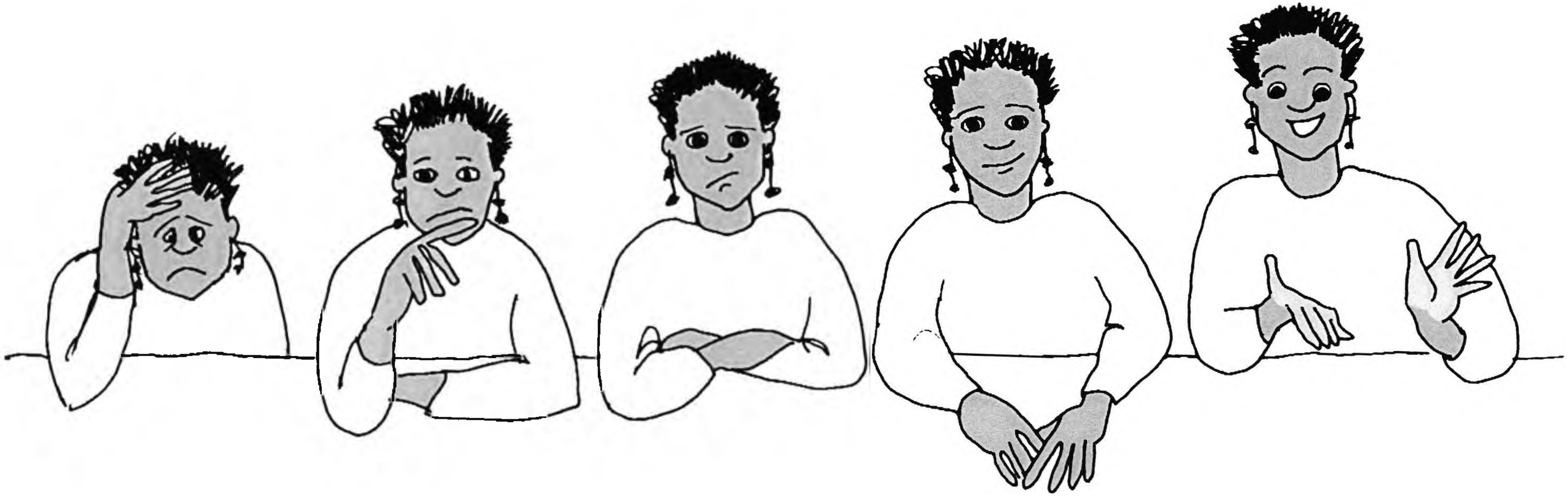


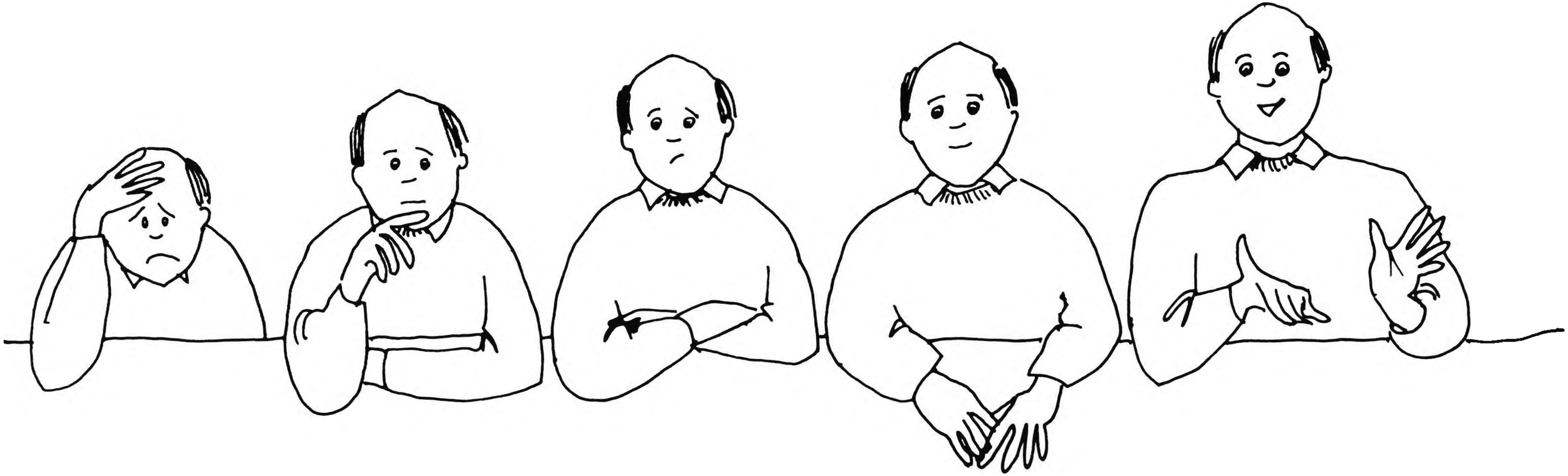


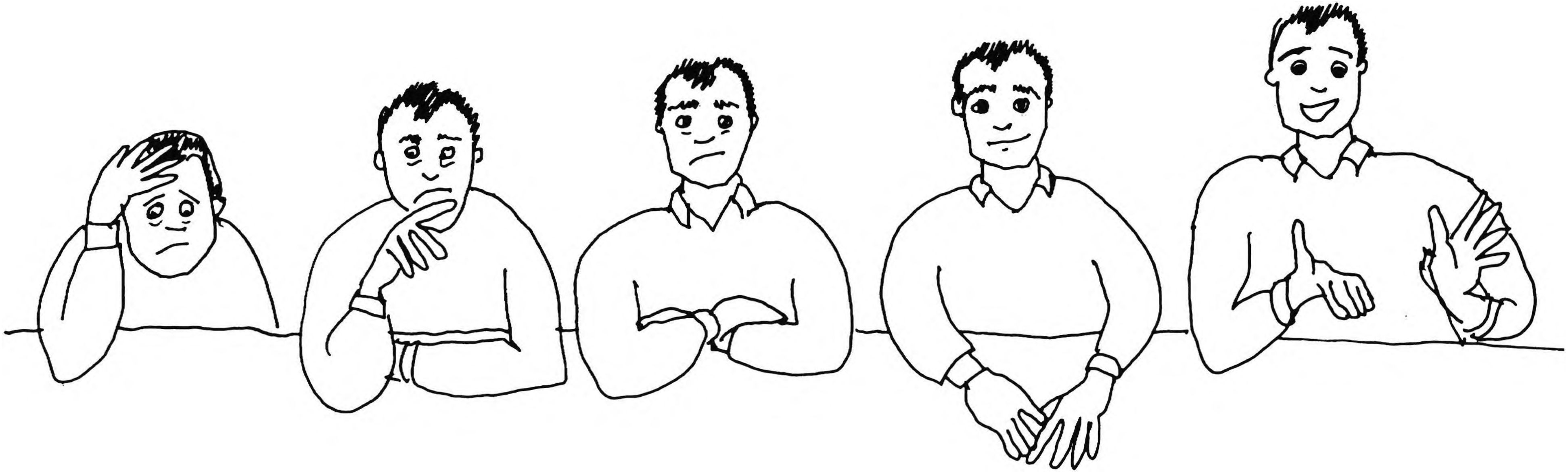


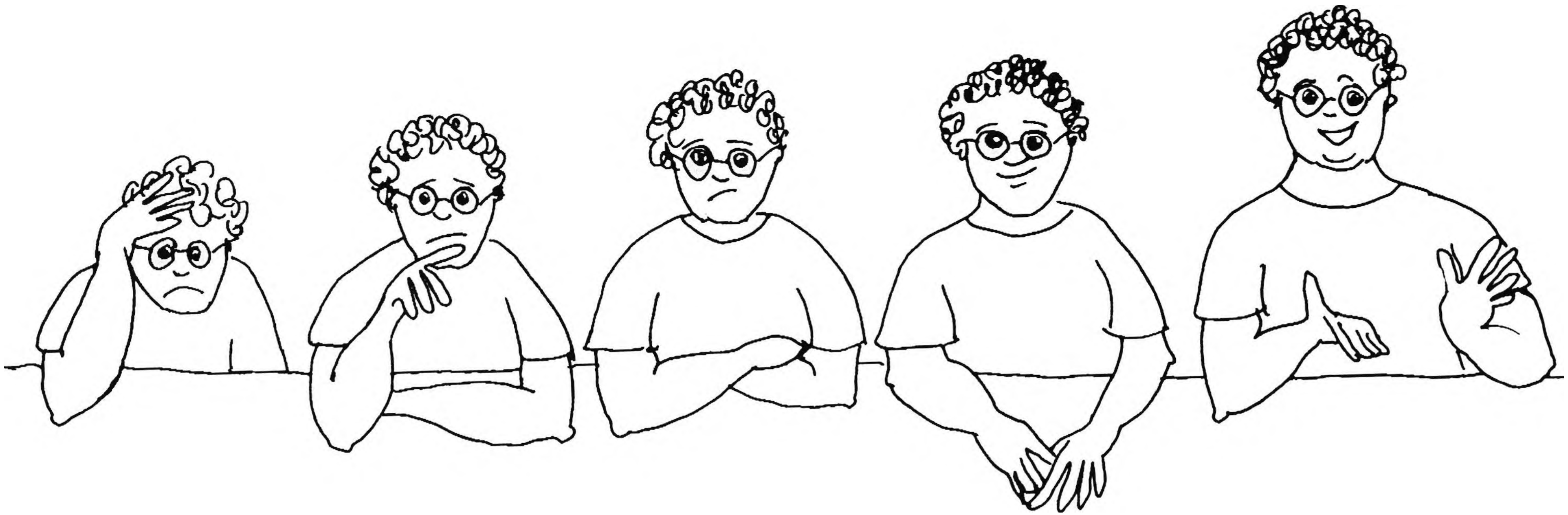


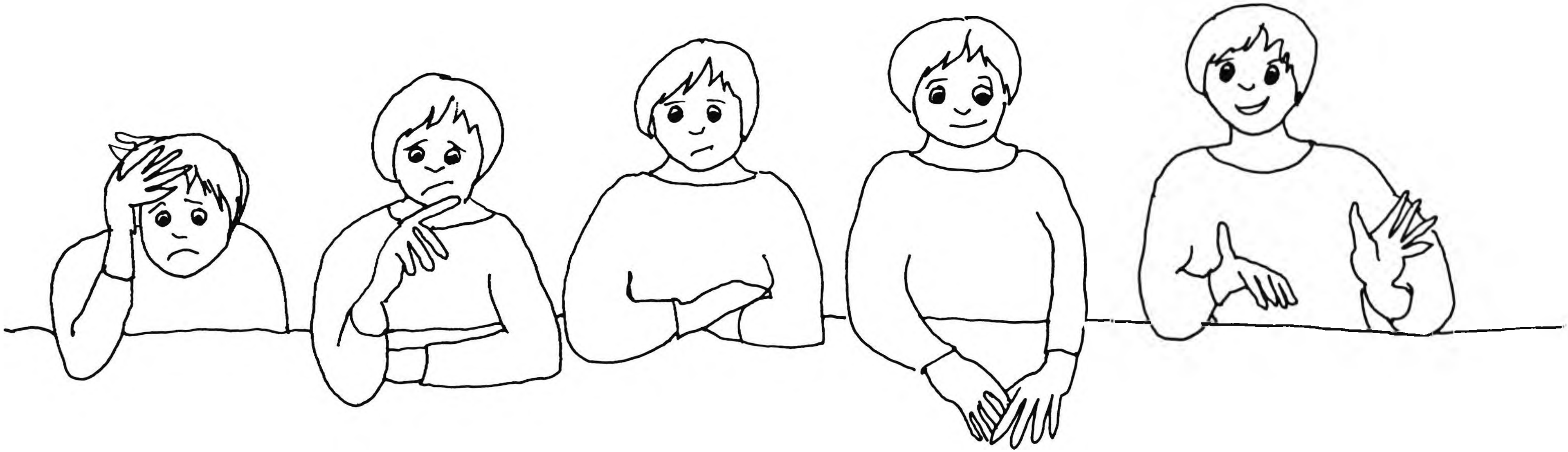




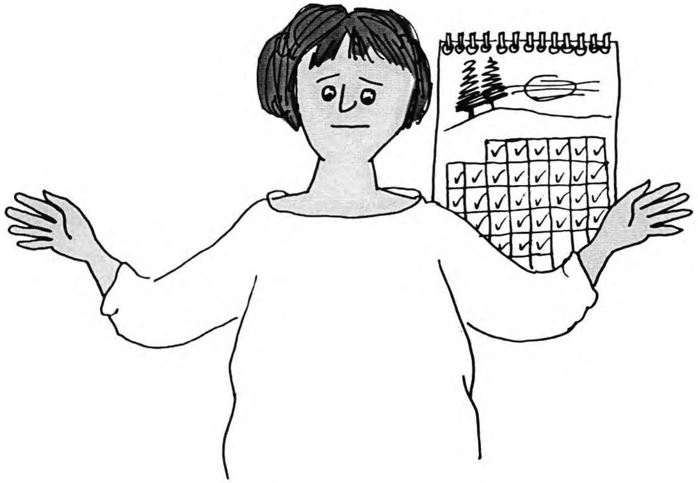








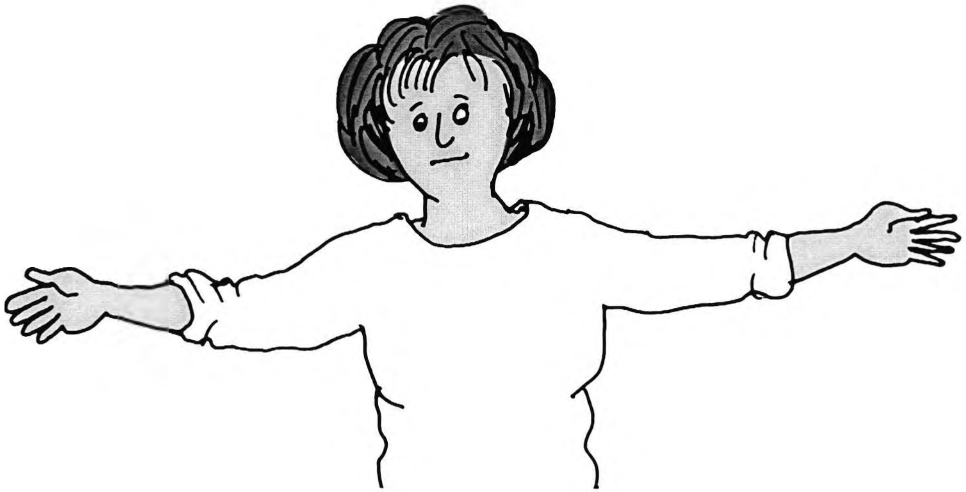
Always

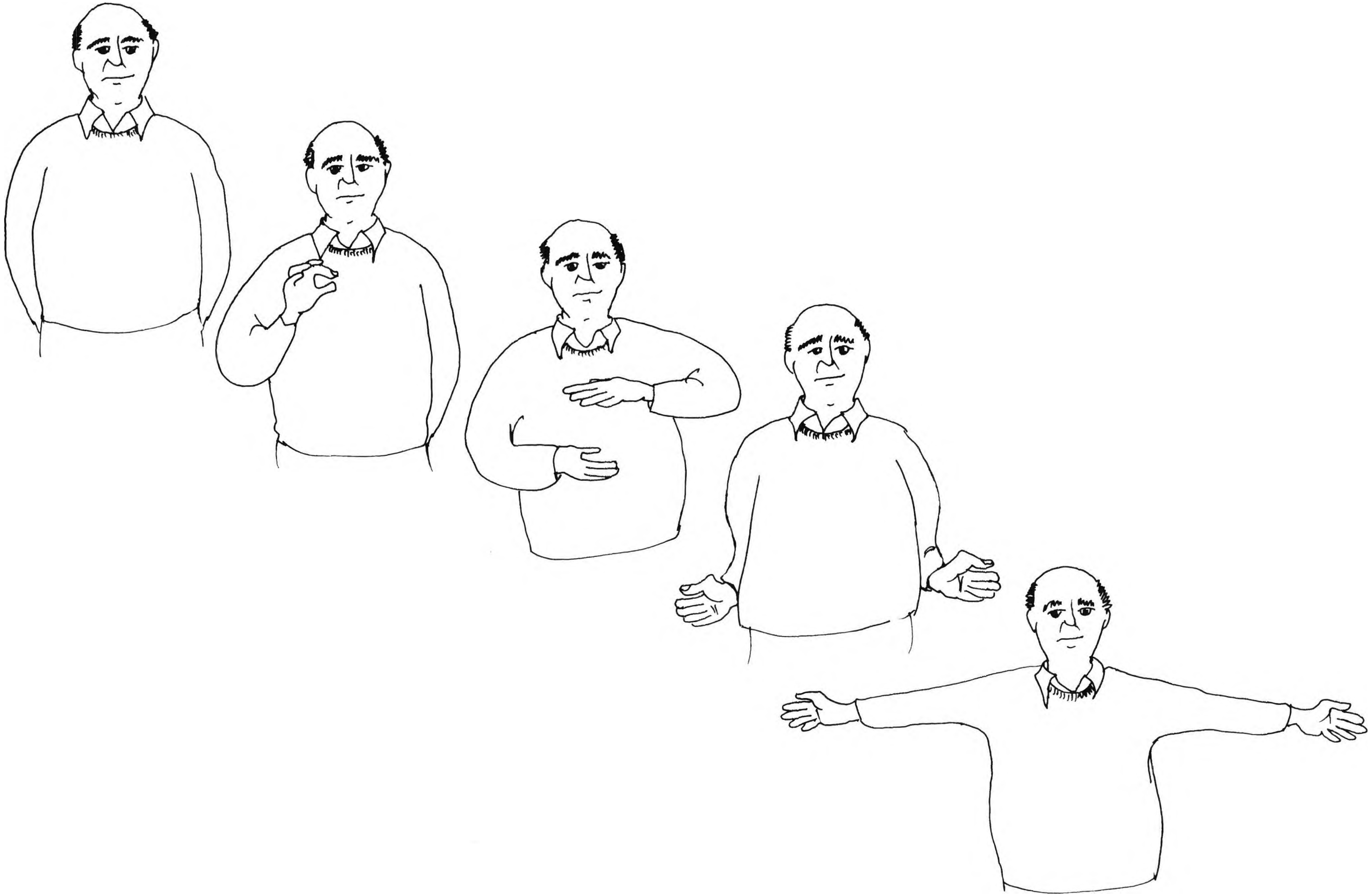


Sometimes

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* **0 1 2 3 4**
Comments:

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

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

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* **0 1 2 3 4**
Comments:

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

Comments:

12. (**picture 21**) *understand when you're <u>under pressure</u>* **0 1 2 3 4**
Comments:

<u>READING</u>

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

<u>Reading: Activities</u>

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

13. (**picture 23**) *read and follow one <u>word</u>* **0 1 2 3 4**
Comments:

14. (**picture 24**) *read and follow <u>a headline</u>* **0 1 2 3 4**
Comments:

15. (**picture 25**) *read and follow <u>a whole story in a paper</u>* **0 1 2 3 4**
Comments:

16. (**picture 26**) *read and follow <u>an official letter</u>* **0 1 2 3 4**
Comments:

<u>WRITING</u>

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 <u>determined</u>?*
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

<u>picture 55</u>
Do any of these show how aphasia makes you feel?

37. *Do you feel <u>unhappy</u>?*
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 <u>worried</u>?*
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 <u>content</u>?*
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 <u>future</u>, 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 <u>today</u>?*
Comments: **Use laminated scale 1**
0 1 2 3 4

42. (choose from **pictures 58, 59 and 60)** *do you have <u>people</u> who are <u>important</u> 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

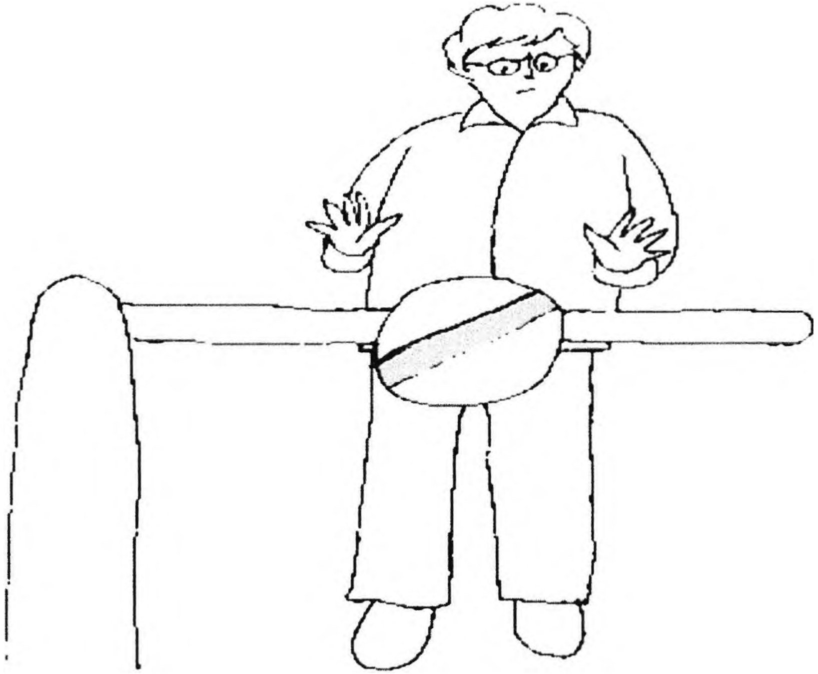
How much does it get in the way - original draft

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?



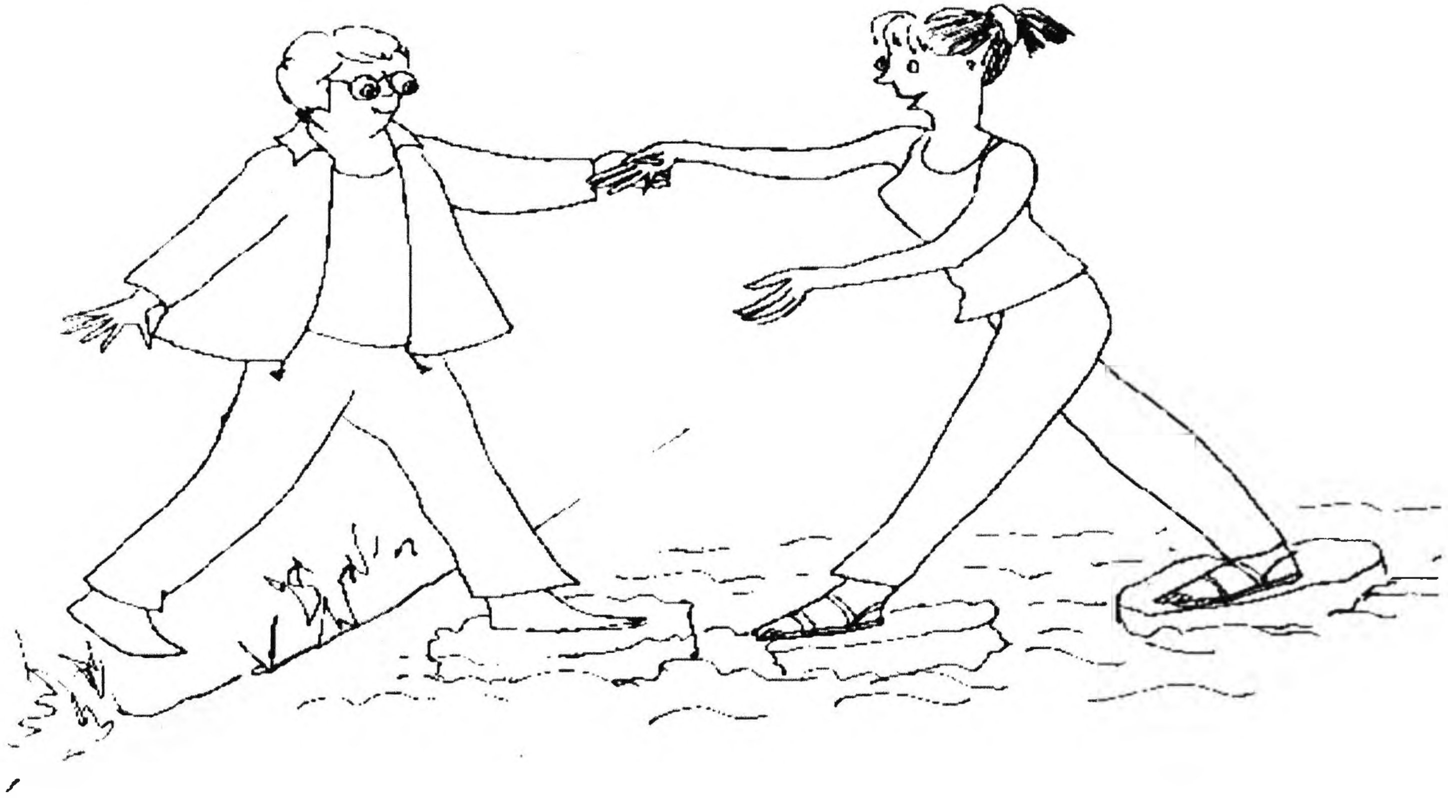
Appendix 5.3
What makes it worse (concept)- original draft

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

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

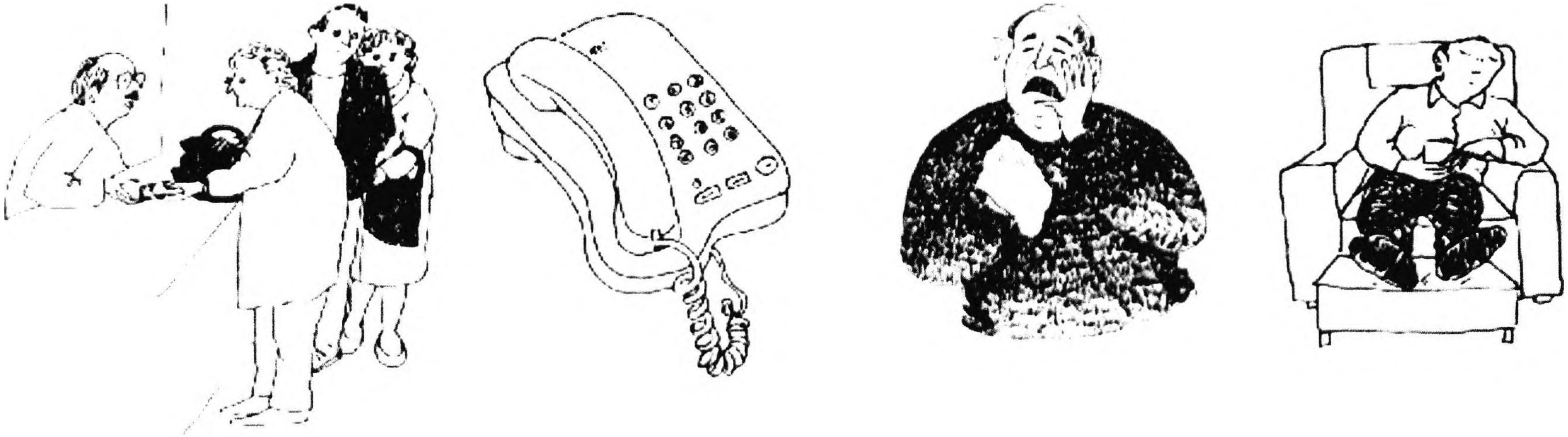
WHO makes talking HARDER (specific)

Who helps your talking?

Appendix 5.13

What makes talking HARDER picture (specific)- original draft

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



Appendix 5.14

What THINGS makes talking HARDER (specific) final draft (one of three pages)

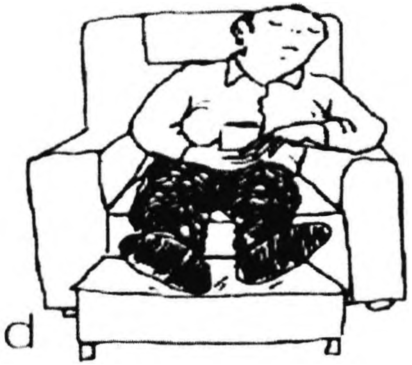
What makes talking harder?

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

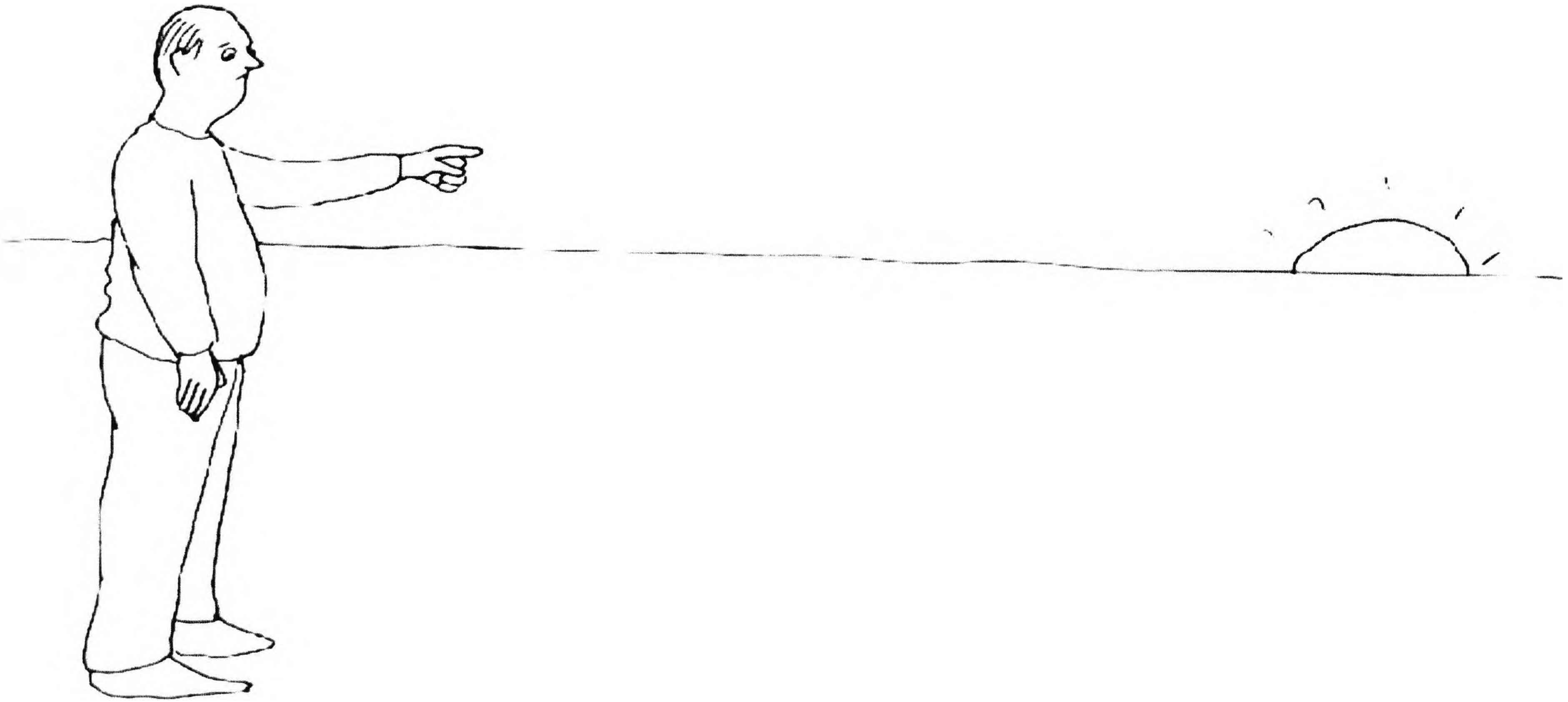
Far away

Appendix 5.16
Talking under pressure original draft

How easy is talking under pressure?

Appendix 5.17
Looking to the future - original draft

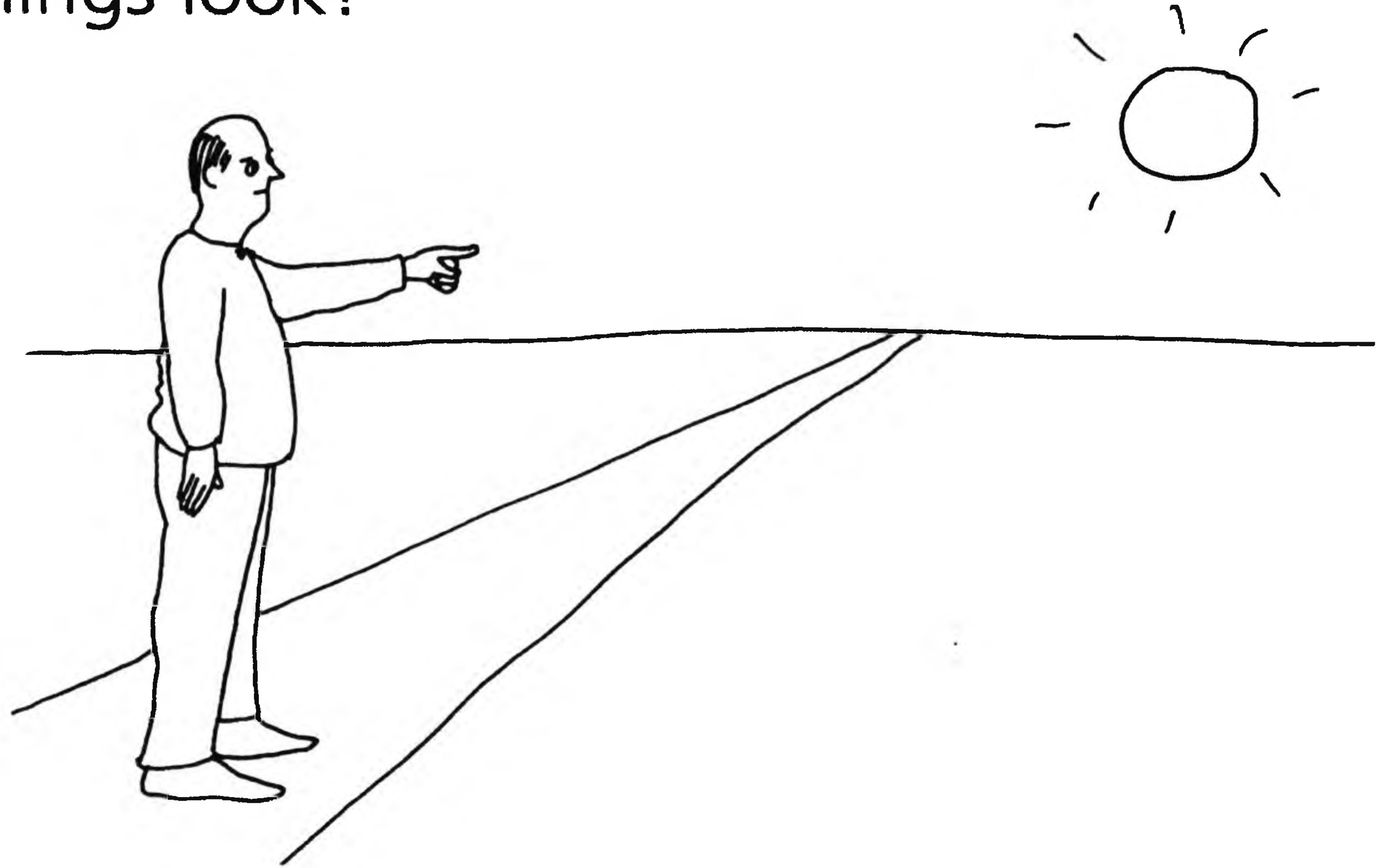
When you look to the **future**, how do things look?



Appendix 5.18

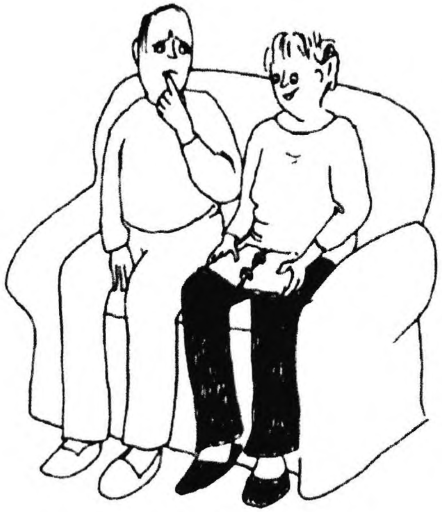
Looking to the future - final

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



Appenidx 5.19
Original 3 per page emotions picture

Unhappy



Worried

Whole

Appendix 5.20

Concepts that appear in the qualitative interviews.

Domain within the CDP	*Exemplar from the qualitative interviews*	*Existing items within CDP (draft 1) that cover this example*
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.

Exemplar from the qualitative interviews	*Existing item within CDP draft 2 that cover this example*	*Domain within the CDP*
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

Exemplar from the qualitative interviews
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

Appendix 5.23

Pilot comments (from people with aphasia) to show to advisory group

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 **lightening 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***

Appendix 5.24

Pilot comments (SLT) to show to advisory group

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***

Appendix 5.25

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?*

Appendix 5·26

The Communication Disability Profile summary score sheet -post field testing

The Communication Disability Summary Score sheet

Name : **Date:**

Q	**Domains**	**Raw scores (circle)**	**Section totals**	**Percentage totals**
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		
	Talk total		*/16*	
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		
	Express total		*/16*	
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		
	Understand total		*/16*	
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		
	Reading total		*/16*	
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		
	Writing total		*/16*	
	Activities total: *(with express yourself)* *(without express yourself)*		*(-express)* */64* *(+express)* */80*	*Activities* %
	Life style/ Participation:			
	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		

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	*Determined*	*0 1 2 3 4		
31	Unhappy	0 1 2 3 4		
32	Worried	0 1 2 3 4		
33	*Content*	*0 1 2 3 4		
34	Less confident	0 1 2 3 4		
35	Less control	0 1 2 3 4		
36	*Able*	*0 1 2 3 4		
37	Lonely	0 1 2 3 4		
38	Embarrassed	0 1 2 3 4		
39	*Valued*	*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

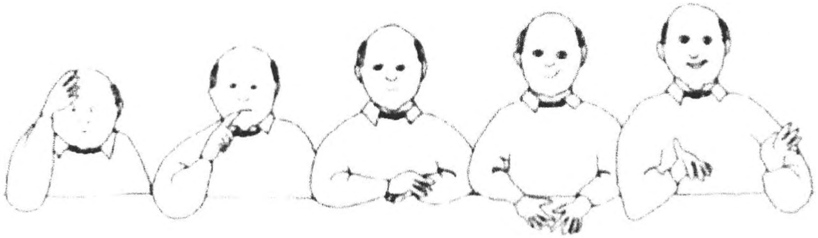
	Grand totals:			
	Activities:	**Participation:**	**Emotions:**	
	/64 %	***/48***	***/56***	
	/80 %	***%***	***%***	

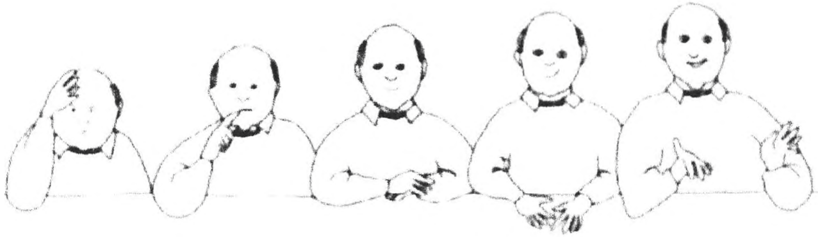
Key people:

Key issues:

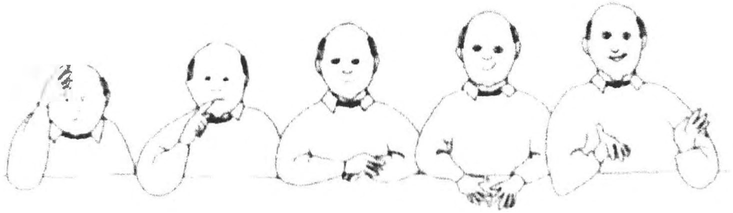
Possible action:

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





4 3 2 1 0

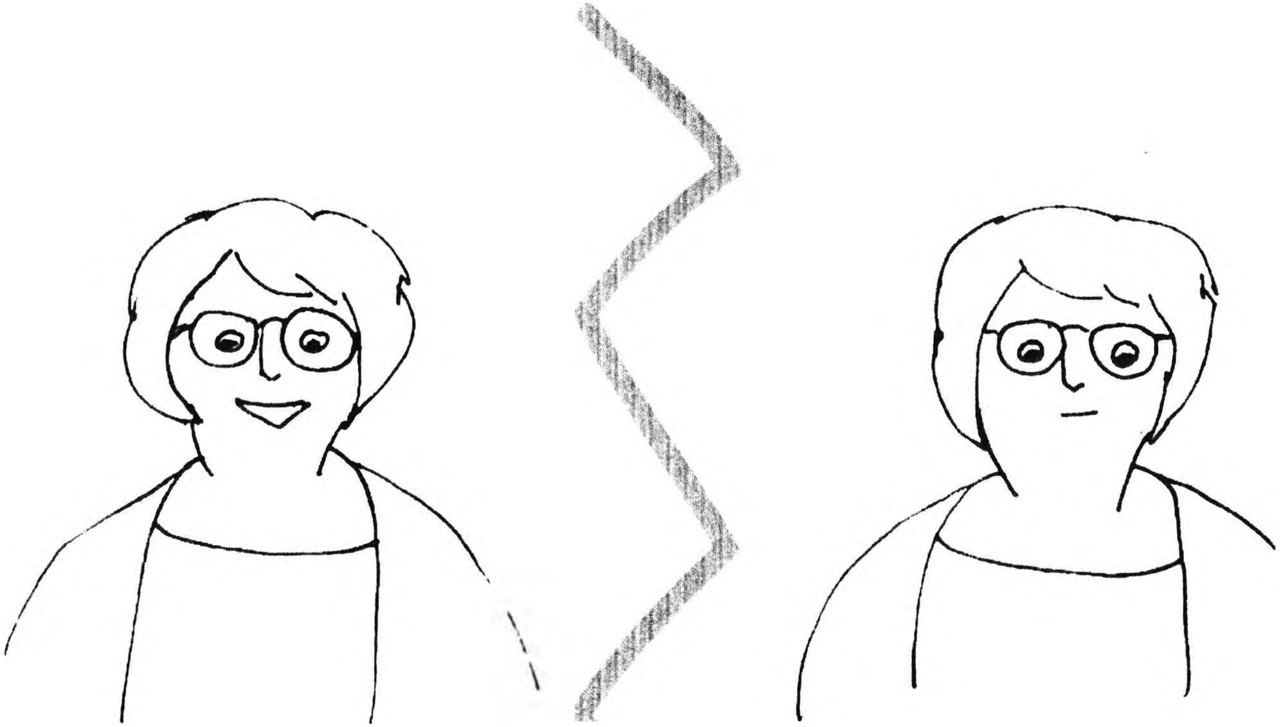


✖✖ ✖ — ✔ ✔✔

Appendix 5.28

Before and after stroke - original draft

Since your **stroke...**



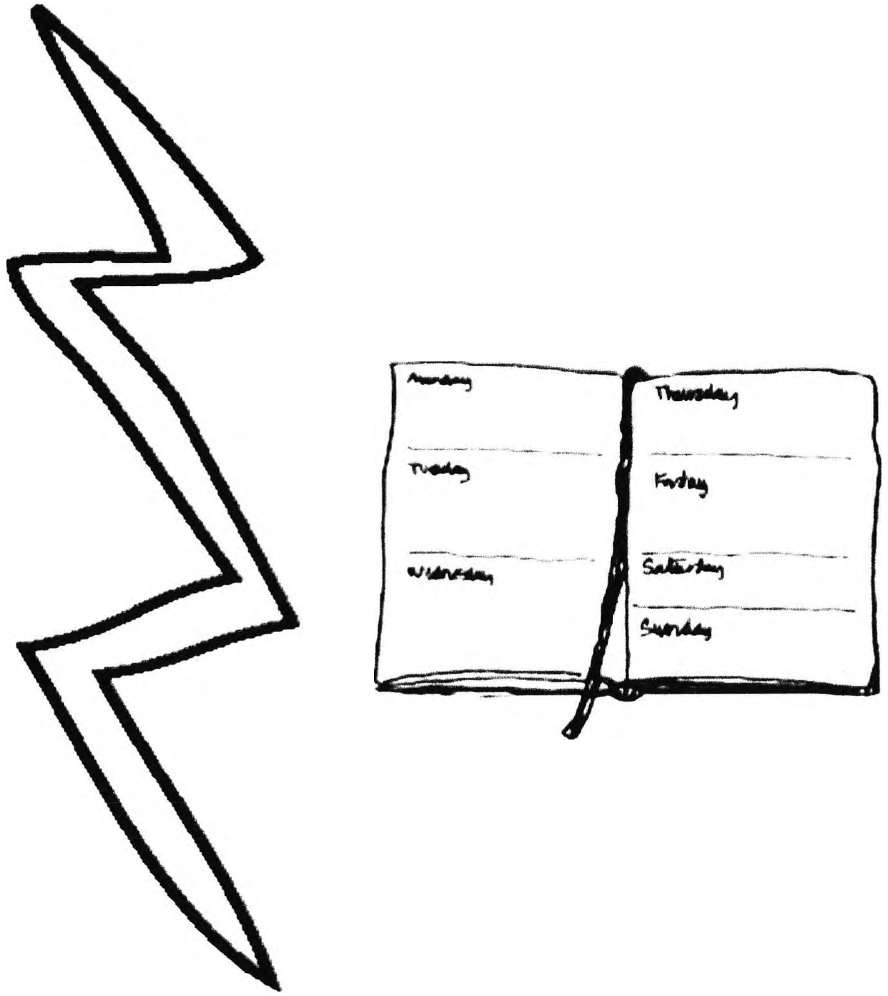
Appendix 5.29

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 – their may be others who were NOT strong minded BEFORE their stroke who would be a bit alientated 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 SOOOOOOOOOOOOOO!

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)? ☐

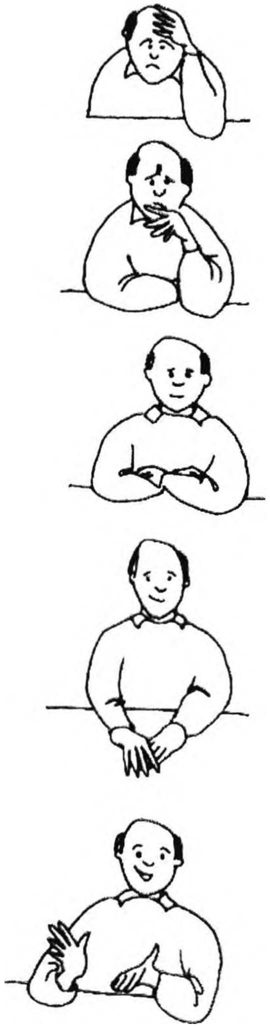
If it's too hard – don't worry – I'll bring it on the 10th to discuss.

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

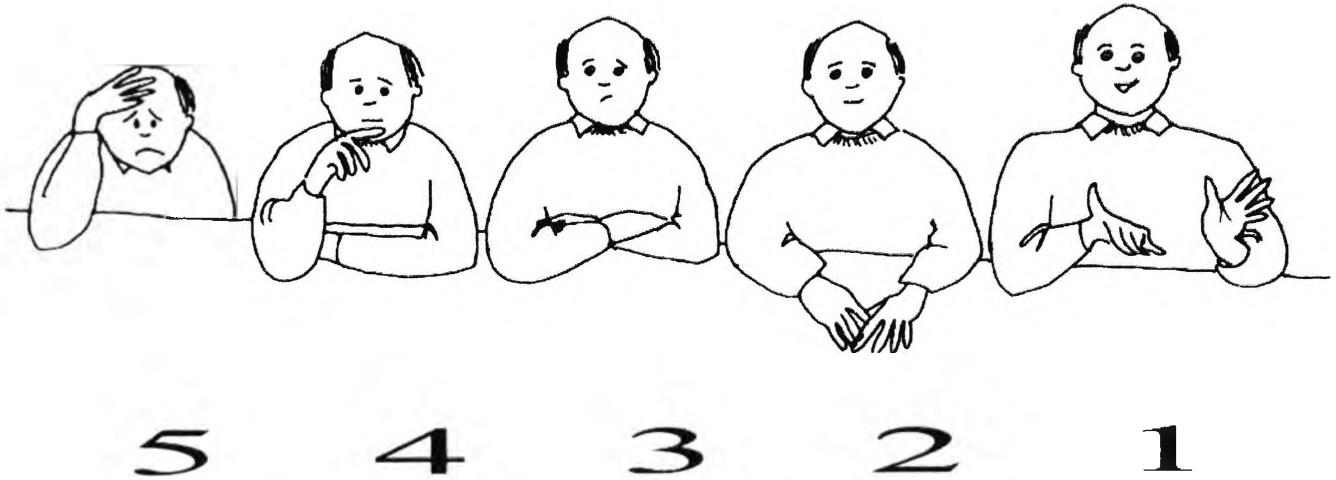
(Home address given)

Thank you!!!!!!!

Appendix 6.4
Rating scale 1 - version 1

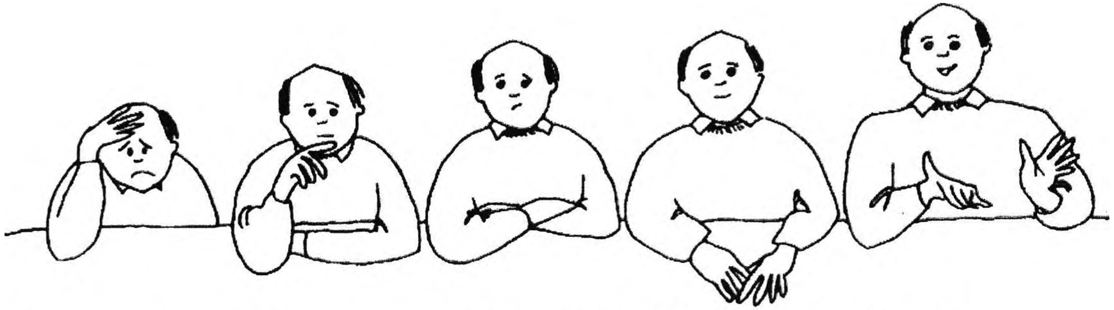


Appendix 6.5
Rationg scale 1 version 2



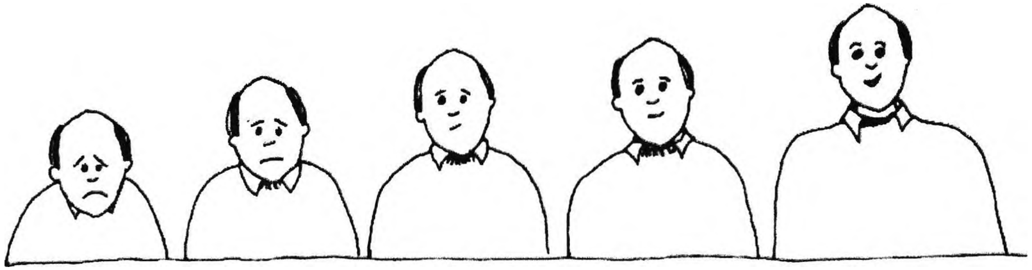
Appendix 6.6
Rating scale 1 version 3

How easy is it for you...?



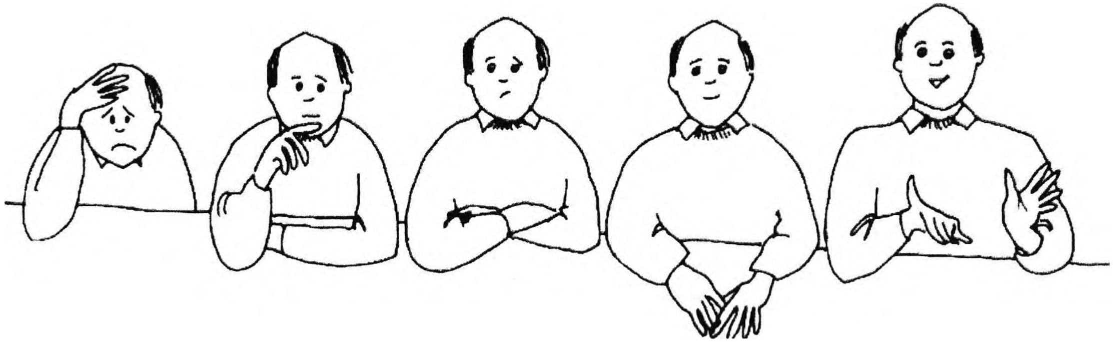
Appendix 6.7
Rating scale 1 version 4

How easy is it for you...?



Appendix 6.8

Rating scale 1 version 5



4 3 2 1 0

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

conducted under the direction 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 1/4 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 receive(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 test 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, of your family have any questions regarding your rights as a subject, any 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 entities.

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 to the subject and the legal guardian agrees that the subject understands the nature of the study and wishes to participate in the study.)

Appendix 6.10
Information sheet for user/field trial focus group (people with aphasia) page 1

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**)

)R

- **ring Kate Swinburn** on **0171-228-8400**

say "I'm phoning about the rating scales project")

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

hey 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.

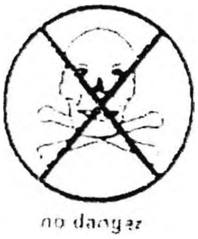
I can **STOP** at any time.

✓

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

It **won't affect** my speech **therapy**.

There is **NO DANGER**



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: