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

by

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DECLARATION

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ABSTRACT

This thesis investigates healthcare measurement for people who live with the language disability, aphasia. It describes how a tool was developed to investigate the impact of living with aphasia.

The first chapter describes why healthcare measures are necessary. It describes some of the complexities associated with measurement when working with people who have traditionally been excluded from health care measurement. It discusses different types of measures currently available and why they are often inadequate for investigating the impact of aphasia.

The second chapter details the initial stages of development of a new tool, undertaken from a professional viewpoint. This chapter describes the rationale behind the items and methods used in the instrument. It details the changes that were made to the tool as a result of pilot and field testing.

The third chapter describes the conceptual and methodological issues that informed the next stages of the development process. There is a discussion of the current issues in healthcare that are seen as pertinent to the development of a tool to explore the impact of aphasia. There is consideration of the relative strengths of qualitative and quantitative research methods, and the tension that can exist between ensuring a tool is psychometrically robust whilst still being accessible and acceptable to the client group for whom it is intended.

Chapters four and five detail how conceptual considerations led to changes in the methodology employed in the next stage of development. They describe two methods of collaborative working; individual in-depth interviews and working with an advisory group of people with aphasia. They detail the changes made to the tool as a result of the consultation processes.

Chapter six explores how these inclusive methods led to examination of the social relations of research practice. It discusses the challenges and benefits presented by this way of working, and the personal effects of inclusive research practices. It investigates these in the light of what has been learnt through the development of the instrument described.

This thesis therefore presents the CDP, a new way of exploring and measuring the impact of aphasia on someone's life. It considers the purpose of healthcare measurement. It exemplifies participatory research with people who have aphasia, including a reflection on the tension that can exist between qualitative and quantitative methodologies when developing a new tool. By doing so, it offers guidance on research practice for those wishing to conduct inclusive research with people traditionally excluded from health care measurement including people with aphasia.

INTRODUCTION

This thesis considers issues associated with investigating the impact of living with language disability. It charts the development of a tool (the Communication Disability Profile), that was designed to measure and explore the significance and consequences of living with the language disability, aphasia. It describes in detail the methods used in the process of developing the tool. This detailed description serves to magnify and highlight more general considerations relating to how and why we attempt measurement within illness and disability.

Clinical practice is guided, to a large extent, by the tools and skills clinicians use to gather information to underpin their decision-making. If the measures that are available focus on impairment then clinical practice will be directed towards that aspect of health and illness. When considering the acquisition of life-long disabling conditions, such as aphasia, this focus on impairment runs the risk of failing to address the wider context within which someone lives his/her life.

This project was conceived as a result of the realization that traditional health measurement and consequently much clinical practice, was unduly focused on impairment.

The thesis therefore describes the issues associated with developing a tool which aims to address the wider impact of living with language disability. It includes examination of current methodological, and conceptual issues in healthcare that are seen as pertinent to the development of a tool with this stated aim. These issues include the WHO classifications of disability and health, disability rights, politics and research, the move towards social models of health care and the inadequacies inherent in working only from a professional's viewpoint. There is discussion about the relative strengths of qualitative and quantitative research methods, and the friction that can exist between ensuring a tool is psychometrically robust, whilst guaranteeing that it is accessible and acceptable to people for whom it is intended.

These philosophical considerations have influenced the process of developing this tool. Notably, people with aphasia have become increasingly influential within the project. In contrast to traditional reporting of research methods, the minutiae of how people with aphasia were involved in the development process are rehearsed. This serves

two functions; firstly it illustrates the practical considerations involved in implementing this inclusive philosophy, including an examination of the issues surrounding the inclusion of a range of groups who are often excluded from the process of healthcare measurement. Secondly, the details of the process demonstrate the complexity of, the need for and advantages of, collaborative research methods when involving the people with whom health care measures will ultimately be used. The thesis concludes with a consideration of the challenges and effects for the researcher of such inclusive working practices. It reflects on the implications of these issues for other researchers investigating within this field.

Chapter 1

Measurement in health care

1.1 What are health, illness and disability?

In broad terms health can be conceptualised in a negative or positive way. Negative conceptualisations of health focus on the presence (or absence) of disease, illness or disability (Bowling 1997a), or the limitations of function, role, or the degree of dependency for example. However, this reliance on the negative definition of health provides little for the estimated 80-90% of the population who do not experience ill health, disability or disease (Bowling 1997a). Positive conceptualisations of health in contrast, seek to provide frameworks for measuring not only the absence of disease but the 'completeness' and 'full functioning' or 'efficiency' of mind, body and social adjustment (Bowling 1997a).

Medical conceptualisations of health often focus on the absence of disease, whereas sociological viewpoints often consider health in terms of mental and physical capability to perform roles within society (Bowling 1995).

The most widely used conceptual frameworks for health, illness and disability are the WHO classifications (1980 and 2000).

1.1.1 The WHO classifications.

The WHO classifications are classification systems that aim to provide a unified and standard language and framework for the description of health and health-related states (ICIDH-2 p6). They aim to provide a scientific basis for understanding and studying health, to establish a common language for describing health, to permit comparison across countries, disciplines, services and time and to provide a systematic coding system for health systems (ICIDH-2, p8).

The first ICIDH was written as a response to the acknowledgement that many acute diseases had been eradicated. There had been a previous classification of illness (the International Classification of Diseases (ICD), now in its 10th edition) that focused exclusively on disease states. Evaluation of the acute disease state can be relatively straightforward. Measuring health outcomes in *chronic* disorders, however, was seen as more problematic and necessitated classification beyond diagnosed conditions and onto the *consequences* of those conditions (Gray & Hendershot, 2000).

The ICIDH-1 (WHO 1980) was an attempt to do this. It represented a significant break from the past. As Gray & Hendershot point out

> "the original ICIDH opened the door to include factors outside the traditional classification of disease, illness, and the functional limitations that framed the concept of disability" (pS10)

This 1980 version divided health states into three separate categories; impairment (the loss or abnormality of psychological, physiological or anatomical structures or functions), disability (consequences of impairments in terms of functional performance and activity) and handicap (the disadvantages experienced by the individual as a result of the impairment and disability).

The ICIDH-1 as a means of conceptualising health and illness in the context of disability, however, was not without its critics. In 1993, the WHO reprinted the ICIDH and included a foreword stating its intention to revise the document to overcome a number of identified limitations. The ICIDH-2 was published in 2000.

The second version (ICIDH-2) used a two-fold classification; body functions and structures, and activities and participation (disability). Additionally, it categorises contextual factors (environmental and personal) that can act in a positive way (facilitators) or a negative way (barriers) on the functioning and disability areas previously categorised.

The WHO classification systems capture and frame the complexities associated with conceptualising health, illness and disability. Both WHO classification publications stress the distinction between impairments on the one hand, and consequences of the impairment on the other. The way they separate the consequences and significance of the impairment varies however. The first version (ICIDH-1) locates the effects of the impairment with the individual; 'disabilities' and 'handicaps' are seen as the resultant, automatic consequence of the impairment alone. The second version (ICIDH-2) locates the effects of the impairment within society. The location of the cause of disability is beyond the individual, and is seen to be the result of barriers within society (environmental, technological, physical, personal, structural (services, systems and policy) and/or attitudinal). A detailed examination of the conceptual relevance of the WHO classifications will be addressed in chapter 3.

When considering exploration and measurement within health care, the way in which health and illness are conceptualised and categorised is of particular significance. When new measures are developed, the subject and domains chosen to be measured will be influenced by the conceptual frameworks that exist at the time of development. Equally, the conceptual framework within which health care professionals operate will influence what they choose to measure, explore and influence. Conrad (1990) suggests, in the context of explanatory models that might be available (such as the WHO classifications), that

> "the definitions people hold on health and illness, as well as the exploratory models they use, affect both their experience and what they do about it" (p1261)

The effect of environmental/external factors (barriers and facilitators or attitudinal influences) was not part of the ICIDH-1. If factors were not perceived as being relevant to a concept of health, illness and disability then it is unlikely that these would be selected as areas to measure (and thus influence). 25 years ago these factors were not seen as relevant, (by the authors of the WHO 1980 document), to evaluation of notions of health, illness and disability. Today, barriers and attitudinal influences are seen as crucial to our conceptualisation of how a disability or an illness is construed and experienced by the individual concerned, and by society. These areas would today be seen as legitimate domains for exploration and measurement where three decades ago they were not. So the WHO classification system shed some light on why certain areas were selected for measurement and certain areas were not. If, at a structural level, society do not conceptualise issues such as environmental factors as being relevant to health states, their importance will not be recognised and measures will not be available to assess their impact. At a personal level, if individuals (including health professionals) perceive disability as being an individually-based construct, they will seek solutions that involve changing aspects of the person with a disability. They may not seek solutions that involve the examining and changing of external barriers erected by society.

1.2 Why explore and measure health, illness and disability?

The link between why and how health is explored is inextricable. As has been mentioned the framework within which health care is conceptualised will influence the methods chosen to explore aspects of health, disease and disability. Health care aims to promote, maintain and/or improve health. To be able to encourage positive aspects of health and reduce or eliminate negative aspects, these aspects of health, illness and disability have first to be identified. As has been mentioned the most influential conceptual frameworks over the last thirty years have been the WHO classification systems, and until relatively recently the 1980 classification (ICIDH-1) was the framework most widely adopted. With the focusing of attention on 'impairment', 'disability,' and 'handicap' those seeking to provide health services saw *measurement* as playing a key role in service delivery.

Measurement makes a number of things possible; measurement enables the assessment of the relative extent of illness, disease and/or disability. It enables changes in health-related characteristics as a result of intervention, time, or other factors to be monitored and communicated. When used in this way, healthcare measures are often termed outcome measures.

Measurement enables the identification of priorities and preferences in health domains that can guide treatment. Nelson et al (1990) for example suggest that measures are useful if they affect the communication or topics discussed, if new or useful information is gleaned, or if new management is stimulated as a result of the process of measurement.

Measurement can be beneficial for clinical partnership, between clinician and person who is the subject of measurement. From the perspective of the client, demonstrating improvement in health-related areas can aid motivation, validate the efforts and progress made so far, or encourage dialogue about a change of direction if improvement is not seen. Paterson (1996) suggests it can also validate the personal experience of illness. The process of measurement, if practised collaboratively, enables the establishment of a partnership between the person being measured and the person measuring. This facilitates a shared knowledge and common expectation of the outcome as a result of any intervention (or indeed in the absence of intervention). Higginson & Carr (2001) suggest that

> "Assessments can help identify the patient's preferred outcome or treatment goals. If these are not known then the treatment may not meet the patient's expectations, and this may affect adherence to treatment and patient's satisfaction with care" (p1300)

At a research and managerial level, collective scores on health care measures can assist in evidence-based practice and informed decision making for purchasing effective health care. As Herrman (1999) suggests

> "Service providers are more and more aware of the need to be accountable, to improve the quality of their work, and to use the available resources in the best and fairest way possible, ensuring that evidence influences practice" (p113)

So it can be seen that the *information* gained from measurement can be used at a clinical level, for research purposes and at the level of service delivery. The *process* of measurement can affect the effectiveness and validity of the delivery of health care. Depending on the purpose of the measurement, different audiences will be involved and interested. As Mc Horney (1999) suggests

> "the feasibility and credibility of different (health status) applications ultimately depends on whether they yield meaningful and useful information for decision-making, whether it be by patients, providers, policy makers, payers, regulators, or legislators" (p313)

1.3 Aspects of measurement design in health care

The types of health care measures that are used (or developed), with be fundamentally affected by the audience for the information and purpose of measurement. This, in turn, will lead to choices being made about *how* this information is obtained. There are a vast assortment of instruments have been developed and used within health care. The diversity of design is a reflection of the range of purposes to which health care instruments can be put. It is also affected by the conceptual framework within which the tools have originated and will be used. Discussion about some of the key aspects of instrument design will inform debate about the measures previously and currently available.

1.3.1 Subjective and objective measurement in health care

Objective measures seek to quantify health facts; features that are not subject to interpretation or perspective. Conversely, subjective measures specifically strive to capture the perspective, interpretation and personal meaning of health, illness or disability. Both are represented in health care measurement leading to two predominant types of conceptual model emerging; function-based (primarily from a bio-medical perspective emphasising maintenance of functional abilities) and meaning-based (focusing on the patterns and experience of illness from a subjective and holistic perspective, derived from people's understanding of their situation and their autonomy, beliefs, choices and relationships with others) (Haase et al, 1999).

There is acknowledgement of the fact that neither objective nor subjective measurement is inherently superior. Felce (1997) points out

> "whether the measure is an objective or subjective indicator, the mark of a useful measure is that it taps some aspect of the experience of living life which can be understood and interpreted by people at large" (p132).

The choice between these two perspectives should be based on the information being sought and the purpose of measurement. The choice will affect the content of the measure and the method of administration employed (including who makes the rating).

Discussions relating to the value of subjective measurement have been widespread within a currently popular field of health related quality of life research. There are those who believe that quality of life is inherently so subjective that it is unmeasureable (Leplège & Hunt, 1997). There are, however, many authors who believe that measurement from the perspective of the subject has a crucial part to play in health care evaluation, (Felce, 1997 and Bowling, 1995). Gladis et al (1999) for example, have demonstrated that it is people's subjective health state that determines their treatment-seeking behaviour, their compliance, and their evaluation of treatment.

There is recognition that subjective measurement can raise conceptual and methodological difficulties and will involve investigating areas that were previously thought unmeasureable (Streiner & Norman, 1995). This will be discussed in chapter 3.

Subjective does not *necessarily* mean from the perspective of the person with the illness or disability. A third party can give a subjective interpretation on someone else's quality of life or health status. Subjective merely means that the information is opinion not fact. It should be noted that the term 'subjective' is used inconsistently within the literature. Though it *can* relate to measurement by someone other than the subject of measurement (as mentioned above), most authors will usually be referring to rating made by the subject. When used within this thesis, the term 'subjective measurement' will always relate to measurement made by the person who is the subject of the measurement, unless specifically stated otherwise.

1.3.2 Subject, observer and proxy rating

Discussion relating to measurement does beg the question, who is doing the rating? Health care rating can be made by the person themselves (self-report), by someone else who knows them or is trained to observe for the behaviours being rated (observer rated), or by someone who is seen as representing the views of the person, who for varying reasons is seen as unable to rate him/herself (proxy rating). All these groups can rate subjectively (interpreting the situation from their own perspective). However, observer and proxy ratings are usually justified on the grounds that the potential respondent is 'unable' to provide a reliable response and therefore relies on a third party (Bowling, 1995).

There are good reasons why the perspective should be that of the person who is the subject of measurement. Lipowski, as long ago as 1969, was marrying personal experience with what was being measured, seeing an inextricable link between the two.

> "how a person experiences the pathological process, what it means to him, and how this meaning influences his behaviour and interaction with others are all integral components of disease viewed as a total experience" (p1198)

On psychometric grounds there may also be good reason to favour self-report. The psychometric validity of an instrument can be increased if using self-report methods. The self–completion version of the McMaster Health Index Questionnaire (Chambers et al, 1987) was reported to be the mode of administration most sensitive to change. Wu & Rubin (1992) enquire

> "are patients' own perceptions of health important? Even very simple health status measures have been shown to be independent predictors of outcome including mortality...patients were asked to respond to the simplest of self-rated health-questions: "how would you rate your health: excellent, very good, good, fair or poor?" At twelve year follow up this question was a better independent predictor of mortality than a host of clinical variables from the history, physical, and laboratory testing (Idler and Angel 1990) " (p254).

The COOP charts (Nelson et al, 1990) are self report measures that aim to measure health and functional status in primary care consultation. The authors describe how using the charts improves physician-patient communication by identifying and promoting discussion of the full burden of illness experienced by patients, that would physicians would have failed to recognise 'spontaneously'. Gladis et al (1999), point to discrepancies between 'patient' and informant (significant others) in their reports of illness. Similarly, several studies have reported differing perceptions between doctors and their patients (Slevin et al, 1988, Hall et al, 1976, and Rothwell et al 1997). All found very low correlations between doctors and their patients' perceptions of their health and illness. In the speech and language therapy profession, studies have shown a lack of concordance between the views of people with aphasia (acquired language impairment) and the views of their primary caregivers, (Oxenham et al, 1995), and the views of the professionals who were providing them with therapy, (Müller, Code & Mugford, 1983, and Oxenham, 1995).

Epstein et al (1989) similarly found intermingling of proxy and subjects measurement led to biased results when examining health status through interview. Sprangers & Aaronson (1992) reviewed a number of studies relating to the use of proxy measurement to study quality of life. They found that; health care providers as proxies tended to underestimate quality of life; health care providers and significant others rated with a comparable degree of (in)accuracy; significant others ratings could be closer to the person concerned's if they lived in close proximity to him/her, but that the rating were biased by the care giving function of the rater.

These findings are unsurprising. Health is a subjective concept, and it should therefore be no revelation that there are differences between how the person interprets her/his own health status, and how someone might see it.

So it appears that where possible self-report should be sought, as it provides more reliable, valid and 'authentic' ratings when investigating subjective aspects of health or illness.

There are, however, occasions where proxy ratings may be acceptable. If the information relates to aspects of impairments or disease state of a biomedical nature, then proxy measurement is needed (blood pressure, cardiac output or such like). There may also be situations where the person who is the subject of measurement is not able to respond. In cases where people are frail, very ill, or have significant cognitive or communication difficulties, proxy ratings are common place (Bowling, 1995). The legitimacy of this position will be discussed later in this chapter.

1.3.3 Type of instrument; generic, disease or domain-specific.

A further distinction must be made depending on who the instrument is designed to be used with. There are three broad types within this classification; generic, disease specific and domain specific measures. The choice of which type of instrument is used will again depend on the purpose of measurement. Each type of instrument has its advantages and limitations.

Generic measures will be used if a comparison is to be made across populations (such as people from different countries, people who are healthy, people with different illnesses or disabilities). They are usually broad in their focus of investigation. Their limitations lie in their reduced ability to identify aspects of a health state that will be specific to the condition or disease. This means that they may lack sensitivity particularly when attempting to document change (Brod et al, 1999).

If the investigator has a particular interest in one domain to the exclusion of others, then a domain specific measure would be appropriate. By necessity, therefore, they will exclude measurement of broader aspects of health and illness states, but provide greater sensitivity to the area that is measured (Jenney & Campbell, 1997).

The final group of measures are disease specific measures. These are designed for use with a specified group of people with a particular disease or condition. They can be useful when a greater degree of detail is required to pick up smaller but clinically significant changes in health or illness states. They can also be useful when the nature of the disease itself presents barriers to assessment through conventional means, in groups of people who are at risk of exclusion, such as people who have dementia (Williams, 2000).

Both domain and disease-specific measures are often long in comparison with generic measures, and need to be so to retain their sensitivity and psychometric properties (Bowling, 1995).

As mentioned the choice between generic versus other types of instruments is often informed by the purpose of measurement. If the information is to be used to guide therapeutic intervention then the measure may investigate in greater detail than if the measure is part of a research project, where HRQoL (for example) is one of a number of outcome measures being used to make comparisons between different groups. When discussing the concept and definition of HRQoL (Felce, 1997 for example) suggests

> "I recommend being flexible in methodological approach. We should recognize the strengths of alternative measures and celebrate their potential for reflecting different aspects of this complex concept" (p134)

As alluded to by Felce, different types of instruments do not have to used in isolation. There are investigators who recommend using a generic instrument together with either a domain or disease specific one, especially when attempting to document change (for example, Ware, 1993 and Bowling, 1995). Though acknowledging circumstances where different kinds of instruments may be used in combination Bowling (1995) urges caution if this results in overlapping questions, fatigue for the respondents, expense or an overwhelming amount of data.

1.3.4 Method of development

A further feature that differentiates health scale measures from one another, relates to the methods used to develop them. One crucial factor involves the degree to which the people who are ultimately intended to be the subject of measurement, are involved in developing the measure.

Some health care measures were developed by interviewing the client group themselves to establish their views and priorities and therefore identify the domains that should be covered. The Nottingham Health Profile (Hunt 1986) and the Sickness Impact Profiles (Bergner et al 1993) for example, were both developed after large numbers of the general public were consulted using interviews about their perceptions of illness behaviours and perceptions of health states. (This is interesting as these two measures emerge as two of the most popular generic health measures out of the vast number of measures that exist (Bowling, 1995)). The WHOQOL instrument used targeted focus groups, whose participants were drawn from populations of healthy people, people with disease or impairment and finally health professionals.

Other scales, however, were developed using professional constructs alone. The authors of the Stanford Center Health Assessment Questionnaire (the HAQ) (Fries et al 1980) did not canvass users when being developed. As Bowling reports

> "The framework used for the development of the HAQ was based on the belief that a patient desires to be alive, free from pain, functioning normally, experiencing minimum treatment toxicity, and financially solvent. Patient outcome was thus represented by (1) death, (2) discomfort, (3) disability, (4) therapeutic toxicity, (5) dollar cost" (p20).

So some scales are developed after consultation with potential users, others have been developed using professional constructs. The relevance of the constructs included therefore will be greatly influenced by the developmental framework chosen.

Methods for measuring health, illness and disability therefore vary depending on the purpose of exploration and how the information gained will be used, the audience for whom it has been developed and with whom it will be used, the way in which the instrument has been developed, and the conceptual context in which the tool has been developed. As a consequence therefore there is a vast array of measures covering differing contexts and suiting different purposes.

1.4 Measures currently available

There are some broad categories of health care measure that are recognised. Measures within these categories will be diverse in accordance with the conceptual influences discussed above. The categories include measures of impairment, function, activity and participation, quality of life, and psychological well-being.

The following section will summarize examples of instruments within these groupings that are currently available within the field of health care measurement. Their relative strengths and limitations will be discussed briefly, with a more detailed examination later in the chapter in relation to their usefulness when measuring the language disability, aphasia.

1.4.1 Measures of impairment

Impairment-based measures, common to both WHO typologies, have had a long history. Impairment measures focus on biomechanical structures and functions. They are usually domain specific, measuring exclusively one aspect of structure and/or function.

In clinical medical trials for example, mortality and morbidity indicators have for many decades, been used by clinicians as outcome measures, focusing almost exclusively on impairment-based measurement (Bowling, 1997a). The domains measured can be as diverse as blood pressure measurements, chemical analyses, visual perceptual tests through to word-to-picture matching and grip strength.

Impairment tools aim to provide objective measurement, and are routinely administered by a clinician or technician, rather than by the person who is the subject of measurement.

These measures are recognised as providing a necessary but narrow and negative perspective of health, illness or disability (Streiner & Norman, 1995).

1.4.2 Measures of function

Functional measures also have a long history. Functional measures are based on the concept of measuring the capability of an individual to perform tasks. They aim to provide objective measures of what activities a person can or cannot complete. Bowling (1997a) describes how

> "some (functional) measures focus simply on basic functioning (e.g. mobility) but, more commonly, they include items of instrumental, or extended, activities of daily living, which encompass the activities that are required for the maintenance of independence, as well as optimum levels of functioning" (p16).

There are many measures of functional ability, the most common of which are described in table 1.1 (Measures of function). They are usually a negative representation of health focusing on the limitations of functional ability. They can be both observer or self-rated.

These measures can be disease-specific but more commonly relate to specific activities of daily life usually mobility, domestic and self-care (Bowling, 1997a). They vary in the conceptual background within which they were conceived; for example, the ADL (Katz & Akpom, 1976) focuses on the elderly and those with chronic illness. The Barthel (Mahoney & Barthel, 1965) on the other hand was developed to measure functional states before and after treatment, for people with long-term neuromuscular or musculo-skeletal disorders.

These functional assessments also differ in the domains they address whilst all aiming to measure 'activities of daily life'. The FIM/FAM (Stineman et al 1994) for example, include communication and cognition, which the other commonly used functional measures do not. All functional measures relate to behaviours and abilities not perceptions.

There is also the problem that different people react differently to apparently similar levels of physical impairment. These measures are usually observer rated and do not take this into account. Perceived severity with both disability and dependency is dependant on a myriad of factors such as someone's expectations, priorities, goals, social networks, and previous history (Bowling, 1997a).

There are also environmental considerations. Functional limitations may be more related to the physical location of aids and facilities like toilets or bathrooms rather than severity of an impairment (Bowling, 1997a). The relevance of assessment in a location other than the one within which the activity will ultimately be performed is therefore questionable.

Functional scales have also been criticised for their lack of sensitivity, (Bowling, 1997a).

1.4.3 Measures of activity and participation

Alongside dissatisfaction with the domains quantified by functional measures and their lack of sensitivity, has come a concentration on the *effects* of health and illness on everyday life and a focus on the *experience* of health and illness. The individual's subjective view on the impact of health and illness is seen as increasingly important in this field.

Activity and participation measures therefore have been developed in an attempt to capture the consequences and significance of states of illness or health, and to capture it from the perspective of the individual experiencing it. This is reflected by the fact that the majority of these measures are rated by the subject of measurement rather than the clinician. Table 1.2 gives examples of some of the measures of activity and participation currently available.

Each one of these measures seeks to record the illness (or health) experience as perceived by the individual. Most conceptualise health in a negative way (e.g. as its name suggests the Sickness Impact Profile), though others, such as the McMaster Health Index Questionnaire (Chambers, 1976), are positive in orientation (Bowling 1997a). Some emphasize behaviours and change in behaviours (such as the Sickness Impact Profile which documents perceived abilities and changes in those abilities) while other emphasis feelings and experiences (such as the Nottingham Health Profile which can be used to survey whether someone thinks of themselves as having a health problem).

Activity and participation measures are designed to be used across general populations and are therefore generic measures. They quantify the activities of daily activities within slightly different typologies, and vary in duration. They range from the WONCA-COOP charts (Nelson, 1990) which take 5 minutes to the Impact on Participation and Autonomy (Cardol et al, 1999) that is reported by the authors as taking up to 45 minutes.

1.4.4 Measures of psychological well-being

A different perspective is taken with the next group of measures. This ‘family’ of measures seek to narrow the investigation to specified emotional states, usually from a negative perspective. Table 1.3 gives examples of routinely used measures of psychological well-being.

These measures are usually disease specific, as most of these scales measure aspects of psychiatric illness. They focus in varying combinations on domains covering cognitive (such as depressed mood, guilt, suicidal ideation) and somatic symptoms (weight loss, gastro-intestinal symptoms, loss of libido etc) of psychiatric illness.

They are usually self-report measures, but they do vary in terms of mode of administration. The Hamilton (Hamilton, 1960) for example combines self report with an observational researcher-administered scale, with interviewer-training, necessary.

Their inclusion here is justified on the grounds that well-being is a domain of significance when considering the impact of stroke and aphasia on someone's life. A number of such measures have been used in research within this filed. They are therefore included within the review.

1.4.5 Measures of health-related quality of life

Quality of life is a concept salient to many disciplines; social science, employment, housing, and conservation for example. The discussion in this thesis will relate only to how health issues impact on quality of life; what is termed health-related quality of life (HRQoL). A discussion around the conceptual relevance of HRQoL can be seen in chapter 3. The discussion in this chapter will be limited to what HRQoL measures are available and how they can be used.

Interest in HRQoL has burgeoned over the last 15 years. Muldoon (1998) suggests that HRQoL was virtually unknown in the 1980s but that now there are a 1000 new articles indexed each year under the term quality of life. Though there is debate about the conceptualisation of HRQoL, most authors working in this field believe there is a consensus on the domains that are included. The four domains universally covered appear to be physical capacity, psychological well-being, social relations and environmental mastery (Williams, 2000).

The WHO (1994) suggests that HRQoL is multi-dimensional and subjective, and that it includes both positive and negative facets of life. HRQoL measures therefore go beyond measurement of abilities, functions, roles and participation. They seek to explore broader concepts; perceptions of an individual's response to the physical, mental and social effects of illness on everyday living, which influence the extent to which personal satisfaction with life circumstances can be achieved, Bowling (1997). This subjective focus is reflected in the fact that HRQoL measures are almost without exception self report measures. Table 1.4 gives some examples of instruments that have been described as HRQoL. As can be seen some measures previously described as activity and participation measures are included. This demonstrates the conceptual overlap.

Despite HRQoL measurement being a huge and ever-expanding field within research, there is little evidence for its clinical utility, as HRQoL tools are rarely used in clinical practice, (Higginson & Carr, 2001). It seems that the concept of HRQoL has been embraced particularly within research. The conceptual difficulties that have hampered the use of HRQoL instruments in clinical practice will be discussed in chapter 3.

1.4.6 User generated measures

As a result of some of the conceptual and methodological difficulties that have arisen for clinicians in attempting to measure HRQoL, a different approach to health care measurement has emerged. This new approach draws on interest in involving the person who is the subject of measurement, and on her/his perceptions of health, illness and health care. These measures have been called, variously, individualised, (Higginson & Carr, 2001), patient-specific (Cairns, 1996), and patient-generated (Ruta et al, 1994 and Paterson, 1996). Whatever the terminology, they represent a departure from traditional health care assessment.

These measures are based on the acknowledgement that perceptions of health are subjective, and that valid estimates of health, disease or disability cannot adequately be assessed using standardised measures that ask every person the same questions and require responses to be selected from a predetermined set, Higginson & Carr (2001). Table 1.5 gives examples of individualised measures.

The SEIQoL (and SEIQoL-DW) (O'Boyle 1992) and the PGI (Ruta 1994) are the two most promising in terms of conceptual and methodological construction (Higginson & Carr, 2001). These two instruments seek to elicit the value system of a person and to quantify HRQoL using this elicited system. Both are novel in that they enable the person completing the measurement to do the following: select the domains of investigation, rate them (using a visual analogue rating scale or points out of 100) and weight the areas relative to the importance that the individual attaches to each identified area. The instruments (having originally been designed for postal use in the case of the PGI) are both administered through interview.

These instruments are in the early stages of development particularly with regard to demonstration of psychometric properties (Jenkinson et al, 1998). However, there is a concern at present over the accessibility and usability of these types of measures. MacDuff (2000) reports that Coen et al (1993) used the SEIQoL with people who have mild dementia. Only 6 out of the 20 recruited were "willing or able to complete the full SEIQoL procedure". Even people who did not have dementia had problems. Similarly, the authors of the PGI themselves found that 37% of people with low back pain were unable to complete the tool correctly (with 49% being unable to complete it for other client groups) (Ruta et al, 1994).

Psychometric reliability is also a thorny issue. As MacDuff (2000) points out there is recognition of the dynamism of HRQoL as an individual construct. This makes comparison for the same individual over time difficult to interpret. An associated issue is that respondents bring different issues to the rating at different times. MacDuff (2000) suggests that this makes comparing overall scores between two time periods, problematic. An intervention may have been very effective at one time, but this may not be reflected in the second score as the respondent's expectations may have subsequently increased (MacDuff, 2000). He recognises the inherent tension between the need to reflect true change (responsiveness) and the need for reliability. In this regard there is debate over whether respondents should select new dimensions each time they complete these instruments, or whether they should be given their original areas and ratings for reconsideration.

Carr & Higginson (2001) discuss user-generated indices. They suggest that some people have difficulty understanding the system of rating and add that people may not readily volunteer some factors that are important to them, particularly those that relate to mood, and the information that an individual is willing to volunteer may change over time.

This additional anxiety leads to concern about how genuinely user generated such indices are. The PGI for example has a prompt list. It is used if the person using the instrument does not supply areas of importance affected by the medical condition without assistance. Some authors have demonstrated an association between the domains on the prompt list and the content/expression of the respondent's answers. MacDuf & Russell (1998) found a strong association and believed it was not clear whether the association was due to the pre-selection of items by the authors being apposite, or respondents being unable/unwilling to think of their own and unduly influenced by the prompt list. Carr and Higginson (2001) when discussing this issue point to the fact that Bowling (1995) demonstrated discrepancies between the free responses that people made about the areas of life that were most affected by disease and those elicited using "prompt cards". It led them to question whether the index is therefore truly patient generated.

Streiner and Norman (1995) suggest that because of ceiling effects, these measures may make intervention look inappropriately effective.

> "if patient A has 11 problems and patient B 76 then any scale that allows for only 5 will show the two patients as the same. They both have only one way to go – downwards therefore intervention looks successful." (p23)

Along similar lines Jenkinson et al (1998) had concerns about the validity of the findings using the PGI. They demonstrated that the PGI detected improvement better than the SF-36 and the EuroQol (EuroQol Group, 1990), but they suggested that the areas in which the improvements were seen actually had limited impact in the first place. The PGI was seen as detecting, but perhaps overemphasising, a real but potentially small (subjectively and clinically) improvement. Macduff & Russell (1998) conclude that the current irony of the PGI is that its conceptual strength (its rejection of predetermined areas and reliance on user generated ones) is one of its main sources of practical and psychometric weakness.

Despite these difficulties, several authors have praised these types of measures. Bowling (1997) describes the PGI as ‘refreshingly original’ and that the PGI ‘shows the way forward for this field’. Higginson & Carr (2001), when reviewing all types of HRQoL measures for clinical medical practice, suggest that

> “The use of individualised measures in *research* has been limited by difficulties in administering and scoring them, but in *clinical* practice they have immediate relevance. They are designed to detect individual’s problems and as such are more readily interpreted in ways that are clinically meaningful. They also provide a basis for sharing clinical decision making between patients and clinicians, identifying patient’s priorities for treatment, and facilitating the setting of realistic goals” (p1304) (emphasis)

It appears that HRQoL measures have found favour in the research domain but may lack clinical utility, while the reverse is true of user-generated measures.

1.5 Those at risk of exclusion from health measurement

The advantages of subjective measurement have been acknowledged. However, there are a number of groups of people for whom measures of the standard kinds reviewed above will present problems. Standard measures may be inaccessible or inappropriate for people who have cognitive or communication impairments, who are frail or in severe distress. There is evidence that such groups of people are frequently excluded from studies where health measures are used, and are excluded specifically because of their impairments. Sutcliffe et al (1999) for example, reported the exclusion of those with dementia from studies of health in elderly people. Eiser et al (2000) suggest that proxy rating is usually employed when measuring HRQoL in children. When looking at ‘meaningful life activities’ in stroke survivors, Clarke et al (1999) reports excluding those “who were aphasic, demented or too ill to complete the handicap assessment". Similarly Niemi et al (1988) reported the exclusion of six people because "three had severe aphasia, two were demented and one refused". Williams et al (1999a) highlight a dilemma caused by exclusion.

> "In stroke research, the disadvantages of generic HRQOL measures are particularly apparent…if generic HRQOL measures do not assess… communication...then how can the effects of these common stroke impairments on HRQOL be measured" (p1839).

Addington-Hall & Kalra (2001) discuss HRQoL in this context. They comment that the people in the groups mentioned above are precisely those for whom inclusion in health care issues and decision-making is most crucial. If they have difficulty voicing their opinions through standardised assessment, it is likely that they may be at risk of having difficulty 'being heard' in any ways, therefore making them vulnerable to being more widely disenfranchised (Hatton, 1998).

1.5.1 Groups of people at risk of exclusion

The groups of people most commonly excluded from health care measurement (and therefore decision-making) include children, people with dementia, people with mental illness or intellectual disability and those with terminal illness. The following sections will identify why these people might be at risk of exclusion, what efforts have been to include these people and what can be learnt about inclusive practice from this discussion.

1.5.1.1 Children

1.5.1.1.1 Issues that have contributed to exclusion of children.

Children present particular problems for those measuring health and illness. Their different level of maturity and experience will influence the way they approach any form of testing. This will therefore make the process of health care measurement different from that seen with adults. When discussing HRQoL for example, Jenney & Campbell (1997) discuss the difficulties of taking into account the normal physical, emotional and social developmental changes that occur and the child's ability to understand the concepts that are being addressed.

Health measures available for adults may simply be inaccessible to children (Smyth, 2001). This may be due to limited reading skills, or the fact that young children are unlikely to be able to make fine discrimination required on a multiple point scale (Eiser et al, 2000).

More subtle barriers are described by Hart & Chesson (1998) who point to the interpersonal dynamics between health care staff and children. They suggest a major difficulty lies in the fact that children's responses to health care staff may reflect what the child thinks the administrator wants to hear rather than the child's true feelings. This so-called 'gratitude barrier' is so powerful that some children will complete a questionnaire despite having not understood it. They may also do this to avoid looking incompetent (Eiser et al, 2000).

Children's perception of issues and priorities related to health and illness may also be different to that of adults, due to cognitive immaturity, limited social experience and continued dependency (Eiser et al, 2000). They suggest therefore that the scales may be not only inaccessible to children, but also unacceptable in the constructs they address.

As a result of these limitations, proxy ratings have often been employed. Caregivers (parents, doctors, nurses) are the proxies who commonly give rating instead of the child themselves. Eiser et al (2000) point out that the results obtained from proxy ratings, however, represent an adult's perception of the child's experiences and are influenced by the age, sex and socio-economic status of the proxy respondent, as well as their relationship to the child.

As with most proxy rating, there is evidence to suggest that proxy responses by parents correlate poorly with the perceptions of the child they are representing (Jenney & Campbell, 1997).

Erling (1999) discusses proxy ratings and proposes that the child's rating is not necessarily the *right* rating merely that it is one perception that will differ from others (such as doctors and parents).

1.5.1.1.2 Strategies to foster inclusion of children

To overcome some of these difficulties a number of strategies have been tried. Eiser et al (2000) suggest a number of strategies to increase accessibility of the measures for children; language should be simple and unambiguous with no complex grammar or vocabulary and short sentences; the use of pictures or props can support both comprehension and expression; children are likely to relate to images, which they identify as looking like themselves or fitting appropriate stereotypes (girls responded better to girl puppets and boys to boy puppets); young children have a short attention span so tasks must be perceived as interesting, enjoyable and capable of completion in a relatively short period of time, if the task or responses required changes regularly children's attention can be maintained for longer; the need to link questions to children's experience and to have concrete rather than abstract examples.

Other authors suggest other options to elicit views from children on subjective health; the use of videos and computers (Jenney & Campbell, 1997), use of 'talking pictures' (King, 1992) and the use of spontaneous drawings in activity booklets and games (Bach, 1991). Bach suggests that these methods often informed her of the somatic as well as the psychological condition of the child.

Eiser et al (2000) point out that children can easily be underestimated and that if the tools are appropriate, then active, reliable participation can be achieved. It has been demonstrated that children are able to solve problems when they were phrased in ways that children could understand and put into a context with which they were familiar (Mohay, 1997). Siegal (1990) for example, demonstrated that young children have no difficulty understanding the concepts of contamination and contagion when questions related to situations that the child could visualise.

Aspects of health and illness that are perceived as important, differ between adults and children. It is therefore not appropriate simply to change wording in a questionnaire devised for adults and use it with children; the concepts that are included need to be different and in accordance with children's views (Erling, 1999). This is a need seen for fundamental research concerning children's abilities to rate statements and use scales (such as visual analogue scales), in addition to the more creative approaches used to eliciting information from young children (Eiser et al, 2000). Issues such as a child's age and stage of emotional and cognitive development are seen as needing consideration (Hart & Chesson, 1998).

1.5.1.2 People with dementia

1.5.1.2.1 Issues that have contributed to exclusion of people with dementia

Mozley et al (1999) reported a concentration on third party informants and observation in health care measurement with people who have dementia. This is worrying as Hickey and Bourgeois (2000) for example found a lack of relatedness between nursing home assistant reports and resident reports of depressive symptoms.

Reasons for exclusion from health care measurement are the result of two main barriers. Firstly, the respondent's ability to comprehend the question being asked may be compromised, and secondly the respondent's awareness of his or her internal subjective state may be unreliable (Brod et al, 1999). Comprehension of the question may be impaired due to shortened attention span, impaired comprehension, or impaired memory. Brod et al (1999) reported that standard methods of administration may be inaccessible to people who have dementia. For example they found that their respondents had difficulty with unlabelled points on the scale.

Mozley et al (1999) suggest that there are three key cognitive abilities necessary for interviewing; namely a minimum level of orientation to place, language skill and attention. All these abilities may present as compromised and thus be barriers to participation in scale completion.

As with children, the challenges for health measurement are not confined to ease of completion and making a tool accessible. The issues and priorities of concern for someone with dementia cannot be assumed to be the same as for someone who does not have dementia. Brod et al (1999) for example when developed their assessment for measuring HRQoL with people who have dementia, discovered that a sense of well-being is defined in terms of mood state (as in population of people who do not have dementia), but also in terms of embarrassment, self-consciousness, and feelings of being useful. The acceptability of the constructs that are included may present a barrier to valid health care measurement with people who have dementia.

1.5.1.2.2 Strategies to foster inclusion of people with dementia

Brod et al (1999) believe that most studies that have looked at the ability of people with dementia to report on their own conditions, have not paid attention to the issue of questionnaire formatting, administration methodology, or comprehension factors. Brod and her co-workers (1999) are among researchers who are actively seeking ways of including people with dementia by investigating *in detail* what the limitations are to participation and how these can be overcome. They propose that there is a growing body of evidence suggesting that many, if not most, people with early and moderate stages of dementia are able to comprehend and answer questions about themselves and their situation.

They suggest that the quality of data obtained from people with dementia can be improved by paying more attention to issues such as item clarity and simplicity, formatting, limited attention span, and response burden. They found for example, (like Hickey & Bourgeois (2000)), that respondents had some difficulty with the unlabelled points on the scale. Therefore in the third and final iteration, all points on the scale were given descriptors, the number of response choices was reduced, with no specific time frame for an item. These changes improved the responses gained.

Mozley et al (1999) also found response option number crucial, discovering the advantage of a five-point 'Likert'[1] scale rather than the seven-point scale used with younger people. Through changes such as these, Brod and her colleagues (like Mozley and hers) were able to demonstrate that

> "All of the scales had at least moderate reliability, and preliminary evidence of validity was found. Thus we consider the items that exhibited problems to be due to *our inability to design adequate measures.* Nearly all demented participants were able to respond to test questions appropriately indicating that comprehension was not an issue" p34 (emphasis added)

McHorney (1996) found that although cognitively impaired patients took twice as long to complete a 245-item self-administered survey, and had a higher proportion of missing data, with few exceptions results of psychometric tests of validity were comparable between people with and without dementia.

It is interesting to consider why the above authors have included people when others have not. Apart for the modifications to the questionnaire construction, there is also a deliberate attempt to understand the real nature of the impairment that leads to potential exclusion. Through a detailed understanding of the condition, the authors who successfully included previously disenfranchised groups, were able to uncover which impairments *necessarily* excluded someone from participation and those which did not. Brod et al (1999) suggest that

> "There is considerable argument over whether awareness is a global or modality-specific phenomenon. We would like to suggest that the awareness of cognitive deficit is conceptually distinct from awareness of one's own feeling states, and that awareness of feeling states may be preserved even in instances where awareness of cognitive deficits is impaired. Feeling states do not require an awareness of *loss,* a memory of one's previous functioning, awareness of current functioning, or the ability to compare the two. Feeling states only require and awareness of *being,* of how and who one is...the depth of response that some questions elicited clearly indicated that the respondent possessed a firm grasp on what was being asked and demonstrated his or her ability to answer appropriately" (p33)

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[1] *Likert (Likert 1952) describes a common type of scale. The rater expresses an opinion by rating agreement with a series of statements. The unique characteristic of a Likert scale (as opposed to other forms of rating scale) is its use of the 'agree-disagree' continuum.*

Without such a detailed grasp of the state of being of their potential respondents, instruments designers would be unable to enable their instruments thereby potentially excluding people with memory and orientation problems (sometimes unnecessarily). Brod et al (1999) suggest that we are better served by obtaining self-report data from cognitively impaired people on a fewer number of domains than by not obtaining any at all.

1.5.1.3 People with intellectual disabilities

1.5.1.3.1 Issues that have contributed to exclusion of people with intellectual disabilities

As with people who have dementia, the issue of health measurement for people with intellectual (learning) difficulties is that of cognition. The design and method of administration of most standardised health care measures make them inaccessible for people who have intellectual disabilities. Health care measures generally assume a lack of impairment in short-term memory, comprehension of abstract concepts or complex instructions, verbal expression, and concentration. The presence of impairment in these areas could inhibit successful completion of typical health scales.

Cumins (1997) reviewed some measures which have been developed specifically for people with learning difficulties. He points out there can still be issues of accessibility and acceptability. He discusses one scale that has a presentation form that is entirely verbal, in another the level of abstraction of several of the items was considerable, others required temporal memory and affective vocabulary, all of which were seen as problematic for people with an intellectual disability. Some scales allowed for the items to be repeated or paraphrased. Rapley & Antaki (1996) however, found that if people with intellectual disability are questioned, and their answer queried by the examiner (because, for example, they do not believe the respondent has understood the question), then the respondent is likely to change their response the second time. Similarly, Kearney & McKnight (1997) when discussing preference and choice suggest that people with intellectual disability are especially susceptible to acquiescence. Cassidy (2000) believes that people with intellectual disabilities have a tendency towards compliance because so many elements of their lives are beyond their control. Thus the validity of a health measure might be in question.

The degree of intellectual impairment and presence of concomitant physical impairments will affect how easy completion of health scale measures can be. As with people who have dementia, physical disabilities can co-exist with intellectual impairment thereby increasing the barrier to participation.

There is also an issue of the role people's expectations have to how they rate their situations. Those who have profound intellectual impairment may be excluded from making subjective ratings due to the measures being inaccessible, but also because the constructs being explored are unacceptable for someone whose life may be so significantly restricted. As Felce (1997) discusses

> "like many other societal groups, disadvantaged economically, educationally, or by class, racial origin or other factors, most people with substantial disabilities lack independence and experience constrained autonomy to maintain or change life conditions in line with subjective appraisal, reports of satisfaction may well adjust to this reality...people whose circumstances, status and options make them particularly prone to having low expectations will report satisfaction rather than dissatisfaction even under adverse life conditions " (p129)

1.5.1.3.2 Strategies to foster inclusion of people with intellectual disabilities

Measurement beyond impairment for people with learning difficulties seems to have proliferated in the 1980s. However, the measures produced did not tackle the issues described above, they merely sidestepped them, by focusing investigation predominantly on proxy measurement. For example, the Assessment of Residents' Satisfaction and Family Perceptions Index, Bowd (1988) with three quarters of the rating being proxy or objective ratings. The Quality of Life Questionnaire, Cragg & Harrison (1984) has 70 items, 53 of which are proxy rating and 17 of which are rated by the interviewer.

In terms of the domains investigated with this group of people, health and broader HRQoL issues have until recently seemingly also been avoided. There appears to have been a focus on satisfaction with accommodation and service provision, to the detriment of health and HRQoL. Kearney & McKnight (1997) point out

> "persons with developmental disabilities have faced two important revolutions in service delivery that have affected their lives dramatically. The first...the process of de-institutionalisation and (second) the accompanying principle of normalisation, broadly defined as the provision of living and working

conditions that, as much as possible, approximate those of typical society" (p217).

Cumins (1997) reviewed 13 self-rated QoL scales for people with intellectual disability. 12 out of 13 do not mention health at all. With the earlier scales, the focus on residential satisfaction is unsurprising given the history of major influences for people with learning disability described by Kearney & McKnight.

More recently however, subjective HRQoL (with or without accompanying objective measurement) has become the focus for health care measurement for people with intellectual disability (for example, the Comprehensive Quality of Life Scale, Cummins, (1993)). This recent emphasis on subjective measurement has highlighted some of the issues of accessibility discussed previously.

Cumins (1997) discusses the issue of response mode complexity. He refers to other health scale developers who have used the most simple form of response rating, binary choice, with people who have intellectual disabilities, in an effort to overcome the cognitive difficulties. He points out, however, that information can be lost unnecessarily as there are those people with an intellectual disability who are able to use more complicated response modes and therefore increase the depth of investigation. He therefore includes in his measure a three stage pre-testing procedure which evaluates the extent of Likert-scale complexity each respondent can reliably handle.

Kearney & McKnight (1997) discuss the difficulty of unreliable reporting and the problem of acquiescence. They propose the use of an 'either/or' format in interviews, or pictures to facilitate accurate answers. They suggest that pictorial presentations have several advantages, including time and cost efficiency, flexibility, direct reference to preferences, enhancing the interview process, and utility for people with poor expressive language. Hart & Chesson (1998) report similar success with pictures and photographs with children with learning difficulties.

Coles (2001) suggests the use of semi-structured interviews and participant observation as a way around the accessibility issues related to more traditional health measurement.

Cassidy (2000) suggests an interesting development in how to gain the views of service users who have learning difficulties. He discusses the use of self-advocacy groups with clients who have learning difficulties. He goes on to discuss ways of ensuring valid and active participation by involvement in the planning process, including aspects of decision making, role expectations and personal characteristics which can make the difference between physical presence or active participation. He suggests that this gentle process of sensitivity, especially to group members' communication impairments and related anxieties, must be maintained at all stages of the group's interaction if inclusion is to be secured.

It is interesting to note that, with the exception of the ideas noted above, there appears to be little debate about the accessibility of health measures to people with intellectual disability. There seems to be scant literature available that addresses *how* people with learning disabilities can be included within health and illness *measurement.* Often qualitative methods seem to be the preferred route for exploring health-related with this client group. (Issues relating to qualitative research methodologies will be discussed later in this thesis). Additionally, the debates seem to focus on the *politics* of inclusion, particularly within research, and around preference and choice more generally (though also within the field of health measurement). When the methodological issues of inclusion of people with intellectual disability in measurement are discussed, the focus is on broader themes of type of methods to be used. The examination of details to increase accessibility, does not appear to be focussed on in the literature.

1.5.1.4 People with mental illness

1.5.1.4.1 Issues that have contributed to exclusion of people with mental illness

There has been much debate about how to include people with mental illness in health care measurement with a view to service provision and planning. The 1990 NHS and Community Care Act recognised the importance of taking note of the users views, and using these views in local mental health strategy planning, (Pilgrim & Waldron, 1998). Many people have developed measures for use with people who have mental illness. Bowling (1995 & 1997b) comprehensively reviews the HRQoL measures available. Many of these have been reported as being both psychometrically valid and psychometrically reliable.

Other authors disagree suggesting that there remain issues relating to the ability of people with mental illness to participate fully in measuring health care. The first issue is that many health-related measures available may focus unduly (from the perspective of those with mental illness) on physical health. Many generic measures widely used in general medical environments place significance emphasis on physical health and well-being, making them inappropriate for people with mental health problems (Gladis et al, 1999).

The second major issue regarding measuring health with people with mental illness is that of insight and awareness. It has been suggested that symptoms of mental illness may affect a person's ability to report subjective well-being, and that reports may merely reflect altered psychological states. Katschnig (1997) describes what he calls 'psychopathological fallacies' - states that distort the perception by the person with psychiatric illness of her/his quality of life and the communication of that to others. People who have significant depression, personality disorders or schizophrenia, by definition, have an altered state of awareness. In general terms people with depression will see her/his well-being, social functioning and living conditions as worse that they appear to an independent observer, or to the person themselves once they have recovered. The opposite is true of someone experiencing mania (Katschnig, 1997). Gladis et al (1999) suggest that other impaired mental states can influence judgements of health status in other ways that can account for why people with significant psychiatric disability report high HRQoL or well-being.

> "the cognitive mediation hypothesis itself suggests different interpretations of high satisfaction ratings. Patients, especially those with chronic psychiatric illness, may resolve the discrepancies between what they want and what they have by devaluing specific life domains." (p322).

Gladis et al (1999) go on to suggest that relying solely on the subjective perspective of the person with the metal illness will mean that HRQoL will probably not prove to be that distinct from symptom status, and may distort judgements about life satisfaction.

1.5.1.4.2 Strategies to foster inclusion of people with mental illness

Many disease specific measures have been developed that focus exclusively on people with impairments of mental state (for a review see Bowling, 1995 or Gladis et al, 1999). These measures have been criticised for the lack of subjective weighting and the potential omission of important personally relevant domains (Gladis et al, 1999).

There is also a query as to the validity of subjective health measurement with people who have severe mental illness that alters perception. Katsching (1997) and Gladis et al (1999) conclude that evaluation based on subjective measurement alone cannot overcome this second problem. Both suggest additional evaluations (by proxies; professionals, family members and friends) to compliment the subjective assessment of the person with the mental disability.

Subjective ratings made by a person with mental illness are seen to benefit from proxy ratings from caregivers. Katsching (1997) is careful in the language he uses. He advocates the use of the term ‘external assessment’, emphasising that all assessments made will be subjective. He is also clear about the reason behind including external assessment. It is not necessarily to override the assessment made by the person with the psychiatric disability.

> “the quality of life assessment issue brings to the forefront a basic problem with psychiatry – it reflects the different viewpoints which exist in society about whether a psychiatric condition is present and whether something should be done about it. Most often there is disagreement in this matter between the patient, the family and the professionals, and such disagreement should at least be documented” (p340)

Though he is discussing HRQoL, the principle he espouses holds true for all assessment with people who have a psychiatric disability. As others have suggested with children, he supports using assessment from multiple sources (patient, family, professional), differentiating the components of subjective well-being, role fulfilment, and external living conditions, and assessing of different domains separately (a person’s HRQoL may be excellent at home but inferior at work for example). The complexity of the assessment reflects the complexity of the issue under investigation.

1.5.1.5 People with terminal illness

1.5.1.5.1 Issues that have contributed to exclusion of people with terminal illness

Measuring aspects of health and illness when someone is near the end of their life is particularly challenging. The instrument will be used with people who are likely to be physically frail, may be emotionally or spiritually challenged and may have different set of issues and priorities prominent from the population on whom most health scales are developed and used. McWinney et al (1994) suggest that those designing evaluations of palliative care services should be prepared to deal with difficulties of collecting data from sick or exhausted people including care givers.

Factors contributing to difficulty completing questionnaires include the presence of pain and fatigue that are likely to be present in terminal illness, Teno et al (2000). Addington-Hall & McCarthy (1995) reported a national survey of carers of

2,074 people who died of cancer. 88% of people were reported to have been in pain, 66% of who reported it to be extremely distressing.

Cancer accounts for the vast majority of people who receive specialist palliative care. Given the invasive nature of the advanced disease, multiple pathology is unsurprising. So beyond pain and exhaustion there may be specific associated cognitive, dextral, visual or linguistic impairments that may interfere with successful self-completion of instruments.

Given the multitude of barriers to completion of questionnaires, self-completed measures have been reported as being inappropriate (McWhinney, 1994). Outcome measures generally have been difficult to employ. Having reviewed 800 papers relating to terminal care, Salisbury & Bosanquet (2000), state that difficulties were described in reporting, due to the use of inappropriate outcome measures, the unreliability of using carers as proxies to provide assessments, and rapid fluctuations in the person's condition.

As with other groups, a further complication beyond accessibility is the lack of relevance of the domains that are usually investigated. The Canadian Palliative Care Association (1995) for example, highlighted the areas of concern associated with people who are dying. Generated from extensive focus group consultation of users and relative/caregivers of users together with professional groups, they include; delivery of care; alleviation of pain and other symptoms; psychological, social and spiritual support; loss, grief, death planning and bereavement support; and the right to choice and empowerment to make informed decisions. They focus on the quality of care given, symptom control rather than function or participation, enabling choice and aspects of care that go beyond the user to the incorporate the carers whilst the user of the services is alive and after that point. These domains are at variance with those seen in other health care measures. Teno et al (2000) suggest that

> "Yet as one dies, life takes on new shape. For the dying patient, the relevance of maintaining physical functioning may not be as important as at earlier time in a patient's disease trajectory. With a change in treatment goals, the domains that define quality of life and of medical care may change dramatically. Typically, current measures of health-related quality of life do not examine such domains as dignity, spirituality, and transcendence. For dying persons, the family's comfort and function may become even more important" (p100)

Teno et al (2000) suggest that we have only limited understanding of what defines quality of care at the end of life, how to measure it, and what specific domains are under the control of health care systems. She goes on to propose however, that, dying is such a crucial period that it warrants efforts to create standards and accountability. The domains that need investigation are however, likely to be different from those measured in other groups of people.

1.5.1.5.2 Strategies to foster inclusion of people with terminal illness

Many different outcome measures have been used with people who are dying, ranging from drug toxicity, to place of death (Garnde, 1999). (For a detailed review of measurement tools and domains included in HRQoL measures used with people who are dying see Teno et al (2000)). However, whatever tools are used in this area there is an acknowledgement that measurement in this field is difficult (Higginson, 1999).

The difficulty with measurement of things other than physical symptoms (particularly pain) has meant that in some cases, as with other groups at risk of disenfranchisement, the issue of measuring has been sidestepped by exclusion. Higginson (1999) suggests that

> "Outcomes such as quality of care, quality of life measures including quality of death, and the best resolution of bereavement are hard to measure, especially when patients are frail and ill. Thus many studies exclude quality of life as an outcome variable, or include only patients who can complete questionnaires...the challenge is to ensure that those aspects of care that are hard to measure do not become a lower priority than aspects – such as survival or function – that are easy to measure" (p463)

McWinney et al (1994) advise how some of the difficulties can be overome. They suggest that although it makes for higher costs, trained interviewers can be used to collect data. By interpreting questions for a person and caregiver, an experienced interviewer can enhance the quality of the responses and take account of factors such as cognitive impairment, exhaustion, and distress.

Other researchers have changed their methodology and focusing on qualitative data collection. Salisbury and Bosanquet (2000) discuss the problems associated with traditional outcome measurement in palliative care and then suggest that well conducted observational studies, and a careful description of the process of care and the context may provide more useful information for evaluating local services.

Bolton and Ahmedzai (1997) suggest the use of writing biographies as an outcome measure.

As has been discussed, and as with other groups of people who are at risk of disenfranchisement, so people with terminal illness are likely to find traditional health status instruments unacceptable in terms of the domains investigated. Teno et al (2000) demonstrated the domains that are perceived to be important are hugely different from domains associated with other health-related measurement scenarios. The debate, as with measurement issues for other groups at risk of exclusion has focussed on service delivery, associated with these alternative domains (Byock, 1999). There is a drive to ensure acceptability of the domains covered but, so far, little debate has centred on the details of increasing accessibility.

For people who are dying, however, Teno et al (2000) suggest that the comfort and function of the family may be included within the domains of most critical importance to the user. Their views, therefore, should be canvassed *as part of the process of measuring the acceptability to the user* of the service and care being provided. In this instance, the care-givers views and functioning becomes a domain of importance for the person who is the subject of measurement, rather than proxy or surrogate information to support or take the place of her/his views.

The work carried out in the field of terminal illness particularly highlights the need for the purpose of measurement to be constantly borne in mind. The domains that define quality of life and of the medical care issues change dramatically in the final stages of life (Teno et al, 2000). The focus in the field of terminal illness is currently on the quality of service delivery, with recommendations for which measurement tools might be of potential use with people who are dying. This focus on quality of *care* rather than quality of *life* is dramatically affecting the development of techniques and tools in this area.

1.5.2 What can be learnt about inclusive practice in measurement development?

There is an acknowledgement by many of the authors cited above that attempts to expand the boundaries of conventional health measurement are still in their infancy, (Eiser et al 2000 and Teno et al, 2000) and therefore that processes of development and design are still unrefined (Hart & Chesson, 1998). However, the examination above does raise a number of key points for those wishing to develop inclusive health care tools so called 'enabled instruments' (Meyers & Andresen, 2000), particularly for groups of people for whom standard measures may be inaccessible or unacceptable.

The first key point is the need to continue to attempt subjective measurement. Experiences of health and illness are unique. This theme of the importance of subjective measurement runs throughout the literature of authors who provide thoughtful analyses of attempting inclusive practice (Brod el al, 1999) with reference to people who have dementia (Gladis et al, 1999) when discussing measurement with people who have a mental illness, and Teno et al (2000) when discussing health related measurement in those who are dying. All suggesting subjective reports are the way forward, despite the barriers to straight-forward administration.

The second key message from this group is that authors who suggest exclusion of certain groups of people may not have considered the methodological issues in sufficient depth (Brod et al, 1999), (Eiser et al, 2000). The acknowledgment brings with it a requirement for detailed analysis to enable inclusion. The deficiencies seen in other studies demonstrate that this is necessary to uncover optimal ways of increasing user participation. All the authors cited above have made robust attempts to get behind the public face of the people they were seeking to include. They have attempted to understand the details of why participation has previously been hampered. They have then thought creatively, and trialled ways of including participants.

With regard to the conceptual basis and process of construction of the measures, the authors mentioned above were at pains to understand the underlying frame of reference for each of the groups of people they sought to include. They thought of innovative ways of presenting the items to their client groups. When they went through the standard procedures of piloting and field-testing they thought innovatively about ways of enabling the respondents to give their best response (for example, identifying the minimum cognitive and linguistic abilities necessary for interviewability (Mozley et al, 1999), the need for extended contact before attempting elicitation of views form people with intellectual disabilities (Cassidy, 2000)). All have made the assumption that their client group could be included if only the test developers persevered in their attempts to break down some of the barriers that existed within standard measures.

In their attempts to include those at risk of exclusion, in the main, these authors do not, however, abandon the basic principles of questionnaire construction. Little of what is focused on as being critical to foster inclusion for these groups of people, is novel. The basic principles relating to self-reporting and questionnaire construction still hold true. Eiser, Mohay & Morse (2000) still stress the need to use simple and unambiguous language, transparent and concise procedures are emphasised by Gladis et al (1999), comprehensible rating methods are encouraged by Brod et al (1999), relevant content of investigation are highlighted by Teno et al (2000).

There is also, however, a tolerance for flexibility regarding some aspects of accepted administrative procedures. Cumins (1997) cautions against repeating questions with people with intellectual disability. McHorney (1996) also unusually accepted lengthy procedures and incomplete data sets, in her perseverance to be inclusive. When reflecting on the barriers to including people with intellectual disability. Felce (1997) says

> "I must admit to a personal lack of rigour in not caring unduly about precise category structure, as long as the content is covered...I recommend being flexible in methodological approach." (p 130)

However, the main novelty with the approaches described above lies is the depth of investigation, the consideration of the minutiae within the broad cornerstones of instrument development, and the time taken to ensure how these principles can be upheld in the face of barriers that others have assumed were insurmountable.

The final conclusion from this literature, unfortunately, is that some people will remain excluded from health care measurement. No matter how accessible measures may become, no matter what attention to detail developers pay, no matter how exactly the developers understand the group's particular needs, the process of comprehending an item, being able to introspect, making a judgement and relay this judgement remains a complex task. There will be some people for whom modifications cannot ensure inclusion in any meaningful way.

In these cases, there are two options. The first is to explore issues of health and illness without the use of measurement. Hickey & Bourgeois (2000) for example, confirm the ability of people with moderate dementia to provide HRQoL information by interview. Hart & Chesson (1998) point out that several indirect methods of consulting children have been developed, by eliciting metaphors for body function and symptoms, such as puppet play. Cassidy's model (2000) of user involvement through self-advocacy groups with people who have learning difficulties is again an example of how to foster inclusion though direct user participation, but not through measurement.

The second option is to attempt measurement but to employ methods that do not require direct user involvement. Brod et al (1999) suggests the use of observations ratings to assess subjective states, proposing that they offer a promising methodology for capturing HRQoL for the people with severe dementia. Similarly Katschnig (1997) suggests that taking the judgement of a person with mental illness alone could be misleading and suggests proxy ratings that run in parallel.

The use of proxy ratings is seen as critical to many who, despite their robust efforts, have failed to make their instruments wholly accessible. Addington-Hall & Kalra (2001) suggest that

> "rather than lose all information on that patient (who is unable to report themselves) someone else (a family member or health professional) may be asked to act as a proxy or surrogate ... although ratings by proxies and patients do not agree exactly, there seems to be sufficient agreement between their assessments of quality of life to make information that proxies provide useful when the patient cannot give it directly" (p1417).

1.6 Measurement in aphasia

The main group of people for consideration in this thesis, are people with aphasia. Aphasia[2] is the breakdown of language as a result of an acute neurological event such as stroke or head injury. It leaves a person cognitively intact but with a linguistic disability, with their language impairment partially masking their ability to understand or express feelings, thoughts, intentions and competence (Kagan, 1995). Aphasia affects 150 per 100,000 people in this country (Enderby & Davies, 1989). The results of this impairment are widespread and devastating. They affect social, vocational, emotional and familial aspects of a person's life.

Aphasia, with its unique combination of intact cognition, in the face of impaired linguistic skills of understanding and expression, presents the person constructing a tool for measurement with a challenge. This difficulty has been acknowledged. Streiner & Norman (1995) in their guide to health measurement scales specifically mention the language difficulties of people with aphasia as

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[2] *Aphasia is the total loss of language following a neurological event. Dysphasia is the partial loss of language. The terms are often used synonymously. Aphasia however, is accepted as the generic descriptor for loss of language (partial or total) following a neurological event.*

exemplifying one group for whom the task of instrument development raises complex challenges.

More people acquire aphasia following a stroke than from any other aetiology. Yet even when measures are designed specifically to investigate stroke and its consequences, the difficulties of accessing people with aphasia are acknowledged (Williams et al, 1999a). Sutcliffe & Lincoln (1998) are direct

> "Patients with aphasia are unable to report feelings or to complete standardized assessments" (p506)

Brumfitt (1993a) suggests that even when by-passing measurement by using qualitative methodologies to explore health related issues, the situation is not straightforward.

As with other groups of people for whom traditional health care measures present barriers, people with aphasia are often excluded from research, even stroke-related research. An example of this is found in Sutcliffe and Lincoln (1998) who report that

> "Patients were excluded from the study if they were unable to complete standardised questionnaire assessments due to language impairments" (p507)

Clarke et al (1999) report that

> "All surviving stroke patients were eligible for the study unless they were aphasic, demented or too ill" (p117)

The following section explores what measurement instruments are currently available to those working in the field of aphasiology. Given that stroke is the major aetiology of those with aphasia, instruments used in stroke medicine will be considered in this discussion where appropriate. The section will review measures of impairment, function, participation, HRQoL and psychological well-being. It will review how these measures have been used, and compare the characteristics of those reviewed. The disadvantages of the available measures will be reviewed in detail in section 1.7.

1.6.1 Measures of impairment

Detailed measurement with people who have aphasia is usually conducted by a speech and language therapist (SLT). Commonly these are the people within the health care arena who focus on evaluating and reducing the effects of this acquired disability. SLTs have been using health measurement tools of various kinds with people who have aphasia for decades. There are many health measurement instruments traditionally used by SLTs that focus on impairment. As Simmons-

Mackie & Damico (1996) point out

> "This focus has resulted in an assessment process dominated by a deficit model applied to linguistic structures and psychological processes in individuals with aphasia...from a practical viewpoint, therefore, assessment of aphasia typically consists of 'tests' that sample a variety of tasks believed to represent aspects of individual language processing such as naming pictures, forming sentences, and following simple instructions" (p540)

1.6.1.1 Language batteries

These tests include standardised language batteries such as the Minnesota Test for Differential Diagnosis of Aphasia (MTDDA) (Schuell, 1965), the Boston Diagnostic Aphasia Examination (BDAE) (Goodglass & Kaplan, 1972, 1983), the Porch Index of Communicative Abilities (PICA) (Porch, 1967), and the Western Aphasia Battery (WAB), (Kertesz, 1983). These broad language batteries are still currently in use in clinical practice. They provide a comprehensive assessment of modalities of language known to be impaired as a result of aphasia. Table 1.6 summarises the domains covered by the various assessments. They are drawn from a number of theoretical standpoints ranging from those based on 'stimulation hypothesis' such as the MTDDA, to those which aim to diagnose and classify people with aphasia into 'syndromes' based on the presenting impairment such as the BDAE; this classification is aimed at localisation of damage in the brain.

The final language battery to mention in the Comprehensive Aphasia Test (the CAT) (Swinburn, Porter and Howard - in press). This is similar to the other assessments in that it seeks to assess, in a comprehensive way, the language impairment associated with aphasia. It differs from the other assessments in two ways; its conceptual basis is that of cognitive neuro-psychology, the most current theoretical framework for exploring linguistic and cognitive impairments. Secondly, it includes a section that departs from impairment assessment. The final section of the CAT, the Disability Questionnaire, assesses the impact of aphasia on the life of the person with aphasia from the perspective of that person. As such it represents a departure from the other standardised language assessments available within aphasiology.

1.6.1.2 Screening tests

At the other end of the scale, assessments that *screen* for language impairment are also available. These include tools and tests of specific language function such as the

Frenchay Aphasia Screening Test (FAST) (Enderby, 1987), and the Aphasia Screening Test (Whurr, 1996). All these assessments aim to provide a quick (and necessarily) superficial overview of the impairment caused by aphasia. These are also detailed in table 1.6.

1.6.1.3 Domain specific language tests

There are also assessments that focus on a specific aspect of language impairment. These include the Boston Naming Test (BNT) (Kaplan et al, 1983), the Graded Naming Test (GNT) (McKenna & Warrington, 1983), the Reading Comprehension Battery for Aphasia (RCBA) (LaPointe & Horner, 1979), and the Psycholinguistic Assessment of Language Processing in Aphasia (PALPA) (Kay, Lesser & Coltheart, 1997). The first three assessments (the BNT, the GNT and the RCBA) focus exclusively on one domain of impairment only.

The last assessment, the PALPA, is a collection of subtests each measuring different components within different language domains or modalities. The administrator selects which of the subtests should be performed to elucidate the exact nature of the deficit in language functioning. It is not intended that the administrator perform the whole of the PALPA. Unlike most of the language batteries described above, the PALPA is based on current theories of cognitive neuro-psychology of language processing.

1.6.2 Measures of function

Measures of function come from two sources. The first source is that of rehabilitation medicine. As multi-disciplinary team working within rehabilitation medicine has increased, so has the use of generic measures of functional ability that have been used with people with aphasia, in the more general context of rehabilitation of people who have had a stroke. These measures focus almost exclusively on physical functioning. Most do not include items on cognition or communication. The second source is from within SLT. The measures available from these two sources will be discussed separately.

1.6.2.1 Measures of function in stroke and rehabilitation medicine

As a stroke can lead to widespread and diverse functional impairment, there are numerous measures that have been used within stroke and rehabilitation medicine more generally to measure these consequent losses. Table 1.7 gives examples of these instruments.

The review of functional instruments here will be limited to those instruments that actively include communication within the domains of investigation; the Scandinavian Stroke Scale, (Scandinavian Stroke Group, 1985), the National Institute of Health Stroke Scale (NIH) (Brott, 1989) and the Functional Independence Measure (the FIM) (Stineman et al, 1994) for example. All are measures designed to be used within neurological rehabilitation settings. They measure both impairment and function.

The NIH has a section on language that scores changes resulting from aphasia following stroke. The FIM includes questions that relate to cognition and communication behaviours, though in some studies using the FIM people with aphasia are specifically excluded (Clarke et al, 1999). The weighting of these communication items relative to the physical domains appears disproportionately insignificant. Finally, the Scandinavian Stroke Scale also includes communication within the domains investigated. It has been used to look into recovery for people who have had severe strokes (Jørgensen et al, 1999). This scale is more relevant to those with aphasia as it includes a section that rates presence and degree of aphasia.

A further novel way of measuring functional recovery from stroke (which could include those with aphasia) was tried by Lindley et al (1994) by asking two simple questions; "in the last two weeks, did you require help from another person for everyday activities?" and "do you feel you have made a complete recovery from your stroke?" These questions were shown to identify 75-83% of those who perceived themselves to have made a poor recovery from their stroke. These two questions were being asked to identify whether simple questions, asked through use of postal or telephone interview, could assess outcome after stroke. The questions were being used to place a person into a binary classification 'good outcome', 'bad outcome'. On the basis of this, the authors, Lindley et al (1994) report that these questions are suitable for

> "all types of very large scale studies of outcome after stroke (e.g. randomised trials, observational studies and multi-centre audits of stroke care)" (p314)

Given the possibility for varying subjective interpretation, and apparent superficiality of both these questions, the usefulness of the information gained is questioned. There is no reference to whether the person being asked the question felt that requiring help with an activity suggested 'poor' outcome for example. Many of us who have not had strokes, ask for assistance with daily tasks (opening jars, reading small print, buying items of shopping for example). The difference between independence and autonomy has been widely explicated (e.g. French 1994a), and the first of these questions does not take that difference into account. The way in which information as superficial as this would be used is also to be questioned. The issue of the purpose of measurement will be explored further in relation to people with aphasia in section 1.8.

1.6.2.2 Measures of function for people with aphasia

> "In the past few years, in response to a call for more functional outcomes in rehabilitation, aphasia clinicians have added 'functional measures' to their array of assessment procedures in order to determine how the patient actually performs in 'real life' situations" (p541) (Simmons-Mackie & Damico, 1999)

Classification around measuring functional language is blurred. Definition of what constitutes functional communication and measures of functional communication are imprecise. Worrall & Frattali (2000) discuss theoretical models that have been applied to functional communication, but suggest that

> "Despite these broad frameworks, there remains a lack of clear definition of the various dimensions (e.g. language impairment, disability, and handicap)... One of the complicating factors in the process is the use of the term functional communication assessments – a term that has grown out of a medical model and one that seemingly encompasses impairments, disabilities and handicaps" (p7-8)

Despite this lack of precision of definition there is a general agreement, as with other types of health care measurement, that there has been a distinction between measures of impairment and measures that focus on functional activities. The majority of functional communication assessments target evaluation of disability in its broadest sense, sometimes attempting assessment of social participation, but sometimes not.

These measures have been particularly popular in America. Some argue that they represent a step forward, away from the restriction of impairment, towards investigation focused beyond the clinic, locating assessment closer to the real world within which a person with aphasia operates (counterarguments to this will be rehearsed in later sections).

Table 1.8 summarises the most commonly described functional assessments used with people with aphasia. All these profiles aim to identify how language is used in everyday communication contexts rather than focusing on the linguistic impairment itself. They vary in how this aim is achieved.

Several rely on the structured observations made by a significant other, usually a relative of the person with aphasia. These include, the Edinburgh Functional Communication Profile (the EFCP) (Skinner, Wirz, Thompson & Davidson, 1984) and the Communicative Effectiveness Index (the CETI) (Lomas et al, 1989). In contrast, the Amsterdam-Nijmegan Everyday Language Test (the ANELT) (Blomert et al, 1994), the Communication Activities of Daily Living (the CADL and CADL-2) (Holland, 1980), and (Holland, Frattali & Fromm, 1999) and the American Speech-Language-Hearing Association Functional Assessment of Communication Skills (ASHA FACS), (1990) have the clinician rate observations.

Some rate performance observed within actual daily communication activities (the EFCP, ASHA FACS, CETI), while others encourage the person with aphasia to simulate these activities and then the clinician rates these role played situations (the CADL and ANELT). The Functional Communication Profile (FCP) (Sarno, 1969), rates behaviours based on “informal interaction with the patient” (Sarno, 1969).

The domains rated by the tests mentioned above are similar, and relate to everyday communication situations usually divided into reading, writing, number use, speech or conversation, and understanding. Many such as the CADL, the EFCP and ASHA FACS also investigate non-verbal communication. The assessments rate the ability and appropriateness of the communicative effectiveness in these everyday communication situations.

The ANELT and the CETI differ from the other functional communication assessments. The ANELT does not rate all the domains associated with communication but focuses exclusively on verbal communicative effectiveness, believing this to be the most important domain in communicative efficiency (Blomert et al, 1994). The CETI on the other hand asks questions relating to a wide range of activities which will necessitate some form of communication. It is unclear exactly what the focus of the CETI is. Some items tap very specific communication activities such as “giving yes/no answers appropriately”, “indicating that he/she has understood what is being said to him/her” and “using writing”. Others seem to be tapping social participation “getting involved in group conversation that are about him/her” and “participating in a conversation with a stranger”. This diversity of domains covered may result for the way in which the CETI was developed. In contrast to the majority of measures used by SLTs, the constructs used in the CETI were generated by people who have aphasia and their spouses, not researchers or health care professionals, (Lomas et al, 1989). It is interesting to note that that the psychometric properties of the CETI have been shown to be good (Lomas et al, 1989). In addition it has been translated into 2 other linguistic and cultural settings (Penn et al, 1992) in South African, and (Pedersen et al, 2001) in Denmark demonstrating widespread interest in it as a clinical tool.

1.6.3 Measures of activity and participation

1.6.3.1 Measures of activity and participation in stroke and rehabilitation medicine

As was mentioned in section 1.4.3 the main distinctions between measures of function and measures of activity and participation is who does the measuring and the focus on daily activities and roles found in measures of activity and participation. The distinction between functional measures and measures of activity and participation however, is not always wholly clear-cut in practice.

There are a number of ways of measuring activity and participation that have been used with people who have had a stroke. Table 1.9 shows examples of some of the measures used within stroke medicine and rehabilitation. Some such as the SIP, the NHP, the IPA and SF 36 have already been reviewed. The 'Reintegration into Normal Living Index' enables the person who has had a stroke to rate his/her satisfaction with their physical, emotional and social life. The degree of detail elicited varies.

Laman and Lankhorst (1994) developed a self-administered questionnaire based on the ICIDH-1 (1980) classification. It sought to measure, in parallel, disability and then impact of various domains (functional, cognitive, and social). The questions are worded as follows "can you use the stairs?" (disability), "how important do you find being able to use the stairs?" (impact). The novelty with this instrument is that it highlights for both clinicians and person who is the subject of measurement, the effect on daily life that a particular disability is causing. It does not go as far as being a measure of social participation though. Of the 39 items only 5 relate to activities that could even loosely be described as social participation (family relations, relatives and friends, leisure activities, speech, reaching goals in life). It does therefore look at the impact of various activities on daily life, but the focus is on functional ability rather than social participation.

Enderby (1997) put forward a further structured methodology for gathering outcome measures from a wide group of people, which includes information on areas that might be considered to lie within the realm of participation. The resultant tool is the Therapy Outcome Measures (TOMs). Unusually for a measure of activity and participation, the rating in the TOMs is made by the clinician. Based on the WHO ICIDH-1, the tool enables rating of a person within classifications of 'impairment', 'disability', and 'handicap' and an additional category of 'well-being/distress'. The TOMs have forms to rate a wide range of groups of people including people with cerebral palsy, mental health impairment, and incontinence and uses a 0 to 4 rating scale. The rating scales use very detailed descriptors for each point on the scale (e.g. the rating of 'handicap' in the TOMs describes handicap along the dimensions of social isolation, HRQoL, autonomy and choice, and self esteem/worth. Rating 0 as no interaction, very little HRQoL, no autonomy, lack of self esteem or self worth, and unable to exercise choice through to 4 described as integrated and able to maintain expected different roles in society, valued by others, exercises choice and autonomy).

The Impact on Participation and Autonomy (IPA) (Cardol et al, 1999) was based on the updated version of WHO International Classifications (available to Cardol in 1997 in draft form). It focuses on person-perceived impact in six life domains (social relationships, self-care and appearance, family role, mobility, leisure and financial independence). The study population included only 4 people who had strokes (out of a total 100 outpatients). No mention was made of any of these people having aphasia as a consequence of their stroke other than exclusion criteria of "did not understand the Dutch language, or had cognitive impairments that would hinder filling in the questionnaire".

1.6.3.2 Measures of activity and participation for people with aphasia

Within aphasiology, measurement of activity and participation from the perspective of the person with aphasia, has not been addressed extensively. Table 1.10 summarises those that have been developed.

The CETI described above measures function but also aspects of social participation. It relies on proxy rating made by the significant person in the life of someone who has aphasia.

The TOMs, also described above, contains material that could be used specifically with the person who has aphasia; these are rating someone with stroke, head injury or neurological disorders. The rating in the TOMs is proxy rating made by the clinician, using the clinician's knowledge of the person with aphasia. This is to overcome the barrier that language impairment might present to subjective rating by the person themselves.

A new tool, the Functional Communication Therapy Planner (Worrall, 1999) has recently been published which sets out to guide SLTs through the process of planning, targeting and delivering therapy that is tailored to everyday communication needs of an individual. It provides a clinical tool for identifying and responding to individual communication choices and priorities, through use of observations in real life, pre-meeting questionnaires and interviews. It has however been criticised for failing to acknowledge the role of external factors in the limitation of participation. Pound (2000) cautions that it may risk leading the inexperienced clinician into a one-dimensional view of functional communication. This carries with it the possibility of failing to address the inside experience of living with communication disability. Pound goes on to suggest that by focusing on the list of the client's communication activities, the FCTP locates itself firmly within the problem-centred discourse of assessment and therapy. It involves an individualistic rather than a socially constructed view of disability.

In conclusion, Ross and Wertz (2002) suggest that

> "At this time however, no specific measures exist to assess participation restriction in individuals with aphasia".

1.6.4 Measures of psychological well-being

Measurement of well-being and psychosocial issues has a long history. Well-being can be measured in a number of different ways depending on the theoretical stance brought to the investigation; on the negative/pathological side there are measures of depression and anxiety. From a more positive/active viewpoint there are measures of self-esteem, life satisfaction and coping.

1.6.4.1 Measures of psychological well-being in stroke and rehabilitation medicine

Many instruments have been used to measure well-being in stroke, and examples of these are summarised in table 1.11.

Bowling reviews measures of well-being suitable for use with people who have a stroke. She separates anxiety and depression from life satisfaction and self esteem. When discussing anxiety and depression she recommends the General Health Questionnaire (GHQ – Goldberg, 1978), the Beck Depression Inventory (Beck et al, 1961) and the Hospital Anxiety and Depression Scale (HAD, Zigmund & Snaith (1983)). The British Stroke Research Group agree, recommending the use of the HAD or the GHQ (Wade, 1992).

Lofgren et al (1999) were able to demonstrate association between psychological well-being and depression in people who have had a severe stroke using the Philadelphia Geriatric Centre Morale Scale (Lawton, 1975). Bowling reports this measure to be popular amongst gerontologists as a measure for life satisfaction (Bowling, 1995).

There are tools available to measure the impact of stroke on self-esteem. Chang & MacKenzie (1998) used a 20-item State Self-Esteem Scale developed by Heatherton and Polivy, and Rosenberg's Self Esteem Scale to measure self-esteem in people who had had strokes. They were able to use the information to show that self-esteem was a consistent predictor of functional recovery in a group of 152 people at three months post-stroke.

Bowling reviews different measures to assess coping and adjustment, and patient satisfaction but reports that these are rarely used with people who have neurological illness.

1.6.4.2 Measures of psychological well-being used with people who have aphasia

As with stroke and rehabilitation medicine, well-being and psychosocial issues have been of interest within aphasiology for many years. The details of some of the measures used are reviewed in table 1.12.

In 1991, Währborg reviewed the ways that emotional and psychosocial states were assessed in people who had aphasia using standardised well-being measures. He reviews standardised measures such as the Zung's Self Rating Depression Scale (1965), Hamilton Depression Scale (Hamilton, 1960), the Beck Depression Inventory (BDI), (Beck et al, 1961) and the Comprehensive Psychopathological Scale (Asberg et al, 1978). Währborg also considers other types of measures such as the Visual Analogue Mood Scales, (the VAMS) (Aitkins, 1969) and the Code-Müller Protocols (Code & Müller, 1992). The VAMS is a non-verbal means of assessing feelings using a drawn line with cartoon faces and abstract adjective descriptors at each end expressing opposite emotions (e.g. happy-sad). The person with aphasia has to draw or indicate a place on the line to indicate her/his mood relative to the two anchor adjectives. The VAMS was accessible and acceptable to people with aphasia, being picture based and sensitive to small changes in attitude to be assessed. This technique has been shown to be reliable, quick and easy to administer with people who had aphasia, and revealed useful information about mood state (Garrett, 1999).

Stern et al (1997) have modified the VAMS scales specifically for people with aphasia. The modified scales are presented vertically (to reduce the effects of any visual processing impairment sometimes seen in association with aphasia). They are also presented in a uni-polar fashion (neutral at one pole and mood state at the other). No mention is made of why this is done. People who have aphasia can have difficulty differentiating between words which are closely related semantically. An assumption is therefore made that the uni-polar presentation is an attempt to minimise the effect of comprehension problems with semantically related items, thus increasing accessibility of the scales for people who have aphasia. No reports are available on the application of these scales.

Brumfitt recently extended the work done by Stern on the VAMS, to develop a mood scale designed specifically for use with people who have aphasia; the Visual Analogue Self Esteem Scales (VASES) (Brumfitt & Sheeran, 1999a). Brumfitt & Sheeran noted the difficulties with existing self-report measures. The VASES use visual analogue rating scales to assess self-esteem in people who have aphasia. This is done by using 10 visual analogue rating scales, each with a written and pictorial description of a mood state at each end of the pole. The mood states include confident, cheerful, trapped, frustrated. The person with aphasia has to choose which picture best depicts them and then rate the degree on the rating scale (++, +, or 0). Brumfitt (1999b) describes the thinking behind its development

> "In order to address the issues about self report measures being too language based, the VASES was developed as a means of exploring the construct of self-esteem with people who have aphasia. It considered that: the use of pictures and not simply words was essential, the pictures would be relevant to the subjects and would clearly represent important thoughts and feeling, the measure was short and easy to administer, the rating scale was simple enough for a language impaired individual to cope with on their own" (p118)

A review suggested the VASES may be a useful tool in the portfolio of measures required to evaluate outcomes of these (social model) approaches (Worall & Cruice, 2000). They suggest that because it does not ask the significant other or clinician to rate the aphasia person's self esteem, it represents

> "an important step in aphasia research and service provision, acknowledging the aphasic person's right to independence of autonomy and decision making concerning their own" (p1153)

The Code-Müller Protocols (1992) were also reviewed by Währborg. They were also designed specifically to be used with people who have aphasia. The protocols focus on the perceptions of individuals on psychosocial adjustment following the onset of aphasia. They do this by using a questionnaire for the person with aphasia, his/her carer and his/her clinician. Each person completes a questionnaire and the ratings are then compared to elicit a discussion, centring on these issues. Wähborg (1991) reports that little is known about the ways in which different perceptions of the same problem might influence rehabilitation, but believed then that they may be useful to help guide counselling and rehabilitation.

The final tool reviewed by Wähborg (1991a) is the Personal Relations Index (the PRI) (Mulhall, 1977). Wähborg suggests that the procedure is not simple to grasp since several stages are required, and the interview is language-based. It suggests it is also too time-consuming to be applied in the clinical setting.

The Affect Balance Scale, Bradburn (1969) is a generic measure of 'happiness' or general psychological well being that has been reported as being used with people who have aphasia (Garrett, 1999).

Sutcliffe et al (1998) have recently reported on a new instrument designed to detect depressed mood in people who have aphasia; the Stroke Aphasic Depression Questionnaire. It is a 21 item rating scale administered by carers. It focuses specifically on depressive symptomatology and does not address functional status or participation or positive attributes of well-being.

The Psychosocial Well being Index (the PWI) (Lyon et al, 1997) is a measure that covers an individual's contentedness and satisfaction with life. It benefits from being 'aphasia-friendly' in the method of administration and in the domains it covers. It is brief and simple. It represents a measure that screens for satisfaction with participation in life.

The final rating instrument is the How I Feel About Myself measure (cited in Thelander et al 1993). It aims to measure a range of behaviours and attitudes. It has a parallel version designed to be used with caregivers. It was developed in Canada. It is un-standardised and unpublished, and not readily available in this country, though has been used in studies in North America (Sarno, 1997).

1.6.5 Measures of HRQoL

1.6.5.1 Measures of HRQoL in stroke and rehabilitation medicine

As with other disease states, those who have had a stroke have been the subject of HRQoL measures, with both generic and domain or disease specific measures have been utilised. Examples of these are shown in table 1.13.

Generic measures used in studies of HRQoL for those who have had a stroke include the widely used EQ-5D (used for example by De Haan et al (1993), Haley et al (1997), Hackett et al (2000) and Pickard et al (1999)), the WHO-BREF (1998b) (a shortened version of the WHOQOL 100 (WHOQOL group 1998a+b) and the SIP (for example used by DeHaan et al 1993), and the Reintegration into Normal Life Measure (Wood-Dauphinee et al 1988).

Stroke-specific HRQoL measures include QoL Index-Stroke Version (Ferrans & Powers, 1985) and the SS-QOL (Williams et al, 1999).

An alternative approach was used by Ahlsio et al (1984) and Lawrence (1979) who both used interviews to assess HRQoL. Ahlsio also used "quality of life graphs" – vertical lines of 100mm height on which the interviewee put marks representing "before the stroke", and "now". These marks were not to represent the static condition but to quantify change.

So methods used to rate HRQoL vary, ranging from interviews, and questionnaires to visual analogue scales, generic and stroke-specific. There is however, little consensus on which are the best methods available to measure HRQoL in stroke and as Bowling (1998) points out

> "the most popular scales of quality of life in neurology are functional ability scales and measures of neurological functioning. However, these require supplementation with scales measuring other domains. Disease-specific quality of life scales (in the broadest sense) have been slow to develop" (p177) (parenthesis original)

1.6.5.2 Measures of HRQoL used with people with communication disability

There has been work on HRQoL with people who have communication disability, not necessarily associated with stroke. These measures (including those used with people who have had a stroke) can be seen in table 1.14. Measures used with people who have aphasia will be reviewed separately in the next section.

HRQoL research with people who have communication impairment has tended to focus on people who have had head and neck cancer. Table 1.14 shows details of the measures described by the authors as measuring HRQoL. There are reports of HRQoL measurement with people who have had surgical procedures associated with cancer of the larynx (e.g. DeSanto et al (1995) who use the PAIS), oesophagus, O'Hanlon et al (1995)), and tongue (Ruhl et al (1997) who use the FACT-G). HRQoL research has also been completed with people who have communication difficulties as a result of experiencing a traumatic brain injury (Webb et al (1995) who use the LSI-A and the FIM).

1.6.5.3 Measures of HRQoL with people who have aphasia

Cruice et al (2000a) suggest why HRQOL may be affected by the aphasia.

> "effective communication is deemed a crucial component of QOL wherein 'effective communication...is...being able to communicate directly with other people of one's choice and having opportunities to broaden the choice of friends, and to deepen the encounter and dialogue with them' (Seed and Lloyd p13.). Because aphasia impairs communication there is an assumption that QOL status will be duly altered." (p85)

There is an acknowledgement that HRQoL assessment in aphasia has been limited, until reasonably recently. Again Cruice et al (2000a) offer some insights into the reasons behind. They suggest that the most important issue is altered language comprehension ability which raises concerns for response reliability and validity, and secondly that there are few appropriate assessments for communication-disordered populations in terms of content.

There have been attempts to investigate HRQoL specifically with people who have aphasia. Table 1.15 documents those HRQoL measures used with people with aphasia.

Sarno (1997) reports on a study of 59 people followed through the first year of living with aphasia. She measured linguistic, cognitive and pragmatic impairments along with functional communication. However she also used three ratings to measure HRQoL specifically. She used the Geriatric Evaluation of Relative's Rating Instrument (GERRI), (Schwartz, 1983), the Functional Life Scale (Sarno et al, 1973) and the Caregivers Burden Interview (Zarit et al, 1980). As can be seen from the dates of these assessments, the instruments chosen did not come from the most recently devised HRQoL 'stable'. They are not as comprehensive in the domains they seek to investigate as more recent HRQoL instruments, but do attempt to capture broader areas of health relating to activities, participation and mood. All rely on proxy ratings.

More recently, researchers within SLT have attempted measurement of HRQoL with people who have aphasia using more traditional HRQoL instruments (Cruice et al, 2000b and Ross & Wertz, 2002).

An interesting study is that written by Cruice et al (2000b). This study sought to ascertain the clinical utility of existing HRQOL measures with people who have aphasia. The study recruited people with aphasia in both Australia and the U.S. They compared a number of HRQoL (the Dartmouth COOP charts, the SF-36, the SIP), and well-being measures (the unvalidated/unpublished Behaviour, Emotion, Attitude Communication Questionnaire (Thelander et al, 1994), the Affect Balance Scale (Bradburn, 1969), How I Feel About Myself (Thelander et al, 1994) also unvalidated/ unpublished) and two one-question global rating using a visual analogue and 5 point Likert scale. The authors were able to establish HRQoL ratings using the instruments with people who had aphasia. The instruments were rated in terms of aspects of usability (e.g. wording of questions, amount of assistance required). The authors recommended the Dartmouth COOP charts and the one question global ratings for use with people who had aphasia (with provisos). The SF36 and the SIP were not recommended for use with people who have aphasia.

The instruments recommended were not without their problems however.

> "structural changes were made to QOL assessments to maximise comprehension of questions for participants. It was found that chunking information, repeating questions slowly, rephrasing questions, and personalising the questions assisted comprehension and completion of the assessments items. For the more difficult assessments (particularly How I Feel About Myself) items were reduced to a series of yes/no questions to arrive at an answer that the speech-language pathologist judged to be reliable and an accurate reflection, based on participant's comments. " (p90)

Ross and Wertz (2002) use two HRQoL instruments, the WHOQoL-BREF, WHOQOL group (1998) and the PWI (Lyon et al, 1997) (previously reviewed as a well-being measure) alongside measures of linguistic impairment (the WAB and PICA) and functional communication (the CADL-2, and ASHA-FACS). The study aimed to examine relationships between language impairments, HRQoL and functional communication.

When discussing the lack of relationships between impairment and HRQoL they point out that no account was taken of contributing factors such as the presence of hemiplegia, an individual's emotional or physical health, personality (coping style) or environment. With reference to the utility and accessibility of the measures for use with people who have aphasia, they merely say that where someone was unable to complete a questionnaire, an interviewer-assisted format was employed.

It is perhaps surprising that what few studies that there have been on HRQoL with people who have aphasia have not piloted the EQ-5D. It is both short, relatively simple linguistically and is reported to have sound psychometric properties (EuroQol, 1990). It includes within it a linear upright scale resembling a thermometer. The person who is the subject of measurement indicates their perception of their own health on the scale enabling graphic depiction of self rated HRQoL. It would appear that this might be useful for someone who has both comprehension and expressive impairment.

Nieme et al (1988) reported on HRQoL four years after stroke. They used an unvalidated questionnaire that covered working conditions, activities at home, family relationships and leisure time activities. They attempted to include people who had aphasia but reported that three out of the nine people with aphasia who could potentially have been in the study, were unable to complete that questionnaire.

Brumfitt (1998) reports on a different way of attempting to measure life satisfaction (a concept closely allied to quality of life) suitable for those with language impairment. She reports an interesting development found by Anderson (1988) is the scale for 'Life Satisfaction' which uses a 'Faces' scale to assess general satisfaction with life for stroke patients. Here the scale consists of seven faces which range from looking very happy to looking very depressed. No verbal labels are attached. The results differentiated people who have had strokes from those who had not who lived in the same community.

There are two recent advances in the area of aphasia-specific HRQoL instruments. The first is the development and standardisation of a HRQoL measure specifically designed for people with aphasia. The SA-QoL (Hilari, 2002), is a response to the fact that traditional HRQoL measures appear to be both potentially inaccessible and conceptual inadequate for people with aphasia. The SA-QoL is an 'enabled tool' - an 'aphasia-friendly' questionnaire designed for self-report and is derived from the SS-QoL. It is designed to be both accessible to people with aphasia but also to cover domains that will be relevant to them. It therefore includes items that rate use of language in everyday contexts (speaking clearly on the 'phone, finding words, understanding what others are saying for example).

Hilari et al (in press) use the SA-QOL to investigate predictors of HRQoL in people with aphasia. The authors were able to demonstrate that increased distress, reduced involvement in activities, increased communication disability predicted poorer HRQoL in people with chronic aphasia after stroke.

The second recent development in this area is a modification of disease is the Burden of Stroke Scale – Communication Difficulty (the BOSS CD) et al (2003). This tool has been which has been developed for use with people who have communication difficulties following stroke. The scale examines self-reported difficulty in domains of functioning, psychological distress and general well-being. It contains 65 items, 7 of which relate specifically to communication. Data so far available shows that the communication difficulty version discriminates people who do and do not have communication impairments following stroke. There are also correlations shown between levels of severity on impairment tests and the BOSS-CD.

1.7 Limitations of current methods of investigation in aphasiology.

The array of potential assessments and scales available for use with people who have aphasia is vast, as demonstrated by the selective review in section 1.6. With such a range of tools available to measure aspects of the impact of aphasia, is there a need to develop any others? As was alluded to in the review, there are problems with the existing tools.

1.7.1 Limitations of impairment-based measures

As has been mentioned, in medicine and health care generally, there has been a move away from measuring impairment, simply documenting difficulties in the absence of social or environmental context. This approach is seen as often being based on a narrow, outdated notion of health and disease (Gladis, 1999). There has also been a concomitant move towards the embracing of measurement from the perspective of the person with impairment rather than the clinician. Focusing on the objective measurement of impairment *alone* as a measure of impact of disease is frequently being rejected in health care measurement.

This general move within health care measurement has been mirrored in aphasiology. There is recognition that standard measures of language often have little clinical relevance in the broader context of the person and his or her life (Penn 1988).

Simmons-Mackie (2000) suggests why this might be

> "an individual with a Broca's aphasia might find the impairment creates significant vocational, emotional and social problems, while another individual with an identical impairment might experience minimal impact in life. To ensure that intervention is efficient and socially valid, the consequences for each individual and their loved ones must be evaluated. This requires sensitivity not only to individual social consequences of aphasia, but also to the social consequences of our therapy." (p167)

This example demonstrates the inadequacy of using impairment-based measures to assess the impact of aphasia on someone's live. Impairment measures can assist in the overall process of information gathering needed to assess the impairment, but not to inform how an individual experiences the impact of acquiring and living with aphasia. This criticism is levelled at all impairment based language tests (other than the CAT, Disability Questionnaire which will be the focus of discussion from Chapter 2 onwards), be they comprehensive language batteries, screening assessments or domain specific language tests.

A further criticism has been levelled at impairment level testing. Jordan & Kaiser (1996) propose that 'diagnostic testing' is likely to be stressful for the person with aphasia as it focuses specifically on problematic areas, and is not expected to produce any immediate improvement for the person with aphasia. They highlight the consequences of carrying out this form of testing on the power relationship that exists between the clinician and the person with aphasia, by placing the therapist in a position of control. This issue will also be explored further within this thesis.

1.7.2 Limitations of function-based measures

As has been seen in table 1.7, a number of functional measures have been used in stroke and rehabilitation more generally. Some have been considered with reference to people with aphasia in the context of documenting change in rehabilitation settings. However, there has been criticism of such measures on the grounds that functional status is just one component of health (Bowling, 1997b). Disease-specific functional measures are better able to locate an individual within 'life space' by focusing on symptoms and functioning directly related to the disease and intervention, but they still provide a narrow view of quality of life (Williams, 2000).

This narrow focus may be problematic for those wishing to explore the impact of a disability on an individual, as there is no direct correspondence between objective functioning and an individual's HRQoL (Addington-Hall & Kalra, 2001). Inferring subjective HRQoL from external circumstances or from more objective domains (e.g. functioning) does not take fully into account the values, needs, and adaptabilities of individuals to various life circumstances (Brod et al, 1999). This lack of correspondence has led researchers who are interested in wider issues of health care measurement to move away from the restrictions of function alone.

The shortcomings of functional measures are even more obvious when assessing health care needs of people who have aphasia. Most generic functional measures do not rate communication at all. Those that do, rate it in such a way that those interested in exploring aspects associated with communication would find disappointing; the information gleaned is minimal, with scant exploration or description of features of language loss. These functional instruments document the presence of a difficulty with language, at best. At worst, communication is not rated at all. This is a surprising omission. Communication is fundamental to most aspects of human interaction and transaction. Communication allows us to transfer information, but also to forge, cement and influence relationships. Our style of communication enables expression of aspects of our identity. Schegloff (1990) is quoted in a video investigating the centrality of language as saying

> "in dealing with talk and interaction, we are dealing with the primordial site of human life. This is where the work of society gets done".

Given that communication is perceived as being fundamental, the fact that it receives such limited attention when measuring health and issues relating to life satisfaction, seems remarkable.

As a result of the inadequacies of these generic functional measures, aphasiologists have developed functional measures of their own (as reviewed in table 1.8). However, functional measures within aphasiology are not without their critics. Manochiopinig et al (1992) discuss some of their inadequacies. They suggest they are limited by the sampling methods employed. They point out that reliability may be difficult to demonstrate. For assessments that rely on samples of conversation or observation of real life communication, there is a dependency on the conversation topic, partner or the situation. This is not to say that such assessments are not clinically useful but to point out that standardisation may well be problematic.

Gordon (1997) discusses the difference between potential capability and actual performance, and the concerns that this raises for use of functional tests that rely on imitating 'natural' communication in a functional test situation. She suggests that for example there is a recognised difference between verbal expression and comprehension performance in a testing situation and a more relaxed atmosphere, or with familiar people. It raises questions about how well an SLT can approximate natural, functional communication situations in the clinic. She questions whether we can possibly expect any outcome measure of communication used in an out-patient rehabilitation setting to accurately reflect typical, stable communicative performance.

Simmons-Mackie (2000) explores this distinction between tested functional communication and real life communication. She neatly emphasises the dual role of conversation as both transactional (conveying a message) and interactional (establishing and maintaining social relationships).

> "Our "activities of daily life" are enriched by social conversation. For example, ordering in a restaurant is an important "functional" task, but the enjoyment of doing it is probably more closely related to chit chatting with our dinner partners. In fact the literature cites conversation as the fundamental site of language use in Western cultures (Clark and Wilkes-Gibbs 1986). All other forms of communication are secondary" (p166)

Functional assessments currently available mainly focus on the transactional, how successfully the message was transferred. Few investigate the role of language in the context of interaction.

A final criticism that can be levelled at functional assessments relates to who does the measuring. The value of subjective measurement has been discussed. Functional measures in aphasiology are generally observational profiles of real or simulated "daily activities", rated by the clinician or the carer, but never the person with aphasia. Sacchett & Marshall (1992) for example criticise these measures for undue dependence on relatives' observations, and more fundamentally, a lack of cultural and socio-economic sensitivity.

So, functional measures can be seen to have a number of limitations. Generic functional measures used in stroke and rehabilitation medicine generally do not address communication. Those that do, measure it in a scant fashion. Aphasia-specific functional measures have been criticised for their potential lack of relevance to an individual's actual life circumstances, for poor reliability, for their undue focus on the transactional nature of language use rather than interactional, and for failing to involve the person with aphasia other than as a source of information.

1.7.3 Limitations of measures of activity and participation

In stroke and rehabilitation medicine the limitations of functional measures have been acknowledged and moves have been made to explore how functional limitations affect the person's ability to participate in life. The resultant instruments are generic measures that are wide ranging in the domains they cover (see table 1.9). One of the main advantages of these measures of participation in terms of conceptual development, is their emphasis on subjective measurement.

This advantage, sadly, comes at a cost when considering them for use with people who have aphasia. To obtain the perspective of the person with aphasia, the tool being used must be accessible and acceptable to that person. Standard questionnaires or even interviews that require understanding of written and/or spoken language, and ability to express views in a verbal or written form, can be problematic for someone with a language impairment.

As has been mentioned, measures of activity and participation that could be used with people who have aphasia are negligible. The TOMs, (Enderby et al, 1998) purports to measures handicap as defined by the WHO ICIDH (1980), which includes aspects associated with participation (degree of isolation, interaction, HRQoL and autonomy). However, the investigation involves one rating only, being made to cover all these factors, and thus the possibility of demonstrating the impact of aphasia in any depth using such a measure is felt to be limited. In addition, the rating is also made by the SLT thus negating the involvement of the person with aphasia, and reducing its usefulness. It should be noted that the TOMs is designed as an outcome measure and not an assessment to guide therapy. Worrall & Cruice as recently as 2000, confirm that there are few measures of the psychological, emotional, or social effects of aphasia that are suitable for people with aphasia. This is disturbing, and again, somewhat mystifying. Simmons-Mackie & Damico (1996) suggest

> "Aphasiologists tend to focus very little on *handicap* associated with communication disorders – that is, the social experience or the disadvantage resulting from impairment and consequent disability. This lack of emphasis on handicaps is somewhat surprising...conversation is the single most widespread use of communication, and social scientists studying conversation have demonstrated complex relationships between an individual's

> linguistic/psychological abilities and the social context within which the individual is immersed." (p541)

Le Dorze & Brassard (1995) comment that though the social reintegration of people with aphasia is one of the goals of speech-language therapy, research has essentially focussed on methods for improving linguistic recovery, in the absence of investigation into factors influencing social reintegration of the person with aphasia. The dominant influence of the medical model of health care delivery that exists within SLT may well be influential here, and will be discussed in greater detail within the thesis.

The need to attempt measurement from the perspective of the person with aphasia in recognized. Shewan & Cameron (1984) observed that though people with aphasia and their spouses tended to agree on the presence of certain communication-related problems, there was often disagreement on the degree to which the problem was troublesome to the person with aphasia. They also found that the number of problems reported was not related to the severity of the aphasia (confirming Simmons-Mackie's view that there is no direct, predictable causal link between impairment and its consequences). There appears to be a discrepancy between carers and the person with aphasia in how they would rate the impact of aphasia on his/her life.

The barriers that exist for the person with aphasia to be involved in measurement of participation have yet to be overcome. Pound (2000) summarises

> "As all clinicians working in this area will be aware, the need for therapists and researchers to develop both clearer conceptual frameworks and more rigorous meaningful, user-friendly tools for measuring change in 'psychosocial well-being' and participation is apparent" (p1155)

1.7.4 Limitations of measures of psychological well-being

The main difficulty with measures of psychological well-being for use with people who have aphasia, is their accessibility. Wähborg (1991) reviews standardised depression scales highlighted in table 1.11 and described in section 1.6.4.2. He concludes that none of these scales are suitable for people with aphasia without considerable alteration of the task requirements by the examiner. They are deemed to be too language dependent for people with aphasia (Währborg, 1991).

This difficulty was one of the prime motivators for the authors who developed the VASES (Brumfitt & Sheeran, 1999b). As has been acknowledged it may well be a useful tool to evaluate self esteem in people with language impairment. It is demonstrably accessible to people with aphasia, with simplicity and self-report approach being its greatest assets (Worall & Cruice, 2000). However, it also has limitations. These relate to the potential lack of relevance of some of the pictures used to represent constructs such as ‘confidence’ and ‘confusion’. Worrall & Cruice (2000) conclude that

> “Although overall the VASES has many positive attributes, a closer examination of some of the concepts and illustrations suggests that alternatives could be considered” (p1153)

There is also an acknowledgement that though self-esteem is a useful concept to consider, it is only one aspect of identity and well-being. It does not investigate the practical consequences, the effect on role fulfilment, or participation in life for example. Though self esteem is crucial and may well be affected by all those things, the VASES does not have the breadth of investigation sufficient to capture the impact of aphasia on someone’s life.

1.7.5 Limitations of measures of HRQoL

As has been noted, there has been a huge amount of work in HRQoL in recent years, which has led to numerous HRQoL measures. The increased emphasis on a more holistic approach, particularly those that utilise subjective measurement, is welcome. However, there are a number of difficulties regarding the concept and the operationalization of HRQOL generally that are yet to be overcome. These areas will be discussed in detail in Chapter 4. Discussion in this section will be kept to the limitations of measures of HRQoL in stroke medicine and with people who have aphasia.

Work has been carried out on using HRQoL measurements in stroke and rehabilitation medicine (Niemi et al 1988, Angeleri et al 1993, King 1996, de Haan 1995, Williams et al 1999 to name a few). Several authors, however, question the usefulness of these measures at present. Williams et al (1999) suggest the situation with HRQoL in stroke is not yet straightforward. They have reported that factors that are associated with post-stroke HRQoL are unknown, that domains known to be affected by stroke are often not included as items in the measures, and that measures lack the sensitivity to identify meaningful change that had been reported by people who have had a stroke.

DeHaan et al (1993) having compared the Barthel, the Rankin, and the SIP suggest that

> "we may conclude that stroke scales measuring at 6 months after stroke only partly explain a patient's level of disability, handicap, and quality of life. The ability of the stroke scales to explain a patient's psychosocial condition is rather poor" (p1181)

It appears therefore that measuring dimensions of HRQoL with a general stroke population is not straightforward. As with other dimensions of health measurement, the situation is even more complex when considering the added component of impaired communication. There are two different issues associated with HRQoL measurement and communication. The first is whether communication is conceptualised within HRQoL, and the second is how to include people with communication impairment in the process of subjective HRQOL measurement.

Authors are aware of the need to conceptualise and measure communication within HRQoL measures in stroke medicine. Bowling (1998) for example specifically mentions the presence of aphasia as a domain of relevance. Despite this acknowledgement, this is seldom seen. The incongruity of this has already been highlighted. Williams et al (1999) suggest that this omission is due to the fact that the effects of language and cognitive changes on stroke-specific HRQoL are difficult to assess.

Cruice et al (2000a) reviewed stroke research into HRQoL assessment in light of people who have aphasia.

> "Within the stroke population, the assessment of QOL has been fraught with difficulties in determining the individual's linguistic and cognitive competence required for QOL assessment. The literature reporting the capabilities of stroke survivors to cope with HRQoL assessment is neither consistent nor thoroughly reported. Studies have neglected to report cognitive or linguistic status, or failed to report qualitative information or difficulties experienced during assessment, or differentiated between data of subjects with and without communication impairments" (p14)

With regard to the second issue (how to include people with communication impairment in the process of subjective HRQoL measurement), the situation is also not optimistic at present. Cruice et al (2000a) point out that HRQoL research in populations with communication disabilities is limited and HRQoL instruments are infrequently used in clinical practice. They suggest that despite the numerous instruments available, none succeeds in adequately addressing the issues of communication in HRQoL.

They suggest that the meaning of HRQoL for people with communication disability has not been defined. As a consequence, there was no model or framework exists for HRQoL within SLT. Cruice et al (2000b) argue that the recent WHO classification ICIDH-2, offers the conceptual basis from which to investigate HRQoL with those with communication impairments.

Despite this potential they argue that there is still the undeniable fact that HRQoL measurement presents an irrefutable difficulty to someone with aphasia as a result of comprehension and expressive limitations. Cruice et al (2000a) ask

> "Perhaps the most fundamentally challenging question is whether reliable and valid information on HRQOL can be obtained from clients with communication disabilities." (p14)

They recommend a number of pre-requisites if HRQoL is to be investigated with people who have communication impairment; a clearer conceptual model of communication and HRQoL, information from people with communication impairments regarding their conceptualisation of HRQoL, identification of variables in HRQoL that are affected by communication impairment, evaluating the psychometric properties of existing HRQoL tools if used by people with communication impairment, evaluation of proxy reporting, and examination of the validity of HRQoL as an outcome measure in the triad of other vehicles such as functional status and client satisfaction.

Ross & Wertz (2002) have perhaps begun part of this process with the empirical study detailed previously, that investigated the relationship between HRQoL and impairment. Work such as that done by Le Dorze & Brassard (1995) and Parr (1994) and Parr et al (1997) could perhaps act as a starting point to guide the more fundamental research necessary to better understand the conceptual issues relating to what constitutes HRQoL for people with aphasia.

The BOSS-CD has only recently become available in this country. It appears to have potential as a HRQoL tool, providing a general overview of the impact of stroke on that person's life. The questions specifically designed to investigate the impact of communication alteration, appear relatively accessible and relevant but brief. There is still an issue of presenting wholly spoken or written information for people whose access to language has been compromised.

The SA-QOL also represents a move forward. It has been designed for people with aphasia and includes items that focus specifically on issues that people with aphasia suggested were relevant to measuring HRQoL in aphasia. However, it is still limited in its relevance to clinical practice. It does not seem to aim to offer information that would guide therapy. It remains weighted towards items that focus on physical tasks or mood, with few items concentrating on the impact of aphasia specifically.

1.7.6 Conclusions

It has been demonstrated that there are many ways to explore aphasia and its consequences on a person who acquires aphasia. None seems to be without limitation. The VAMS, the VASES and the PWI represent those that are most accessible to people with aphasia but the scope of all of these instruments is limited.

We can also see that there is no agreed best practice within SLT relating to measurement. The debate about best practice has been going on for several years. Worrall in 1992 pointed to what she felt was a state of crisis in speech and language therapy, given the surrounding environment of accountability and rationalisation within health care. She proposed that there was a need to decide how communication should be assessed. She cautioned that if those in the field of aphasiology did not decide how this was to be done then the end result would be fewer, if any, SLTs around in the 21st century to offer a service to people with aphasia. As recently as 2001 Duchan commented that

> "The practices of SLTs are many and varied. So much so that there have been complaints within the profession that there are too many things to choose from, with too little attention to how one should go about making these choices or the impact of those choices on our service provision." (p37)

She goes on to argue

> "the current sense of fragmentation and difficulty that clinicians have in deciding on best clinical practices arises not from the variety of choices, but because the impairment approach is operating out of context. It is difficult to determine what to assess, teach, and evaluate about a client's communication problem if one does not know what gets in the way of that client's participation in everyday life contexts or if one has not gone through a planning process with the client to see what sort of changes may be needed for him to attain his life objectives" (p41)

1.8 Motivation for this study

The following has been demonstrated;

- that health care measurement has a role to play in supporting evidence-based practice;
- that the perspective of the person who is the subject of measurement must be included in health measurement;
- that participation in health care measurement remains problematic for a number of groups of people;
- that people with aphasia might be considered to one of these groups;
- that within aphasiology there is no consensus on the 'gold standard' for evaluating the impact of aphasia;
- that there are a huge number of assessments available to evaluate language impairment and function;
- that all available assessments of aphasia have some degree of limitation, if considering the *impact* of the language impairment on an individual's life.

The need for a new tool was therefore demonstrated. So what are the requirements of an enabling tool for exploring and measuring the impact of aphasia on someone's life?

1.8.1 A therapeutic measure.

This term is chosen knowing that the role of *measurement* when discussing issues relating to participation is controversial. Simmons-Mackie (2000) for example compares a clinician-driven emphasis on objective measurement with a client-centred focus on subjective experience, suggesting that measurement and subjective, client-focus care are mutually exclusive.

The term 'therapeutic measure' therefore is chosen to encapsulate several levels. Cardol et al (1999) suggest that

> "The relevance of health care assessments can be determined by the specific goals of health care interventions. The ultimate goal in rehabilitation is to reduce handicap. As a consequence, measurements in rehabilitation must aim at quantifying the long-term health needs and outcomes at the level of social participation and functioning in society. This information is essential for the development of relevant and effective rehabilitation interventions, especially when further reduction of impairments and disabilities cannot be obtained." (p412)

There are a number of factors that will militate towards a measure being therapeutic.

1.8.1.1 Empowering process.

If the role of health care assessments is to, ultimately, increase social participation and functioning in society, then the *process* of measurement must be therapeutic. There is a suggestion that traditional SLT assessment focusing on impairment can, as a process, put the equal partnership of therapy in jeopardy from the start (Jordan & Kaiser, 1996). If the process of assessment and measurement itself leaves the person with aphasia feeling less confident, less competent, less powerful, as has been suggested by Jordan & Kaiser (1996), then this aim has been undermined. The therapeutic process must be established from the outset. The process itself therefore must be as accessible and acceptable as possible to the person with aphasia. The process itself will engender feelings of competence, confidence and strength.

The way in which this can be achieved relate to numerous factors (many of which will be discussed within the thesis). Factors include the contribution of the domains of measurement (investigating beyond symptoms and functional limitation), but also on the way the tool sets the context of measurement (setting the scene for a joint discussion or exploration, with equal value being given to the expert views of the person with aphasia, and control of, and power within the process being shared). At this level, if the tool is accessible and acceptable and the process is empowering, then it will also be therapeutic.

1.8.1.2 Acknowledging the experience.

At a second level, the tool would enable the clinician to understand the experience of living with aphasia to some degree. The role of merely acknowledging the perception of the situation is seen as hugely beneficial for the person with aphasia. Kleinman (1988) suggests that

> "it is possible to talk to patients, even those who are most distressed, about the actual experience of illness, and that witnessing and helping others to order that experience can be of therapeutic value" xii (preface)

1.8.1.3 Ordering the experience.

The aim of helping begin to order the chaos in which people can find themselves, is yet another level at which the well-designed tool can be therapeutic. Maclean et al (2000) show how merely establishing a dialogue between staff and users on rehabilitation wards had beneficial effects in terms of motivation.

> "Some high motivation patients described how information from staff led their thinking away from "magic "solutions to their problems...to focus instead on taking an active part in rehabilitation...other high motivation patients explained how information helped them to understand rehabilitation goals, and to recognise that they were making progress" (p1052)

1.8.1.4 Establishing a dialogue.

The beneficial effects of positive motivation are acknowledged. However, the effects of a tool that takes the dialogue beyond information from staff, could be more facilitative than simply raising motivation. Cardol et al (1999) have already noted how a well-designed tool, tailored to the needs of people with aphasia can encourage this therapeutic dialogue.

> "use (of the VASES) has already been noted by SLTs who were piloting it and found that the task of completing the VASES has provided the basis for a conversation about feelings and expression of distress which would otherwise have been difficult to start" (p119) (text in parenthesis added)

The role of dialogue within the therapeutic relationship is shown to be key by Little and his colleagues (2001a). In a study looking at outcomes in general practice, they demonstrated that

> "if doctors don't provide a positive, patient-centred approach patients will be less satisfied, less enabled and may have greater symptom burden and higher rates of referral" (p908).

1.8.1.5 Identifying the goals of intervention.

The next level at which a well-designed tool could be therapeutic is perhaps the most predictable. It should identify where the goals of therapy lie. To be able to guide therapy towards meaningful activities that reflect physical, psychological, and social well-being, these areas or activities must first be identified.

1.8.1.6 Being accessible

There are reasons why health measurement may not be therapeutic for someone with aphasia. The traditional design of tools may present barriers for people with aphasia. With this in mind, there will be a review of the things that must be considered when constructed an enabled tool for people with aphasia.

People with aphasia, more than those without, may benefit from language that is structured in a simple, though not simplistic, way. Linguistic structure should therefore be kept as straightforward as possible whilst remaining appropriate for adults. Choice of words should similarly be kept to those that appear commonly, so called high frequency words. Words should also be chosen, where possible that represent things that are concrete rather than abstract in nature. They should be short. Gesture and use of pictures have both been found to enhance comprehension. Gestures and pictures are iconic and by definition therefore negate the need to process words as they are received, as the information about meaning is graphically or gesturally represented.

There are those people for whom speech is easier to understand than the writing, and those for whom the opposite is true. People with aphasia usually find pointing the easiest response mode, as it bypasses the need for speech.

Additionally, impairments that can co-occur with aphasia for people who have had a stroke should also be borne in mind. People with aphasia can have difficulties with seeing across the entire visual field. It is not uncommon for people with aphasia to be unable to see one side of the page, unless their line of sight is specifically directed towards things presented on that side by verbal or gesturally cues.

As processing of verbal information is more taxing, tasks requiring this needed greater concentration and effort. Switching from one task to another is often problematic for people who have had a stroke.

So to facilitate tasks using words, therefore, information should be kept as short as possible, with repetition of task requirements being an advantage. If words used are short, high frequency, concrete words, within simple linguistic structures (be that spoken or written or both), supported with pictures, this will facilitate better comprehension for people with aphasia (Nickels & Howard, 1995). Pointing as a response mode will be helpful for those with aphasia.

All the issues mentioned above ensure that a tool is as accessible as possible for someone with language impairment.

1.8.2 The perspective of the person with aphasia

As has been mentioned, the perspective of the person who is the subject of measurement, is seen as a crucial aspect of health care measurement today (Eiser et al, 2000).

The overview of other groups of people at risk of exclusion, emphasises how this is still the case despite there being barriers to people giving their views in standard ways. Le Dorze & Brassard (1995), note that subjective measurement is not commonly employed in aphasiology, and that few studies have analysed the perspective of people with aphasia.

As has been exemplified, enabling a tool requires consideration of content as well as format and structure. The constructs within an enabled instrument must be specific to the people with whom it will ultimately be used to be maximally relevant.

By ensuring that the goals set are of personal relevance, the tool should enable the person with aphasia to set the agenda. Simmons-Mackie (2000) suggests the goal is to assist maximising communication and participation as defined by the client.

1.8.3 Measure of impact

The tool should go beyond the measuring and identification of functional limitations. As has been highlighted, there is a need to cover aspects of participation and emotional consequence if the impact of aphasia is to be addressed in a broad sense.

When looking at the effect of acquiring any disability, Hogan (1999) suggests that acquiring a disability signals a massive change in a person's social position and can constitute a personal crisis for the individual. Identity as a social phenomenon becomes apparent as individuals are perceived, by themselves and others, as different. Simmons-Mackie (2000) reports similar phenomena when someone has acquired aphasia.

> "People often act with surprise or negative emotion to communication differences. Such reactions potentially create the stigma of aphasia and serve to further diminish feelings of self worth (Goffman 1963). Kagan (1995) identifies communication as the means through which others judge our social, intellectual and emotional competence. Thus, when communication is impaired others might perceive the individual as generally incompetent. The effect on identity can be devastating" (p182)

These challenges to deep-seated feelings of identity and emotional response to the world, are seen as being intrinsic to the experience of acquiring aphasia. These issues will be returned to within the thesis. Kleinman (1988) sees these areas as at the very heart of health care.

> "When viewed from the human situation as of chronic illness, neither the interpretation of illness meanings nor the handling of deeply felt emotions within intimate personal relationships can be dismissed as peripheral tasks. They constitute rather the point of medicine" (p253)

Therefore there is a need seen to encompass the personal significance of acquiring aphasia as well as the practical consequences of living with aphasia. As Zarb (1994) suggests the occurrence of disability as a significant event in an individual's life is only a starting point for understanding the practical and personal consequences of living with a disability. Other factors, such as the social environment, material resources and the meanings which individuals attach to situations and events, are also essential to the development of an adequate conceptual framework.

Developing a measure to investigate the consequences and significance of aphasia on someone's life is challenging. The tool must be accessible and acceptable, to enable the person with aphasia to express his/her views on issues around the impact of acquiring and living with aphasia, despite the barriers of language processing.

If this could be achieved the advantages are wide reaching. The need to take the client and his/her life circumstances into consideration is becoming more widespread. Given the parallel demand for evidence-based practice, there is a need for instruments, which can measure these subtly altered parameters. If intervention is going to be person-centred and focused on issues associated with participation, then assessment must be too. Assessment at this level will enable the SLT together with the person with aphasia, to identify the priorities for therapy. It will enable identification of the barriers and facilitators to inclusion that exist for that person in her/his daily life. Once identified, therapy can be both personalised and targeted. With careful attention to the design and introduction of the tool, the process of measurement can contribute to the empowering of the person with aphasia, through acknowledgement, ordering, and elucidation of the impact of aphasia on that person's life. This thesis sets out to describe the development of a tool that meets the criteria described here.

Chapter 2

Development of an instrument: the Disability Questionnaire

2.1 Background to inception of Disability Questionnaire

An opportunity arose that began the process of developing a tool specifically designed for people with aphasia, that aimed to fulfil a number of the criteria set out at the end of the previous chapter; the tool would acknowledge the experience of acquiring and living with aphasia; it would begin the process of establishing order in a seemingly chaotic situation; the tool was designed to encourage dialogue between the clinician and the person with aphasia about the impact of aphasia; it aimed to utilize this dialogue to identify meaningful goals of therapy, based on the perceptions of the person with aphasia.

The development of this tool has taken many years and has gone through a number of processes. This thesis focuses on what lessons have been learnt about methodology and concepts associated with investigating the impact of aphasia by going through these processes. In this chapter though, the focus is on describing the first stage of the development process during which the tool was developed under a medical model.

In 1994 a research project was instigated; the aphasia recovery project. This project set out to enable clinicians (doctors and SLTs) to predict language recovery of people with aphasia up to one year after stroke, using initial paper-based neuro-psychological test scores alone. People with aphasia were assessed within six weeks of having a stroke and serially, every three months, until a year after their stroke. It was suggested that the information gleaned would be useful to guide clinical decision-making. It could be used to provide people with aphasia and their relatives with information about expected rates and patterns of recovery. A test battery was developed by a multi-disciplinary team, to measure linguistic aspects of aphasia at the level of impairment. It drew on current literature in the fields of aphasiology and cognitive neuro-psychology. This assessment was called the Comprehensive Aphasia Test (the CAT) (Swinburn, Porter & Howard – in press). The table of contents of the CAT can be seen in Appendix 2.1.

Some months into the recruitment stage of the aphasia recovery project, discussion took place about the clinical utility of the CAT. The use of triage was mentioned, suggesting that speech and language therapy could be allocated (or denied) on the basis of results from the CAT alone. I reflected on the rationale and motivation behind the study and the tool being used. Impairment was the sole focus of measurement. The impact of acquiring aphasia and living with aphasia was not being addressed. Management decisions by clinicians based solely on impairment measures were seen as under or ill informed and so risked being misguided and could be inadequate.

2.2 Rationale for writing the Disability Questionnaire

The lack of necessary concordance between impairment and disability has already been discussed (Simmons-Mackie, 2000). Though no 'tests' targeted disability in the CAT, observation and conversation with people recovering from aphasia indicated that the lack of correspondence between impairment and disability for certain people could be clearly seen in the prediction study. As language impairment improved, a person's perception of the effect of the aphasia on his/her everyday life was in no way predictable. For some people in the study the disability seemed to improve in line with impairment, for others it appeared to go in the opposite direction.

There was also a realisation that the CAT would be an inadequate measure of the *impact* of aphasia without an additional section focusing on disability. I held the belief that different people experienced similar impairments differently, depending on a number of factors relating to external influences (barriers and facilitators), and their own value system and personal biography. (Discussion about these issues will be contained within this thesis). I agreed with Simmons-Mackie (2000) who suggests that it is fundamental for health care providers to understand the individual's perspective on the impairment and its consequences, to enable them to plan appropriate management within the unique context of that individual's life.

These two beliefs; that impairment and disability associated with aphasia were not necessarily causally related and that insight into disability associated with having aphasia could only be gained from the perspective of the person with aphasia, motivated the writing of an additional section for the CAT. This new section was called the Disability Questionnaire and will be referred to as the DQ.

Table 2.1 gives an overview of the procedures and phases of development of the instrument. A detailed chronicling of the stages of development is crucial as it acts as a backdrop to a number of issues relating to how the impact of aphasia on someone's life could or should be investigated.

Stage 1 began with the writing of the DQ. The DQ required reflection by the person with aphasia on the impact of living with aphasia. It was developed to enable the systematic rating of the consequences of aphasia. It aimed to produce a set of scores for the disability that may be associated with acquiring, and living with, aphasia. In contrast to most measures used in aphasiology (such as those described in chapter 1) the DQ would be based on the perception of the person who had aphasia, as it was rated by them not the SLT. The DQ was designed to be administered, when possible, whenever the rest of the CAT was administered. The philosophy behind this was firstly, that the client's perspective was always to be seen as an integral part of the assessment of the person with aphasia. Furthermore, the inclusion of disability ratings alongside impairment scores could guide more socially valid management of the person with aphasia.

2.3 The Disability Questionnaire

The DQ was written on the basis of clinical experience of working closely with people with aphasia and their families. Streiner & Norman (1995) report this as being a valid starting point.

> "Clinical observation is perhaps one of the most fruitful sources of items… scales are simply a way of gathering these clinical observations in a systematic fashion, so that all observers are ensured of looking at the same thing , or all subjects of responding to the same items." (p17)

The original draft was not produced in consultation with any experts (be they people with aphasia, SLTs or psychometricians). Appendix 2.2 shows the original items included in the DQ. Table 2.2 gives an overview of the rationale behind the items included. The DQ contained the following sections;

1. *Disability*
    - a. *understanding*
    - b. *talking*
    - c. *reading*
    - d. *writing*

2. *Handicap*[1]

3. *Emotions*

The classification used in the DQ was based broadly on the WHO ICIDH-1 (1980) prevalent at the time of writing the DQ. The addition of an emotions section emphasised the emotional impact that was felt to be a reality for many people with aphasia that was not captured elsewhere in commonly used assessment procedures or indeed within the ICIDH 1. Discussion about the relevance and validity of this typology is discussed later. In its original form the DQ was a self-report questionnaire, with rating scale response format. The end product was a set of figures summarising each of the three categories described above. It was the intention that these figures be supported by comments made as the person with aphasia and the SLT explored each item.

2.3.1 Item inclusion

The items chosen aimed to explore real situations that could be affected by aphasia. They covered everyday communication activities (called at this stage 'disability'); the DQ investigated whether the person with aphasia felt the difficulties they had mentioned in those areas affected their daily life and to what extent (called at this stage 'handicap'); finally it explored emotions associated with aphasia (called at this stage 'emotions').

The everyday activities rated in the 'disability' section related to the modalities routinely assessed in traditional language assessment used by SLTs. The specific activities chosen were derived from situations described by people with aphasia seen during routine clinical practice. These situations were intended to span common everyday events that were reported as being affected by aphasia, and of significance in everyday participation. The items were intended to be hierarchical in terms of difficulty. It was quickly established, however, that though the hierarchy might hold true for some people with aphasia, unsurprisingly, it was not universal.

The second section included items that attempted to focus attention on how intrusive the communication difficulties, previously rated, were to that person in everyday life. As has been mentioned, there was a belief that the link between altered behaviour and its effect on everyday life was unpredictable and idiosyncratic. This section sought to explore this by establishing the impact of aphasia for that individual

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[1] *The controversial use of the term 'handicap' will be discussed elsewhere within this chapter and within the thesis.*

in the context of her/his unique circumstances.

The final 'emotions' section quantified the emotional impact of aphasia and its sequelae on the individual. The emotions selected were based on clinical experience. However, a number of authors have written about the emotional consequences that altered communication can have. Brumfitt (1999) for example, describes some reactions associated with having aphasia including frustration and anger. Brumfitt (1998) also describes how self-esteem can be affected in a negative way, leading to anxiety and depression as a result of having aphasia.

Emotions described in measures of psychological well-being typically cover such areas as depression, anxiety, pessimism, and dissatisfaction. (For a detailed review see Bowling 1997a). As can be seen from appendix 2.2 many of the emotions mentioned above were included in the final section of the original draft of the DQ (see Q18 and Q21).

2.3.2 Methods of administration

2.3.2.1 Type of instrument

The DQ was originally intended to be a self-report measure. It was designed to be self-administered i.e. given to the person with aphasia to administer alone without the help of the clinician. It had been thought that given the time constraints of the aphasia recovery project, additional sessions would not be possible. The fact that health-care questionnaires are traditionally designed for self-completion also affected this decision. The wisdom of this decision will be examined later in this chapter.

2.3.2.2 Type of scaling response

At its inception, the focus of DQ was on *measuring* the subjective experience of living with aphasia. This would enable data about the impact of aphasia to be included alongside, and compared with, measurement of the impairment of aphasia obtained from the other sections of the CAT.

Rating scales were seen as the best way of accessing this information. Section 1.6.4. confirms that rating scales are often used in measurement when investigating feelings, attitudes and behaviours. They contrast with dichotomised responses (e.g. yes-no, agree-disagree) by allowing a continuum of response. In measurement of feelings, attitudes and behaviours there are several advantages to using a continuum of response. As Bowling (1997a) points out

> "attitudinal and behavioural issues are not easily dichotomised; they often lie on a continuum...offering a wide variety of choices is likely to reduce

> potential for error due to confusion, although the continuum should not be too great, or meaningless responses will be elicited". (p13)

Rating scales also allow visual representation of the phenomena and were seen as transparent in terms of ease of completion for people with linguistic impairment. As Bowling (1997b) points out, the Likert-type method is the most commonly used response choice for health status and health-related quality of life, with the form of five- to seven-point Likert scales generally preferred because of their ease of administration, analysis and interpretation.

Alternative methods of response format were not trialled. There seemed to be clear advantages to rating scales and people with aphasia seemed to be using this type of scaling response in the pre-pilot phase with ease.

2.3.2.3 Method of scoring

Having decided to employ a rating scale, a decision had to be made as to how many points there would be on the scale. Streiner and Norman (1995) report that though there is no theoretical maximum to the number of points on a scale, scale developers rarely go below three and above 10.

In the DQ each item was scored using a 5-point scale, 1-5, with numbers and adjectives bounding each end (see appendix 2.3). Though this is not a true Likert scale as it is not on an agree-disagree continuum, this scaling method is recognised as Likert-type (Bowling, 1997b). The choice of 5-point scale was intuitive. However, there is evidence to suggest that healthcare ratings benefit from the simplicity of the 5-point scale. Mozley et al (1999) describes adopting a 5-point 'Likert' scale in preference to a 7-point one, after pilot testing iterations of a test for people with mild dementia. Cummins (1997) reviews measures for people with intellectual disability and found the 5-point scale to be the most commonly adopted.

The exception to 5-point scaling method in the DQ, was the 'emotions' section. Here a three-point scale was used (with the descriptors of 'Very', 'a little' and 'not at all' used). It was assumed that making a choice across a 5-point scale would take longer, was seen as emotionally taxing, and somewhat tortuous. This position has been revisited and overturned (details are described in chapter 5). The 5-point scale with 'yes a lot' and 'no, none' as end point anchors would have been more informative, and I believe, would not have been any more taxing than the 3 point scale.

The item scores in the DQ were then summed to give a domain score. Each section contained 4-9 items and the results were summed to give a domain score (understanding, talking, reading, writing, 'handicap' (or intrusion) and 'emotions'). Bowling (1997b) points out this process of summing within a domain is useful as it cancels out any item error or bias by averaging the scores.

No item or section was weighted. Differential weighting of the items was considered. The section that was considered for weighting was the 'handicap'/intrusion section. This section carried less numerical value relative to the 'communication activities/disability' section that had been described earlier (possible maximum total of 80 for 'communication activities/disability' section, verses possible maximum total of 35 for the 'handicap/intrusion' section). However, anything that might detract from easy use within the clinical setting was to be avoided unless absolutely necessary. Weighting was seen to complicate the scoring. Streiner and Norman (1995) agree that weighting is a complex area, and suggest that differential weighting contributes very little, apart from an additional complexity to the scoring. Bowling (1997b) suggests that

> "in practice, however, it is frequently found that weighting items makes little difference to subjects' relative scores, despite the inherent logic of this technique" (p14).

Nunnally (1970) suggests that if a scale has more than 20 items weighting is not useful; the DQ effectively had 30 items. No weighting was therefore introduced. The issue of the relative importance of the 'handicap/intrusion' section however, will be returned to later in Chapter 5.

The other consideration relating to items and section scoring, was whether to have an overall score, a quotient. Many scales give a final quotient. The reason for quantification is for the numbers to mean something, to tap into domains and be a short-hand for that information being explored. For all the reasons mentioned in chapter 1, having a numerical score is useful if it informs decisions in some way, or adds to the exploration of an issue under investigation.

In the case of the DQ, one overall total would represent an 'aphasia impact or disability score'. This was not considered to be useful. It would give little information on its own. Comparison between domains was of interest. It was useful to know *relative* ratings of reading versus talking, everyday activities versus intrusion of those difficulties, talking difficulties versus emotional consequences for example.

Bowling (1997b) again suggests that sub-scores will lead to more refined information than total scale scores. All the sections covered aspects relating to the impact of aphasia on someone's life, but each section explored identifiably different aspects of this subject. It therefore seemed appropriate to employ a simple summing of scores within each section covering the different domains, (namely 'understanding speech', 'talking', 'reading', 'writing', 'handicap' and 'emotions'), but not to sum these section scores.

It should be noted that the anchor words[2] for each section differed. The anchor points for the 'communication activities/disability' section were 'unable/very difficult' and 'easy/no problem,' the anchor words for the 'handicap/intrusion' section were 'yes, a lot' and 'no, none at all' and finally the descriptors used for the 3-point emotional scale were 'very', 'a little' and 'none at all'. The anchor words and descriptors changed between sections because the questions posed between the sections changed (as illustrated in appendix 2.2). Each set of anchors were chosen to correspond with the question posed in that section. This anomaly will be discussed later.

2.3.2.4 Proxy rating

As has been discussed, proxy rating are rating obtained from someone other than the person who is the subject of the rating such as family members, friends or health-care workers who knows the person in question. They are often used when there is doubt over the person's ability to rate him/herself. As has been discussed there are reasons why the standard health care tool may be inaccessible to a person with aphasia.

However, the benefits of self-report and limitations of proxy ratings have been highlighted in chapter 1. The thrust of the rationale for the DQ was to establish a common understanding of the situation, and the perception of that situation from the perspective of the person with aphasia. Though care-givers opinions and viewpoints are of crucial relevance to understanding life with aphasia, this was never the main focus of enquiry.

Therefore, the decision was taken early on in the process of developing the DQ, that proxy responses would not be sought. It was decided that if a person with aphasia was precluded from participating in the process of completing the DQ, then

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[2] *Anchor words relate to the words located at the far end points of a Likert-type scale. They describe the extreme positions which guide the respondent when s/he makes her/his rating.*

other ways of investigating the impact of aphasia should be found. These other methods are beyond the remit of this thesis but can be reviewed in 'Beyond aphasia' (Pound et al 2000) chapter 2. The issue of caregiver perception of the impact of aphasia on both the person with aphasia and themselves is seen as one that needs further thought and investigation but again is beyond the remit of this piece of work. Further discussion of these issues takes place in chapter 5.

THE DEVELOPMENT OF THE DQ

Having been written, the DQ was subject to a variety of processes that contributed to its evolution. These processes can be grouped into four stages; stage 1 included a pre-pilot (phase 1), pilot (phase 2), and field-testing (phase 3) of the DQ. Stage 2 included user consultation exercises. Stages 3 and 4 involved significant changes to the methodology employed which will be discussed within chapters 4 and 5. It also involved a name change of the instrument to the Communication Disability Profile. A summary profile of the processes within the development appears in table 2.1. These phases have been divided into stages as they represented qualitatively different approaches to the development process. Each stage involved people with aphasia in different ways which will be the focus of discussion in chapter 6.

This chapter will describe the methods employed and the results obtained in stages 1 and 2. Methods used in stage 1 of the development process will be discussed in section 2.4.1 with the results being discussed in section 2.4.2. Stage 2 results and methods will be discussed in section 2.5. The processes involved and the iterations of the tool can be tracked by referring to table 2.1.

2.4 **Stage 1 – Indirect user involvement**

2.4.1 Methods used in stage 1

2.4.1.1 Phase 1: Pre-piloting the DQ with 15 people with aphasia

The first stage of development was to pilot test the DQ (draft 1) with people who had aphasia. Streiner & Norman (1995) point out why this process is valuable.

> "Perhaps the best way to ensure that the items are understood, unambiguous, and jargon-free is to pre-test them on a group of people comparable to those who will be the ultimate targets" (p58).

These people were the next 15 people routinely referred to participate in the aphasia recovery study. Each volunteer was assessed using the CAT, which now contained the DQ (draft 1) as the final section. Obvious administrative or conceptual difficulties were noted and action taken to eliminate these. These observations were combined with feedback given by the people who had aphasia who had completed the administration and used to make changes described in section 2.4.2.

2.4.1.2 Phase 2: Further pilot testing and external advice

Having modified the DQ in accordance with the comments made by people with aphasia and observations during pilot testing, the DQ (draft 2) was administered with a further 15 volunteers (each time as part of the CAT assessment). Suggestions and comments made were incorporated.

External advice was also sought. Streiner & Norman (1995) comment on the use of 'expert' groups. The term 'expert' is used by Streiner & Norman with exclusive reference to healthcare professionals. Streiner & Norman suggest that 'expert judgements' can be gained formally or informally. They conclude that there is much to be gained by seeking the views of those recognised as leaders in the field, as they will represent the most recent thinking in an area. This maximises access to the accumulated knowledge and experience of others who have worked in the field, without much effort. (The issue of who constitutes an expert is discussed in relation to disability politics and the power relationships within research production later within this thesis).

An informal group of 'expert colleagues' was convened with the purpose of commenting on the conceptual basis and construction of the DQ. The group was comprised of mainly SLTs with the exception of one woman, formerly a teacher, who had been living with aphasia for five years as a result of a stroke. All four SLTs consulted had many years experience of working with people with aphasia. Two also had backgrounds in research into theoretical and social aspects of aphasia. The majority of people consulted had particular expertise or interest in the field of disability politics and the social model of disability as it applied to living with aphasia (this conceptual model will be discussed in chapter 3). Though they were recognised leaders in the field of the aphasia, with a clear understanding of the social model of disability in relation to people with aphasia, the perspective the majority of the panel brought was professional (authentic consultation will be addressed later in the thesis).

The group was convened to enable a broader overview of the DQ (draft 2) to be gained. Advice from other people experienced in aspects of living with aphasia would focus issues specifically related to item inclusion, style, classification and most importantly relevance to people with aphasia and overall clinical utility.

2.4.1.3 Phase 3: Extensive field-testing of DQ (drafts 3, 4 & 5)

Phase 3 involved field-testing the DQ (in various iterations) with a much larger number of people who had aphasia. When beginning this process, an initial pilot with 10 people with aphasia (using DQ draft 3) indicated that though the changes suggested by the 'expert' colleagues were improvements at a conceptual level, there were various items that were shown and reported as still being inaccessible for people who had aphasia. Changes were made to the DQ. This new version, changed on a conceptual level as a result of the colleague advice, and on an administrative level following advice from the people who were the subject of the measurement, was the DQ (draft 4). The changes that produced it will be described in section 2.4.2

This iteration of the DQ (draft 4) was field-testing on 40 occasions, with people who had aphasia, all of whom were volunteers for the aphasia recovery project. A number of these administrations represented test, and retest three months later, with the same individual. As a result of comments made by people who did the DQ and observations on my part, further changes were made resulting in DQ draft 5. These changes will be described below. This iteration of the DQ was then administered on a further 47 occasions with people with aphasia, (again with a small number being two administrations at three month intervals with the same individual). This represented the end of stage 1.

2.4.2 **Results of stage 1**

When reporting the modifications that took place in this first stage (phases 1-3), the descriptions will largely fall into two broad categories;

1. changes to increase acceptability (ensuring the concepts included were relevant and sensitive to the needs of people living with aphasia).
2. changes to increase accessibility (making the administration of the tool easier for the person with aphasia and/or SLT).

The changes were made incrementally.

Certain key methodological and conceptual issues arose as the tool underwent development. These issues will be alluded to in this chapter but discussed in depth within later chapters. The changes between the iterations of the DQ are summarised in tables 2.3-2.6.

2.4.2.1 Changes to make the DQ more acceptable

There were many changes during stage 1 to make the DQ more acceptable to people with aphasia. Very early in stage 1, there was an alteration of mode of administration. The DQ was originally intended to be a self-completed self-report measure. It was envisaged that time pressure would negate the possibility of SLT-administered completion. There was also a notion of self-completion being closer to a 'gold standard' of objective assessment.

However, there were people referred to the project who could not read and who therefore had to have the DQ administered face to face. Trials of using the DQ in this way demonstrated that people welcomed the opportunity to discuss the issues raised, in person. Some questionnaires *were* given out, to be completed without assistance from a clinician. However, problems were identified with the procedure: some questionnaires were not returned, some were returned partially completed, some had been completed by the caregiver. Self-completion was therefore abandoned in favour of a SLT-guided administration.

Altering the administration mode proved beneficial. People who had auditory and/or written comprehension difficulties could complete the DQ facilitated by the SLT explaining, gesturing, and using supported communication. This ensured that more people were included in the process than would not have been if the DQ had continued to be self-completion. The clinician was able to reiterate, clarify and rephrase to ensure the questions had been understood and that the answers were valid. As Bowling (1997b) points out, without assistance, structured questionnaires can be potentially problematic, due to the assumption that researchers and respondents share the same theoretical frame of reference and interpret the words, phrases and concepts used in the same way. This is particularly pertinent to those who have difficulty with interpretation of language due to the nature of their impairment. The final advantage was to enable the respondent to discuss the items rather than merely rating them. This facilitated a useful dialogue, and additional pertinent information to be shared.

In retrospect, the advantages of face-to-face administration with this client group (in terms of accessibility, ease of administration and so validity) were always going to outweigh logistical factors imposed by restricted time pressures.

Another early change to improve acceptability was to the rating scale used in the emotions section. Previously the rating scale had been a 3-point scale with response options relating solely to the degree of emotional impact experienced (very-a little-not at all). As a result of comments made by people with aphasia, suggesting that this was inadequate and lacked sensitivity, the scale was changed to a 5-point scale, rated in a 2-stage process. The person with aphasia firstly had to rate whether they felt an emotion 'all the time', 'sometimes' or 'never'. Having established the frequency with which they experienced an emotion, they were then encouraged to rate the intensity of the experience by rating whether they felt this emotion, 'a little' or 'a lot'. Table 2.3 includes details of the resultant scale.

The title of this section was also altered. 'Emotions' was changed to 'Distress'. This was justified by observation of the emotional impact of the acquisition of aphasia for the 15 people seen in this initial pilot phase. At the time the TOMS, which was being introduced to SLTs, also used this word to describe this domain. This change does, however, demonstrate the entrenched professional 'care and cure' ethos under which the DQ was being developed. Issues relating to the power and significance of language, the assumption of negativity associated with disability and the evolution of associated conceptual issues are discussed in chapter 6.

The content of the emotions section was also altered incrementally in line with disquiet expressed by people with aphasia, and as a result of 'expert' colleague advice. Most of the positive emotions in the emotional section were deleted during stage 1. These emotions had been included originally in an attempt to reduce the negativity of the DQ. However, the response of the people with aphasia to these was that they were patronising and inappropriate. In retrospect, it is felt that it was not the inclusion of positive attributes themselves which was the source of tension but the way in which the specific items that were chosen and expressed. In phase 1 and 2 the item 'optimistic' remained and the scoring was simply reversed by the administrator when calculating the emotional section total, to enable the same rating scale to be used. By phase 3 (draft 5) 'optimistic' was deleted. There were two difficulties identified. The first was that as an item, the ratings it received seemed to be polarised, being either very optimistic, all the time (scoring 0) or never (scoring 4). Secondly, the presence of its opposite (pessimism) as a separate question, led to confusion, as some people felt they were being asked the same question twice – the conceptual root being the same. It was therefore deleted. Methodological and conceptual issues associated with reducing negativity in a tool that focused on disability will be discussed in chapter 6.

Further changes related to the acceptability of concepts to people with aphasia, were fuelled by suggestions emanated from the colleague advisory panel. For example, discussion took place within the colleague advisory meeting about the use of the term 'handicap'. It related to the unease with which the Disability Rights Movement viewed this term. This type of nomenclature was seen as unhelpful and was therefore abandoned. The 'daily life' section became subsumed within a broader section looking at impact of the aphasia. At this stage the term 'emotional impact' was used to cover the final section, acknowledging the rejection of the term 'distress' for this section.

The emotional impact section was also expanded to make the items included more acceptable. Many authors have noted the importance of self-image and self identity to an individual's sense of well-being and the disruption to aspects of this that aphasia can bring (Brumfitt, 1993a). Compton (2000) for example suggests that

> "Researchers have generally agreed upon a set of variables that are consistently strong predictors of subjective well-being. That set usually includes high *self esteem*, internal locus of control, optimism, *positive social relations*, *extraversion* and a sense of meaning and purpose in life" (p156) (emphasis added).

Emotions such as isolation, self esteem, loneliness and whether the person with aphasia thought other people understood were raised by the 'expert' colleagues, as being relevant for inclusion within the emotional section. These items were added to the confidence rating in this section.

2.4.2.2 Changes to make the DQ more accessible

There were many changes to 'enable' the instrument for people with aphasia. These included the introduction of help-sheets, the elimination of double questions (questions that mention two activities are ambiguous as the two activities can be differentially easy or difficult for a person with aphasia, making double questions unanswerable), and simplifying of language (these can be seen by reviewing the changes shown through the iterations in tables 2.3-2.6).

When the DQ was originally administered written, help-sheets to aid completion of the tool, were not used. An item was read aloud by the SLT and the person with aphasia made a rating on a score-sheet (appendix 2.3). This was found to be unsatisfactory. The verbal presentation of the question, in isolation, proved difficult for people with comprehension difficulties. Help-sheets were therefore written to provide the item in a permanent form while the person with aphasia made her/his judgment on which rating s/he wished to select. The help-sheets provided a number of key words used in the spoken question to act as a communication 'ramp' to aid impaired comprehension (examples are shown in appendices 2.4 and 2.5).

Other changes related to the negative wording within the DQ. An example of this was the altering of the rubric from 'how *difficult* is it for you to…' to 'how *easy* is it for you to …' This was an attempt to reduce the assumption that communication impairment will automatically lead to communication disability, a theme that will be returned to.

Table 2.5 gives examples of some of the changes originated directly from people with aphasia. People with aphasia made comments asking for clarification or pointing out the ambiguity within questions. As a result of these, changes were made to the wording. Sometimes this necessitated simplifying the wording as in questions 2, 21 or 22. Sometimes it required a change of emphasis as in the case of the question 7. Similarly, comments made by respondents highlighted the subtlety of how language impairment can be affected by external influences. This can be seen in changes made to questions 7 or 11.

2.5 Stage 2: Direct user involvement

2.5.1 Methods used for stage 2: DQ user focus group consultation.

The DQ had undergone a number of changes during stage 1. It now had a degree of stability. The obvious difficulties with it had been removed and the DQ (in its various forms) had been administered on 127 occasions with 97 people with aphasia. Stage 2 was an attempt to establish aspects of the tool's validity. This section proved instrumental in altering the future direction of the DQ, and challenging the conceptual and methodological basis of the research process itself.

2.5.1.1 Conceptual issues

There was an acknowledgement that all the changes made in stage 1, though often motivated by the comments made by people with aphasia, were decided on and worded by me (a discussion relating to the relevance of this can be found in chapter 5 and 6). Stage 2 therefore sought to address this issue directly. A validity exercise was undertaken. A brief summary of issues relating to validity will precede the description of the validity exercise for the DQ.

2.5.1.1.1 Rationale for investigation of content and face validity

When administering quantitative assessments of any type, consideration must be given to psychometric aspects of the tool. Whatever the method of investigation, it is useful to demonstrate certain qualities; a measure should be valid – it should measure what it sets out to measure; and a measure should be reliable – it should produce the same score if re-administered in an identical situation. If the tool is not valid or is unreliable, then differences between scores are difficult to interpret. Judgements based on comparisons for the same person over time, after intervention, or between people, must be interpreted with caution. Any differences seen could reflect deficiencies in the tool rather than real change over time, through intervention or between people.

Validity addresses whether a tool assesses the domain or issue it sets out to measure. It is divided into a number of different types of validity; content, face, criterion (concurrent and predictive), construct (including convergent-discriminant and factor analysis). Content and face validity were explored for the DQ, the details of which following below. The other forms of validity in relation to the DQ will be discussed in chapter 5.

Content validity assesses whether a tool covers all the relevant concepts or domains. Additionally, the number of items given over to different sections should reflect their relative importance. The instrument should therefore cover the characteristics in a balanced, logical and comprehensive way (Bowling, 1997).

Face validity is a component of content validity. It indicates whether a tool, subjectively, seems to be reasonable. Does it, on the face of it, have the desired qualities sought for measuring this domain? It is a more superficial but related construct than content validity.

Consideration was given to exploring criterion validity. However, to do this a similar assessment would need to be used for comparison. The VASES (Brumfitt & Sheeran 1999b) represents the assessment that was comparable in terms of *some* shared domains of investigation. At that point the VASES was unpublished and unknown. Predictive validity is the second aspect of criterion validity. The starting point for developing the DQ had been the assertion that the disability associated with aphasia could not be predicted by language impairment, nor could it be predicted over time. Investigation into criterion validity was therefore not pursued.

Construct validity is the final aspect of psychometric validity. A small statistical exercise to examine an aspect of construct validity was undertaken. One measure of construct validity is internal consistency. A widely used statistical test to measure internal consistency is Cronbach's alpha (Streiner & Norman, 1995). This test uses correlation to investigate the correspondence between each item and the total score. Results above 0.7 are suggested to represent good internal consistency (Nunnaly, 1978). Using the data taken from phase 3, a small number of results were analysed and are summarised in appendix 2.6. All scores were high, suggesting the items in the DQ are all tapping a similar domain.

2.5.1.1.2 Rationale for the use of qualitative methodology

The aim of stage 2 was two-fold; first, to explore the psychometric robustness of the DQ, in terms of face and content validity, but secondly, to begin to investigate *social* validity, in terms of meaningfulness and utility to users. In this context there are two sets of users, people with aphasia and SLTs. There would be little point in developing a psychometrically robust instrument if it did not examine concepts relevant to people with aphasia's everyday lives, or that SLTs did not feel was useful to them in their everyday clinical practice with people with aphasia. Though these areas are touched on within the realms of psychometric validity, they are not the same. A tool could perfectly describe or rate one's experience of the manifestations of having aphasia but if it does not put the experiences in context for that particular individual, or establish priorities for action, then the meaningfulness and usefulness of the tool may be questioned.

Content and face validity judgements are usually based on a review of the measure by an 'expert' panel (Streiner & Norman, 1995). Though other aspects of validity and reliability testing are routinely explored using quantitative methodology, content and face validity are often investigated by employing qualitative methodology (Streiner & Norman, 1995). Different methodologies are considered necessary for different aspects of investigation. Pope & Mays (1995) point out quantitative methods aim for reliability (that is, consistency on retesting) while qualitative methods score highly on validity, by examining how people really behave and what people actually mean when they describe their experiences, attitudes and behaviours.

Damico et al (1999) discuss qualitative methods in relation specifically to aphasia research. They highlight what they see as the inadequacies of quantitative methods when considering areas relating to the 'social handicapping conditions of neurological impairment', and suggest instead the application of qualitative research methodologies to assist understanding, especially in relation to the impact of aphasia in authentic settings.

The aim of stage 2 was to establish whether or not the DQ was both psychometrically valid in terms of content and face validity and to explore whether the tool was seen as useful and meaningful, by users (both people with aphasia and SLTs). Qualitative methodology was therefore chosen. As Felce (1997) summarises

"the point being made is not that one approach is better than the other, but that they are different, with different strengths and weaknesses to illuminate aspects of people's quality of life. Both qualitative and quantitative methodologies have a part to play." (p134)

2.5.1.1.3 Rationale for the use of focus groups

The qualitative method chosen for stage 2 was that of in-depth, semi-structured interviewing. In-depth, semi-structured interviewing is a well-recognised technique used within qualitative methodology (Bowling, 1997b). Such interviews have been described as a conversation with a purpose (Kahn & Cannell, 1957). Their purpose is to explore issues or topics in depth, without the use of preset questions, but shaped by a defined set of topics or issues (Pope & Mays, 1995). Marshall & Rossman (1989) suggest the researcher explores a few general topics to help uncover the participant's meaning perspective, but otherwise respects how the participant frames and structures the responses. Semi-structured interviews can be used flexibly to allow the interviewer to probe, and to enable respondents to raise other relevant issues not covered by the interview schedule (Bowling, 1997b). Such in-depth interviewing can be conducted in an individual or a group setting, each offering its own advantages.

Focus group interviews (as opposed to individual in-depth interviews) enable a variety of potential viewpoints to be discussed and by doing so develop participants' thinking on the subject. Kitzinger (1995) believes that group processes can help people to explore and clarify their views in ways that would be less easily accessible in a one to one interview.

If a viewpoint is thought to be negative or critical this could make the respondent feel uncomfortable in an individual interview. Focus groups afford a degree of intimacy and security when discussing potentially sensitive topics (such as opinions) that may be lost with individual interviews. Kitzinger (1995) points out that this may be due to the mutual support in expressing feelings that are common to their group but which they consider to deviate from the mainstream culture.

Focus groups may be particularly useful for eliciting views from people who may perceive themselves as in someway disadvantaged or less likely to voice opinions (such as people with disabilities). Kitzinger (1995) suggests that dis-empowered people who are often reluctant to give negative feedback or may feel that any problems result from their own inadequacies, are empowered through the security of the group situation.

Focus groups are seen as particularly suited for people who have difficulty with expressing views due to communication impairment. Kitzinger (1995) again suggests that this is because the focus groups do not discriminate against people who cannot read or write, and they encourage participation from people reluctant to be interviewed on their own or who feel they have nothing to say. Similarly, Maclean (2000) believes that the control of conversation allowed during interviews is an efficient way to investigate an under-researched topic and to allow people to explain their beliefs accurately in their own terms.

2.5.1.1.4 Sampling issues

Sampling is the process whereby people to be included in a research process, such as focus group interviewees, are identified. Sampling within qualitative research differs from that of quantitative research sampling. Sampling in quantitative research is based on generalisability and randomisation. The idea is that if the sample size is large enough then the probability is that the sample will be representative of the population from which that sample is taken. This representative sampling therefore is done at random. There are different methods of representative sampling, but all rely on the assumption that the ultimate sample is representative of the population from which it is derived.

Sampling in qualitative research is different from representative or probability sampling. The researcher sets out to *select* people who come from specific populations or groups thought to have a relevant perspective on the issue under investigation. Mays & Pope (1995a) suggest that

> "informants are identified because they will enable exploration of a particular aspect of behaviour relevant to the research. This approach to sampling allows the researcher deliberately to include key informants with access to important sources of information." (p110)

This type of sampling is called systematic or non-probabilistic sampling.

Selection of the participants for the focus group is based on trying to capture opinions from people with differing characteristics. Kitzinger (1995) highlights that most focus group studies use a theoretical sampling model whereby participants are selected to reflect a range of the total study population. She proposes that it can be advantageous to bring together a diverse group, to maximise exploration of different perspectives within a group setting.

2.5.1.2 Sampling for the DQ user focus groups

Relating these theoretical considerations to the development of the DQ, the need was seen to identify and sample the users of the DQ to inform me about the face and content validity of the DQ (draft 5). Two groups of users were identified. The first group were people who had aphasia who could rate themselves on the DQ. The second were SLTs who would administer of the DQ. Both groups of people would take part in the process of field trialing the DQ (draft 5) and then report back their feelings and perceptions in relation to face and content validity. Ruta & Garratt (1996) confirm the strength of in-depth interviews with people who have completed an instrument as fundamental to assessing qualitatively its face and content validity.

2.5.1.2.1 Sampling for the DQ user focus group of people with aphasia

Experiences of acquiring and living with aphasia may be influenced by a huge number of factors. The ones chosen to guide the sampling, were those personal characteristics thought to be the most significant to the experience of acquiring and living with aphasia; age, gender, ethnicity, type and extent of language impairment, duration of living with aphasia, and whether the person was living alone or not. The rationale for these inclusion criteria when recruiting people for the DQ user focus group of people living with aphasia is described below.

Advice was taken from the director of the Qualitative Research Unit at Social and Community Planning Research in London, regarding the numbers of people who should ideally be within each category. Table 2.7 summarises the resultant target sampling grid.

Age is seen as influential in terms of how people experience life, including acquiring and living with a disability. Zarb (1993) discusses issues relating to the experience of ageing with a disability. There is recognition that there may be different issues that are relevant to someone who acquires aphasia in their 40s (who may still be working, and/or have a young family) compared with someone who is in their 80s (whose social participation may be less extensive). Effort was made to recruit across the range of decades most commonly associated with having aphasia.

Similarly, gender plays a role in life experiences. Men and women experience life differently. Morris (1993) discusses issues relating to gender and disability, highlighting the different perspectives that gender brings to living with a disability. Recruitment of men and women in equal numbers was therefore attempted.

Ethnicity and race are also established as contributing to different perspectives on a situation. Bhopal (2001) for example suggests that racial and ethnic inequalities in health and health care are abundant, but their underlying causes, and the contribution of racism, are controversial. Stuart (1993) suggests that the experience of disabled people within ethnic communities represents a double oppression, and is fundamentally different to the oppression experienced by white people. Senior & Bhopal (1994) suggest therefore that racial background is used increasingly as a key variable to describe health data.

Ethnicity and race are difficult issues, however. It is recognised that simply sampling people on the basis of skin colour into white versus non-white is simplistic in the extreme. Skin colour does not identify ethnic background or characteristics. However, to sample across all racial groups would be unrealistic and impractical. Had one ethnic or cultural group predominated in the sampling area, and the DQ was to be used specifically with that population, attempts would have been made to recruit more people from that particular background. Recruiting within London meant that there was no one majority ethnic group, as London is culturally and ethnically diverse. Similarly it is intended that the DQ be administered with people of a variety of ethnic and cultural backgrounds. On recommendation, the target of having at least one person who was not white, whatever ethnic or racial background s/he came from, was arrived at.

The degree of language impairment was also seen as important in how an individual would experience living with aphasia. Gladis et al (1999) agree that the level of symptomatology influences judgments. The sampling relating to language impairment related to degree of impairment expression and comprehension judged by the SLT who knew the volunteer.

Comprehension of the spoken word in this context however is problematic. The degree to which someone is able to follow conversation is seen as enormously influential on experiences of life with aphasia. However, a pre-requisite for participation within the group setting is an ability to understand the questions asked, and comprehend at least in part the group interchange that then follows. Therefore people with severe comprehension impairment were specifically excluded from participation in the focus group. This is a flaw in the study, as those people with severe comprehension impairment are not represented and potentially disenfranchised.

This difficult is not seen with the degree of expressive impairment that someone lives with. Someone may have no speech but still be able to contribute successfully within a focus group given the right communication 'ramps' (such as extra time, pen and paper, communication books, an informed and skilled facilitator, for example.) Sampling deliberately set out to include people with differing degrees of expressive impairment, including those with no speech at all.

The type of language impairment was seen as important. The experiences of a person who has a fluent aphasia, whose speech may be abundant but empty in terms of meaning conveyed, may differ significantly from someone who says little but is able to convey a lot (who has a non-fluent aphasia). Their feelings of success, of participation in life, others reaction to them and to communication with them, may all differ. Efforts were made to ensure that people with both fluent and non-fluent types of aphasia took part in the focus groups.

The duration of living with aphasia was also felt to be pertinent. It was felt that someone who had been living with aphasia for less than a year, may have a very different viewpoint from someone who had lived with their altered communication status for some time. Efforts were made to recruit a number of people who had been living with aphasia for less than a year, and some who had been living with aphasia for over two years.

The participants were also recruited on the basis of their living status. Living alone and having aphasia, may be very different to living with family and/or a partner. Parr et al (1997) describe the differing experiences of people who have aphasia and how aphasia can affect patterns of partnership, relationships and friendships. Sarno (1993) demonstrates that family support is tremendously influential in terms of reaction to aphasia. Attempts were made to reflect this in the make up of the DQ user focus group.

2.6.1.2.2 Sampling for the DQ user focus group of SLTs

As with the DQ user focus group of people with aphasia, SLTs were recruited on the grounds of the perspective they could bring to the discussion, through their personal and professional characteristics.

Gender is seen as an important sampling characteristic. Male SLTs are not great in number but may well bring a different perspective to the debate. The aim was to recruit at least one male SLT.

Age is also seen as influencing perspectives on working with people who have aphasia. Someone in their 20s may respond differently to someone in their 50's who has been trained in a different generation and has different life experience. The aim was to recruit across a diverse age range.

Closely linked with age, is experience. For sampling for the SLT DQ user focus groups, this dimension was related specifically to experience of working with people who had aphasia, rather than experience working as a SLT generally. SLTs with less than 2 years experience and those with over 5 years, for example, may be expected to bring different dimensions to the discussion. An attempt was made to recruit people in both categories.

The type of work setting was thought to be potentially influential on perceptions of working with people with aphasia. SLTs who work with people who have aphasia work in acute medical settings, in rehabilitation units and within the community. People with aphasia may be experiencing very different emotions, reactions, thoughts, situations, barriers, depending on where they are physically located. If they are on an acute ward as an in-patient, these experiences may differ significantly from the same person, some time later, living with aphasia in the community. Given this, it was felt that the SLTs should be recruited from differing work locations. These differing locations were seen to influence the SLT's experiences of people with aphasia, the circumstances within which they, as SLTs, had to work and the way they may be able to deliver a service to people with aphasia. It was decided to recruit SLTs who represented working within a mix of these locations.

More broadly, the geographical area in which the SLT worked was seen as potentially influential. SLTs living and working in the capital may have access to different resources, a different client-base, and different influences in terms of working experiences. Efforts were made, therefore, to recruit SLTs from outside London.

Table 2.8 summarises the target sampling grid for the DQ user focus group of SLTs. The success in recruitment will be discussed in section 2.5.2.

2.5.1.3 Procedure for the DQ user focus groups

It has been suggested that a valuable means of assessing face and content validity is to conduct qualitative interviews with people who have completed the instrument being developed (Ruta & Garratt, 1996). So, before the DQ user focus groups could take place both sets of volunteers had to gain experience of the administration of the DQ.

2.5.1.3.1 Administering the DQ with people living with aphasia.

Each person who had volunteered was contacted to arrange a mutually convenient time to administer the DQ in preparation for the DQ user focus groups. A meeting then took place (usually in the person's own home, unless the person with aphasia preferred an alternative location). The person who had volunteered had already seen and signed an information and consent form. The consent and information forms had been designed to be aphasia-friendly[3] (see appendix 2.7a, b and 2.8a. and b.)

At this meeting, the purpose of the project was reiterated, and consent confirmed. The DQ (draft 5) was then administered. It was reiterated that the purpose of the person's participation was to help the development of the DQ; that the perceptions of the person with aphasia about the procedure and the instrument were the focus of interest. Discussion took place about the logistics of attending for the DQ user focus group itself some two weeks later.

2.5.1.3.2 Training the SLTs in the administration of the DQ.

All the SLTs attended one afternoon of training together. The purpose of this was; to give the background to the DQ's development; to discuss the relevance of the DQ in terms of the social model of healthcare delivery (the concepts and practice associated with the social model will be discussed later in this thesis); to train the SLTs in the correct administration of the DQ; to give the SLTs a copy of the DQ and recommended administration; and to discuss the logistics of attending the DQ user focus group.

The training included discussing the administration of the DQ (draft 5) line-by-line (with rationale for the method of administration), playing a video of myself administering the DQ to exemplify the suggested administration, and role-play of administering the DQ.

SLTs then had a three month period in which to administer the DQ as many times as they felt appropriate, and then bring their responses back to the group for discussion.

2.5.1.3.3 Conducting the DQ user focus groups

A colleague, independent to the project, facilitated each focus group. This independent facilitator was skilled and experienced in interviewing people who lived

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[3] *Aphasia-friendly means as accessible as possible to someone with language impairment. They are written in large font, using short sentences, simple grammar, commonly occurring words, with language being kept to a minimum. The language is supported with pictures or symbols. They have a pictogram on the top to represent the whole concept of the task involved (a group discussion). This pictogram was used in all correspondence with the participants, to ensure that they knew who the correspondence was from.*

with aphasia. It was important that the person facilitating the discussion was independent from me. Her independence ensured that the feedback given about the DQ could be as honest as possible and not biased by a desire to please the designer of the instrument.

Each DQ user focus group took place at an independent location. All participants who had aphasia had given their informed consent to take part in both administration of the DQ and the interview, as mentioned above. Each interview was audio-taped and took approximately 2 hours. The DQ user focus group for people with aphasia had a tea-break in the middle. The tapes were then transcribed verbatim, and themes relating to content, face validity and clinical utility extrapolated. These themes and resultant changes to the DQ will be discussed below.

2.5.2 **Results of stage 2: Direct user involvement**

The changes that resulted from stage 2, arose from a deliberate attempt to formalise and codify the process of analysis and development, by conducting the focus groups of users (both people with aphasia and SLTs). There will be an examination of the success of the sampling exercise, followed by a description of the changes that resulted from the suggestions made by the DQ user focus groups.

2.5.2.1 Sampling success for the DQ user focus group of people with aphasia

Table 2.9 shows how successfully people with these characteristics were recruited to participate in the focus group.

The target characteristics were achieved, suggesting that the group represented people who were diverse in the views and perspectives that they may hold relating to the experience of living with aphasia, and the relevance of this to the DQ and its administration. The group were evenly matched in terms of age, gender, living status and the duration of their experience of living with aphasia. More people who were from an ethnic minority background would have been beneficial. However, there was only one volunteer participant from a non-white racial background. One of the women present was Jewish which added to the cultural mix but the participants could not be described as ethnically or culturally diverse.

People with moderate comprehension difficulties were included (in equal number to those with mild comprehension difficulties). This included one person who had a total loss of verbal expression. She used the written word, and a personalised communication book to convey her thoughts and opinions. This fact was brought to the attention of the focus group facilitator to enable inclusion of this group member in discussions.

It should be noted that none of the group were known to me, or the facilitator, before we met them to conduct the DQ with them in their homes. Half of the group members were however, known to each other before the focus group met, through attendance at a self-help group. Kitzinger (1995) suggests that using pre-existing groups can be beneficial as the members may feel able to challenge each other on contradictions between what they profess and how they actually behave.

2.5.2.2 Sampling for the DQ user focus group of SLTs

Table 2.10 shows how successfully people with these characteristics were recruited to participate in the focus group.

The target numbers for recruitment to this focus group were achieved with the exception of older therapists. All the volunteers were under 40. SLTs older than this may well have added different viewpoints. The volunteers recruited were evenly matched in relation to years of experience, and type of work. Speech and language therapy is a predominately female preserve. A male SLT did participate in the group. In retrospect greater emphasis on acute settings would have been preferable, as this is where the majority of speech and language therapy is currently offered. However recruiting for the focus group in this area was difficult. One of the criteria for acceptance into this group was that the SLT would be able to administer the DQ with at least 3 people with aphasia in the following 3 months prior to the focus group. Many of the SLTs approached reported that they would not be able to fulfil those criteria as the vast majority of their work revolved around people with swallowing difficulties or that DQ administration was not appropriate in these early stages.

One SLT who volunteered lived and worked in the market town of Canterbury. Though it would have been advantageous to recruit someone working in a rural location as well, the sample did contain non-metropolitan representation.

2.5.2.3 Changes resulting from stage 2

The aim for the DQ user focus groups was to establish users' reactions (both people with aphasia and SLTs) to the DQ, to enable content and face validity to be examined. A number of changes were suggested to the DQ (draft 5) as a result of these focus groups. These were combined with the observations and suggestions that arose from field-testing the DQ draft 5. Table 2.11 summarises the details of all the changes made.

Both DQ user focus groups felt that, in the main, the DQ addressed the domains it should cover. They agreed with the balance of the items within each section, and the comparison of the sections. Both groups were positive about the potential of the tool. However, there were a number of concerns raised which are detailed in table 2.11.

Both focus groups commented on experiencing difficulty navigating between sections as the assessment progressed. This resulted from the anchor words used on the rating scales changing from section to section, effectively requiring the respondents to use a different rating scale for each section. The tool was restructured to try to reduce this difficulty.

As a result of the observation that navigation through the tool could be problematic a new format was established; the SLT focus group suggested that for each modality (talking, understanding, reading and writing), there would be a set of questions about experiences in specified communication situations, followed by a series of questions that examined the effect of (talking etc.) difficulties in everyday life, and the degree of anxiety associated with those changes in daily life. This had the effect of directly linking the communication difficulties with the consequences of these difficulties in both social and (to some degree) emotional terms.

Changes were also made to make wording simpler to follow and attempt to reduce the need for a new scale for each section. These modifications made the instrument easier for the participant to follow, by deleting the second scale.

The order of the sections also changed so that the 'talking' activities came first. Talking was the modality perceived as being most likely to be of concern for a person with aphasia, and therefore requiring attention first. Starting with items relating to understanding had caused confusion for some people with aphasia particularly those with comprehension impairment.

The prescriptiveness of the tool was criticised particularly by the SLT focus group. This was addressed by adding items that asked for other situations not covered by the pre-selected items i.e. 'any other situations or things that make (talking, understanding, reading, writing,) difficult?' It was also dealt with by rewording. For example changing from 'how easy is it for you to understand *someone in authority e.g. a doctor or a benefits officer'* to 'how easy is it for you to *understand under pressure'*. Hence assumptions were not made about which situations would be stressful, nor which situations would be commonplace for a person with aphasia.

A major criticism in terms of face validity on the part of the SLT focus group was the perceived negativity of the DQ. This criticism was particularly influential in changes made to the emotional section. Interestingly, the people with aphasia did not voice concerns about this, the SLTs felt uncomfortable with this section.

Changes were made to alter the wording to make the items neutral or positive. Several items were deleted. Discussion of the following three items will serve to exemplify the kind of reasoning behind changes made. One example was the item 'unfair'. This item was seen as being unhelpful as well as negative. It was felt that it was a state of mind rather than an emotion. Additionally, with all the other emotions discussion may explore avenues that led to change, whereas the SLTs felt little could be done to affect the position if the person with aphasia did feel the situation was unfair. The item 'unfair' was therefore deleted. (The inclusion of items in relation to the purpose of the tool is returned to later in this thesis).

The construct of 'helpless/hopeless' was again seen as misplaced (by the SLTs). The constructs of control (rather than being helpless and therefore being unable to control anything) and looking to the future (rather than being hopeless with nothing in the future) were suggested to replace them.

'Stupid' was discussed at length. Everyone felt it was valuable to have something tapping degree of competence, to enable people with aphasia to voice the recognition that competence may be masked by aphasia but that it is not diminished. The retention of this item was secured as a result of the strength of feeling exhibited by many people with aphasia. They welcomed being able to acknowledge that aphasia led to incorrect assumptions being made and consequent threats being felt to self-esteem.

Both groups suggested or concurred with the idea that pictures would significantly increase the accessibility of the tool.

So some items were deleted, others were reworded to ensure that the same emotional concepts could be addressed but worded positively or neutrally. Many items were reconsidered and the constructs behind the emotions examined and redefined.

So from the original DQ list, the constructs of frustration, sadness, anger, loneliness, stupidity/competence, control and looking to the future were all included in the final version. The precise wording and whether the construct appeared in the negative or positive form, however, had yet to be finalised.

The changes described above increased how acceptable the tool was for people who had aphasia and SLTs. The changes made as a result of stage 2 seemed more significant to those from stage 1. They involved re-conceptualising constructs behind items, and attempting to relate the views and needs of people with aphasia to the way the DQ was being developed. Information from both focus groups led to consideration of issues beyond the ease of administration of the DQ. It led to a fundamental re-examination of the DQ. The information gained forced me to revisit the fundamental purpose of the DQ, including the need for quantification. I was questioning the negativity and the professional bias of the DQ. The process of seeking users views through interviewing had also raised more fundamental theoretical and conceptual issues about the inclusivity, (or otherwise), of the research *process* itself.

Chapter 3

Conceptual and methodological influences on investigating the impact of aphasia

The previous chapter has reviewed the initial stages of development of a tool to explore the impact of aphasia on someone's daily life. The final stage of this development was the implementation of user focus groups. The most significant consequence of these groups was a realisation that quantification had been the motivation for the DQ, that the DQ had been based on professional constructs, and had been developed within a negative conceptualisation of health and disability. These insights had a major impact on both the direction of the development of the tool and on the framing of relationships within the research process.

The process of collaboration within the focus groups suggested it was necessary to explore the theoretical underpinning for the tool and widen the framework of exploration. It was also felt that people with aphasia needed to be closely involved in the future development and refinement of the instrument. People with aphasia had been involved in the project but as research participants rather than as collaborators. The next stage of the process sought to address these issues.

Consulting the literature was seen as the next step. This process would ensure that pertinent conceptual and methodological issues influenced and informed the future development of the DQ. The areas of literature addressed included the following: the WHO classification of health and disability, HRQoL research, and ideas emanating from the field of sociology and disability politics specifically those ideas relating to a new conceptualisation of disability called the social model of disability.

These conceptual areas will be discussed in general terms first, then in relation to their relevance to aphasiology, and finally to their contribution to the development of the DQ specifically.

3.1 The WHO classifications

When the DQ was being field tested, the ICIDH-1 (WHO 1980) was the common currency for health and illness typology. As has been mentioned, the ICIDH-1 as a means of conceptualising health and illness in the context of disability, was criticised.

The ICIDH-1 had emerged from a pathology-based, biomedical model. There was a need seen from a number of sources to site a person within society, and acknowledge the role society had to play in shaping someone's personal experience of illness or disability. As Nettleton (1995) points out in the medical model of health care

> "The body is isolated from the person, the social and material causes of disease are neglected, and the subjective interpretations and meanings of health and illness are deemed irrelevant" (p3)

The most vociferous dissention to the medical model came from the ranks of the disability movement. The disability movement was extremely significant in influencing the future direction of the ICIDH. As a result, the ICF (ICIDH-2) (WHO) was published in 2000. Gray & Hendershot (2000) suggest that

> "The ICF (ICIDH-2) is responsive to the evolution of disability models that now include environmental factors as important contributors to understanding the complexity of sources for disability " (pS14)

The major difference between ICIDH-1 and ICF (ICIDH-2) was the re-conceptualization of disability. The ICF (ICIDH-2) (WHO 2000) emphasised the role of external factors on a person's experience of health, illness and disability. It rejected the term and concept 'handicap', in favour of reclassification into functioning and disability.

> "Disability serves as an umbrella term for impairments, activity limitations and participation restrictions." (p6)

It highlighted the lack of a *necessary* causality between impairment and disability. It lists environmental factors that might interact with these constructs (to amplify or reduce social disadvantage that may occur as a consequence of having impairment) (ICF (ICIDH-2)).

These two internationally recognised frameworks (the ICIDH-1 and ICF), provide a window into the political and social contexts from which the DQ, and its subsequent iterations, emerged. The discussions that had framed the changing of the ICIDH-1 to the ICF (ICIDH-2) influenced how the DQ was to develop by affecting both my thinking and my research practice. For example, the role of external barriers and facilitators to participation for an individual was noted. The power relationship within which the research was taking place was also subject to scrutiny. The details of the development process, mirroring these contexts, will be discussed in chapter 4.

3.2 The social model of disability

The ICIDH-1 was written within a 'medical model' framework. The 'medical model of disability' proposed that the disadvantages associated with impairment were located within the person; that to improve the life of the person the impairment must be reduced or eliminated.

The main source of criticism of the ICIDH-1 came from within the disability movement– often from authors and activists who were themselves disabled. Authors from this group were critical of the medical model's central assumption; that the source of the disadvantages associated with being disabled was sited within the impaired individual. They supported an alternative conceptualisation of disability, the social model of disability.

3.2.1 Tenets of the social model of disability.

3.2.1.1 Rejection of the focus on the individual

Philips (1990) interviewed disabled people and summarises their oral narratives

> "They note the underlying message, embedded in both the medical and rehabilitation models, of the essential wrongness of their bodies." (p855)

People such as Swain et al (1993), and Zarb (1992) suggested that on the contrary, the disadvantages experienced by disabled people were due to factors within *society*. These authors supported what has come to be termed 'the social model of disability'. They contended that society constructed barriers (physical, attitudinal, cultural, linguistic), which resulted in disabled people being further disadvantaged beyond the disadvantage that may or may not accompany the impairment itself. This oppressed people with a disability.

Such authors suggested that any description or classification that did not acknowledge the role of society as being the source of disadvantage was deficient. Swain et al (1993) propose that

> "The experiences of disabled people are of social restrictions in the world around them, not of being a person with a 'disabling condition'. This in not to deny that individuals experience 'disability'; rather it is to assert that the individual's experience of disability is created in interactions with a physical and social world designed for non-disabled living" (p2).

The shift in the conceptualisation of disability is not without significant potential for alterations in how health and social care are delivered. If, for example, limitation on participation within the workplace is seen as a direct result of impairment then the need to change the environment might be unrecognised. It is for the individual with the impairment to militate for change, they have the 'problem' they must attempt to effect a 'solution'. If the 'problem' is located outside the individual and with society, then it is the obligation of society to effect a 'solution'. Social barriers (architectural, attitudinal, physical, linguistic, technological, political) demand social responses, not individual ones.

3.2.1.2 Challenging assumptions relating to identity

3.2.1.2.1 The assumption of normality

Those who espoused the social model of disability rejected the view that disabled people are in some way 'deviant' and that this 'deviance' should be 'cured'. This view is highlighted by Phillips (1990).

> "the basic flaw with the medical model is its assumption of normality. Both disease and disability are assumed to be deviations from the norm...since the majority of those with a permanent disability can never be cured, restored, or normalised, they (people with a disability) perceive themselves between the sick role and normality, between wrong bodies and right bodies" (p851)

An example of the conflicting ideologies was highlighted by the concept, and use, of the word 'handicap'. Handicap is defined by Badley (1995) as

> "a disadvantage for a given individual, resulting from impairment or disability, that limits or prevents the fulfilment of a role that is normal depending on age, sex, and social and cultural factors" (p53).

This definition highlights the medical model view of disability. There is no consideration of the role society has in shaping the world, to empower people with a disability to fulfil the roles they aspire to. Those advocating the social model of disability, see this as erroneous and oppressive. The term itself, 'handicap', was seen by many people within the disability movement as being derogatory, and reminiscent of the association of disability with charity (hand-in-cap). Those advocating the social model therefore rejected the idea and use of the word handicap. Hughes & Paterson (1997) point out that

> "The eclipse of 'handicap' is an important moment in the recognition of the power of discourse. The use of the concept 'non-disabled' to reverse the

> stigma of 'otherness' and throw it back at the oppressor is a second example of the development of a lexicon that helps to sustain the process of emancipation" (p333)

Beyond challenging linguistic usage, the ideology itself was challenged. The medical model has little to offer those who have to live with long term disability that, in the vast majority of cases, will not benefit from medical treatment. Alongside this came the assumption that though "nothing can be done to help", somehow people with a disability would still wish to be different from how they are. Swain & French (2000) suggest that the central assumption of the tragedy model is that disabled people want to be other than as they are, even though this would mean a rejection of identity and self.

There were those who went further to challenge there being 'a problem' to locate at all. They suggest an 'emancipatory framework' or 'affirmative model of disability'. Swain & French (2000), for example, point out that

> "Whereas the social model is generated by disabled people's experiences within a disabling society, the affirmative model is borne of disabled people's experience as valid individuals, as determining their own lifestyles, culture and identity. The social model sites 'the problem' within society: the affirmative model directly challenges the notion that 'the problem' lies within the individual or the impairment." (p578)

3.2.1.2.2 The centrality of disability to identity

Schlaff (1993) pointed out that there was also an assumption that having a disability is central to the disabled person's self-concept, self-definition, social comparisons and reference groups. She suggests, for example, that a woman who is paralysed may be as likely to compare herself with other women of her age, others of her occupation, others of her family, class, race, or a host of other people and groups who function as reference groups and social comparison groups for her. Hughes and Paterson (1997) similarly suggest that

> "identity is complex and problematic, and it is – in an individualistic and rapidly changing society – a precarious source of solidarity. Open recognition of this precariousness is useful. It mitigates against rather than encourages factionalism" (p338).

3.2.1.3 Rejection of the traditional role of rehabilitation

A further rejection was that of the role traditionally played by professionals involved in rehabilitation. Healthcare providers, be they doctors, nurses or therapists, were being criticised by those in the disability movement for the role they played in oppressing disabled people. Jordan & Kaiser (1996) summarise the positions of other authors

> "Professionals are in a position to wield a considerable amount of power over disabled people, for example by defining their needs, determining their access to resources, 'managing' interactions with them and controlling many aspects of their lives (French 1994, Oliver 1990) " (p137)

Healthcare providers had traditionally been educated within the medical model framework, and have sited the 'problem' of disability with the individual. They assess a person's needs and set out to 'cure' the person by reducing or minimising the impairment and thereby the assumed associated disability (Woolley, 1993). The assumption was that professionals assessed and treated in an 'objective' way. The healthcare provider saw him/herself as the expert, leaving the disabled person with little part to play. Finkelstein (1991), for example, suggests that

> "The administrative 'cure and care' approach to disability set service providers apart from those who wished to serve under the illusion that they were being 'objective'. We now see this 'professionalism' as having legitimised the imposition of able-bodied assumptions that to have a disability is to experience social death. In this respect the promoters and defenders of existing services can themselves often be experienced as disabling barriers inhibiting the control of disabled people over their own lives" (p35)

The criticisms mentioned above led to the role of the person with the disability as the expert being highlighted. Finkelstein (1993) was one of the first protagonists for these arguments. He suggests that all service-providers should be re-educated to ensure that there are more fitting criteria for determining appropriate intervention models, so that their analytical and organisational skills are better focused on barrier identification and removal, with less emphasis on functional assessment. Health care professionals should be seen as *a resource* for people with disability to draw upon in a way that they see fit (Finkelstein, 1993).

Healthcare providers were therefore seen to disempower disabled people. They were seen to hold assumptions of normality, and provide health care within a medical model, negating the expertise of the person with the disability. There was a call for healthcare providers to make their skills and resources available the person with a disability, for them to use as they see fit. Issues relating to this are further discussed in the last chapter of this thesis.

3.2.1.4 The role of positive social action

Whilst rejecting the assumptions of the medical and rehabilitation model, the social model authors suggested ways that positive action could improve the situation. They suggested that social, not medical, manipulations (be they physical or attitudinal) could empower people with a disability to experience the world on an equal plane to those without a disability. If curbs and entranceways were lowered, and lifts installed, being in a wheelchair is less of a disability than if there is no awareness or action taken to acknowledge the physical barriers that exist for a wheel-chair user. If equal rights legislation is in place to ensure that employers are made aware of their potentially discriminatory recruitment practices, then employment opportunities for people with disabilities come closer to being on an equal footing to those without a disability. Advertising campaigns that depict a world where the vast majority of people are wheel-chair users, and the 'otherness' of the person not using a wheel chair is highlighted, can challenge social attitudes towards people with a disability. None of these actions manipulate the individual with a disability. They all rely on social action. All have the potential however, to reduce the disadvantages and oppression people with a disability experience, without addressing the impairment at all.

With the rejections exemplified above came a politicisation. If the impetus for change/improvement should come from within society rather than within the individual, then quickly the focus moves the debate to civil rights. If it is society's responsibility to ensure equal access and participation for all, then civil rights are being challenged if this is not the case. Those people who belong to a minority group, might potentially be ignored by the majority, and the rise of collective identity demanding equal rights for all, is a natural consequence of this changed perception. Discussions about social oppression and the politics of power naturally follow. Philips (1990) interviewed a number of people with disabilities. In the quotation below she reports the words of one of her informants.

> "We aren't medical models. There is nothing *wrong* with us and our bodies. We are a minority to be dealt with" (p851) (emphasis original)

Here Philips highlights that human rights and political action should be seen as critical to understanding disability. In a similar way to race, gender, and sexual orientation, so oppression by the majority was seen as the problem for the minority group of people with disabilities. As a minority group the disabled movement demanded the same rights as the majority and issues of power became highlighted.

So the social model of disability challenged the medical model. It rejected the idea that disability was deviance. It rejected the idea that being disabled was the *only* identity someone who was disabled could have. There was a rejection of the assumption that to improve the lives of disabled people there was a need to reduce or eliminate the impairment. There was a demonstration of the fact that society had a significant role to play in reducing or eliminating disabling conditions and attitudes. The role healthcare providers had in relation to people with disability was challenged. There was a rejection of the assumption of professional objectivity. The influence of these ideas in the development of the instrument will follow later in this chapter.

3.2.2 Impairment within the social model of disability

As the models within which disability was framed developed, so discussion came to centre on the role of impairment within disability theory. Within the medical model the role of impairment was central - the cause of all disability for that individual. With the social model, impairment became somewhat marginalized. Hughes & Paterson (1997) point out that

> "there is powerful convergence between biomedicine and the social model of disability with respect to the body. Both treat it as a pre-social, inert, physical object, as discrete, palpable and separate from the self...a body devoid of history, affect, meaning and agency" (p329)

Within the social model, impairments were seen as givens, around which society had to change. They were not to be discussed, acknowledged, they were almost to be denied. Any focus on the impairments themselves was seen as, at best as a distraction, and at worst as providing ammunition for those with the power to oppress and prevent progress (French, 1993a).

Within the more current emancipatory framework, however, impairment returns to being acknowledged. There is recognition that disabled people do have impairments and that in some instances they *cannot* be reduced or eliminated by social, physical or attitudinal alternations (French, 1993a). Drawing on personal experience of visual impairment, French describes an incident with her neighbours. There was uncomfortable interaction. It was affected by her neighbour's reactions to the consequences of her visual impairment, her response, and the misunderstanding that ensued. She describes how

> "The difficulty I have just described is not entirely due to my impairment, for it involves other people's responses, but neither is it easily modified by social or environmental manipulation; it occupies a middle ground" (p18)

She goes on to highlight a further difficulty. She points out that if disability is defined solely in terms of 'socially imposed restriction' then there is a risk that many people who define themselves as disabled, through symptoms such as pain and vertigo are not regarded as such by other disabled people, a situation which many regard as oppressive.

Paterson & Hughes (1999) also reflect on the need to incorporate the lived experience of impairment into the conceptualisation of disability theory. They use another circumstance where social manipulation cannot effect change. They describe how social norms for communication (such as the timing allowed for different modes of interchange) impose barriers that, as with social reactions to the consequences of visual impairment, cannot be reduced by environmental manipulation.

Emancipatory theory suggested that impairment should be acknowledged and that to do otherwise is to deny an experienced reality that might, in itself, be further oppression. Paterson & Hughes (1999) suggest that 'social competence' is defined using judgements made by non-disabled people, who draw on non-disabled norms and conventions. They suggest that 'otherness' results from the violation of these conventions and is therefore a product of social processes, difficult or impossible to manipulate, that produce a hierarchy of identities.

There is the suggestion that the experience associated with impairment should be realistically acknowledged. One could recognise the limitations imposed on an individual by certain difficulties, believe that social and political action are still the way forward for the disability movement, but acknowledge that experiences of certain impairments are difficult and negative. Morris (1991) for example protests that society disables people by its prejudice and its failure to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude with oppression.

> "Unfortunately in our attempts to challenge the medical and the 'personal tragedy' models of disability, we have sometimes tended to deny the personal experience of disability. Disability *is* associated with illness, and with old age (over two-thirds of disabled people are over 60) and with conditions which are inevitably painful...unlike other forms of oppression, being disabled is often an additional drain on the resources of the individual, i.e. it is not inherently distressing to be black, whilst it may be to suffer from painful arthritis" (p164) (emphasis original)

She goes on to say that the individual experience of disability is socially constructed, but that there is a need to make the personal experience of disability political, including the negative parts to the experience.

Extensions of this theory of disability go further to suggest that the experience of impairment should not be merely acknowledged but celebrated. Hughes & Paterson (1997) for example suggest that impairment must be reconstructed in terms of pride and positivity, rather than as the site for existential fears of the non-disabled community. Swain and French (2000) propose what they term 'an affirmative model of disability', which is a non-tragic view of disability and impairment, which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle and life experience of being impaired and disabled.

As a consequence of these suggestions there is a call for impairment to be revisited, and for impairment to be seen as a valid personal experience (both positive and negative) within an empowering model of disability. Hughes & Paterson (1997) suggest that the social model must be expanded to incorporate an *embodied* notion of disability to acknowledge the irresistible fact that impairment enters into the experience and the politics of disability and is central to the lives of disabled people. Highlighting both the positive and negative aspects of disability within the social emphasises the emergence of identity differentiation amongst disabled people (Hughes & Paterson, 1997). Impairment can therefore be seen as valid personal experience within the social model of disability, as an experience that emphasises aspects of one's own rich and complex identity.

3.2.3 The social model and research.

Much of the debate within disability theory related to the role of research and research workers particularly the existing power relationships. These issues relate to who holds the power within the research relationship, who benefits from the research, and the legitimacy of non-disabled or healthcare provider researchers undertaking research into disability. These issues were highlighted by the processes undertaken at the end of stage 2. I was challenging my role as an able-bodied, health care worker undertaking research into the field of disability. Reflections on these aspects will be considered in depth in the final chapter.

3.3 Sociology of health & illness

A third pertinent field of study that influenced the development of the tool was that of sociology. Sociology was contributing to the debate on long-term illness and disability. Disability is not an illness. However, research and debate in the field of chronic illness (including acquired conditions) offered insights into how individual's conceptualised new identities and the role society had to play in shaping the influences around them. There was an acknowledgement that the major influences on living with long-term illness or disability are likely to be social rather than medical (Conrad, 1990). Sociologists were considering the role society had to play on interactions between people with and without disabilities (Phillips, 1990), and on the experience of becoming disabled and living with disability (Bury, 1991).

Much sociological work focused on the meaning of chronic illness. Meanings were individually experienced but socially defined. Work focused on the inadequacy of the medical model with the chronically ill/disabled person cast by society in the 'sick' role, again conceptualising illness as deviance and healthcare providers as social control agents (Conrad, 1990).

Conrad (1990) suggested that the way individuals (be they disabled or non-disabled) conceptualise health and illness is socially defined. With resonance of the ideas emanating from the disability movement, he separates the physical from the social. He draws a distinction between disease (an undesirable physiological process or state) and illness, which is a profoundly social phenomenon that may or may not rest on disease as its foundation. It has more to do with perception, behaviour and experience than with physiological process. Kleinman (1988) concurs and suggests that the illness experience it is always distinctive.

Kleinman also emphasised the role society has to play in enabling or undermining the person who has a disability. He suggested that impaired social support and oppressive relationships amplify the disabling effects of impairment, whilst strong social support and positive relationships dampen the effects. He suggested that 'acting like a sponge, illness soaks up personal and social significance from the world of the sick person'.

Sociologists also considered the concept of 'otherness' when looking at stigmatisation. Kleinman for example cites Goffman, who as long ago as 1963, suggested that the stigmatised and the non-stigmatised are not persons but perspectives. Kleinman went on to say the stigma begins with a social reaction, but rapidly becomes internalised (as the person experiences the negative reactions of others) and these reactions become expected, hence shaping a negative self-image. The need for social action to eliminate these prejudices and support positive identity is demonstrated, and again echoes calls for positive social action described earlier.

Phillips (1990) suggested how these two facets of the social and personal, interact when considering the lives of people who live with a disability. She suggested the role of society is crucial in framing and perpetuating negative images of people with disabilities. She proposed this is done partly through media representations of disabled people as either 'damaged goods' or 'heroic', both of which deny the person with a disability a role within society as they are - ordinary people. Again, the resonance with the writings emanating from within the disability movement was apparent. Phillips (1990) suggested that telethons, for example, present disabled people as extraordinary, and in need of help or a miracle cure to 'normalise damaged people'. People give generously. She contrasted this with the social reality of being reticent to accommodate disabled people in public settings, denying that disabled people should be facilitated to lead 'ordinary' lives.

One way in which negative representations are perpetuated is through the use of language. Phillips (1990) suggested that

> "Linguistic conventions that subsume persons to their physiological parts have two effects, the devaluing of the social self and the damaging of the private self...negative words and images not only reflect but also reinforce condescending attitudes towards disabled persons. Such words and images effectively penetrate the cultural consciousness, predicting social interactions" (p851)

Those within the disability movement who were so vocal in their rejection of the word (and concept of) 'handicap' would agree. The use of language will be discussed further in final chapter.

Phillips gave other examples of how the two facets of the social and personal, interact when considering the lives of people who live with a disability. She interviewed people with a disability who report how attitudinal and structural barriers denied them the opportunity to demonstrate their competence. One informant contrasted her experiences and self-image during rehabilitation as a child, with university life at an institution 'where disabled persons had independent mobility, a voice and a new philosophy about disability'

> "she is convinced that her negative childhood rehabilitation experiences exacerbated her physiological deterioration...most architectural and attitudinal barriers removed (at her university), there she could demonstrate her ability to control her life, to determine her own potential and her limitations" (p855) (text in parenthesis added)

Phillips pointed out that all her informants share the above interviewee's experience of medicine and rehabilitation that they noted the underlying message, embedded in both the medical and the rehabilitation models, of the essential 'wrongness' of their bodies. She concludes that

> "(the oral narratives of disabled people she had interviewed) affirm the transformational and liberating effects on self image of those philosophies which demonstrate not their deviance, but their social minority status, and which strongly disavow the status-quo notion of disabled-as-damaged-goods" (p855) (text in parenthesis added)

When reviewing the sociology of chronic illness, Bury (1991) confirmed the reality of positive, proactive aspects of chronic illness. However, in contrast to Phillips who cites structural and attitudinal change as contributing, Bury stressed the personal coping styles and strategies employed by people who live with chronic illness or disability.

Bury (1991) pointed to the emergent nature of chronic illness that would have parallels with someone who has acquired a disability, rather than being born with one. He stressed that there is a pathway along which a person travels, and that the beginning of the journey is one of 'biographical disruption', as the identity one has lived with up until that point is dramatically altered. He suggested the meaning of this disruption, in terms of consequences and significance, are markedly different for each person. Equally, how each illness or disability is viewed by society varies. Bury

(1991) noted the relevance of such things as the visibility of symptoms, the burden of treatment, personal coping styles and strategies in the integration of a new positive identity. He discussed 'coping' (*cognitive processes* someone learns to tolerate the effects of illness, to maintain a feeling of self worth, cohesion and confidence), 'strategy' (*actions* taken to mobilise resources and maximise favourable outcomes, 'support' (the ability to *confide in others*, with language and communication being major ingredients in adaptation) and finally 'style' (*the way* people respond to, and present, features of their illnesses, including different forms of communication about symptoms and their effects). Bury suggested that with acquired illness comes a lack of confidence in the body which leads to loss of confidence in social interaction.

The concentration on the individual contrasted with the emphasis on the social seen in other fields previously discussed. However, the suggestion regarding the potential for positive action is welcomed. The discussion also highlighted the role played by communication in enabling a person to accommodate disruptions to her/his life, brought about by illness and change.

Some sociological writing within the field of chronic illness is not helpful in terms of emancipation of people living with chronic illness. The emphasis was very much about how the individual experiences illness and disability. There was very little discussion around the politics of power, nor a challenging of the existing social and political structures that perpetuate the disabling culture. However, there was an acknowledgement of the role society has to play in conceptualising and understanding illness.

3.4 Quality of life

The final field of study pertinent to the development of the DQ was that of HRQoL. The DQ set out to measure the effects of changes in health status on daily life, and as such it potentially shared a number of features with HRQoL (the commonality and discrepancies between HRQoL instruments and the DQ will be explored later in this chapter). HRQoL has been one of the major influences within health status measurement over the last 30 years. As has been discussed the 'industry' now serving this interest is enormous, despite there being a lack of concensus regarding the definitions and typology of HRQoL (Williams, 2000). Bowling (1997a) points out that

> "it is becoming fashionable to equate all non-clinical data with quality of life which is likely to be a source of conceptual confusion." (p6)

This exemplifies the difficulty with the term 'quality of life'. It is a broad term that has been borrowed from everyday parlance. This muddies the water when attempting to conceptualise HRQoL. In spite of this (or as Katschning (1997) suggests, maybe because of this inherent vagueness) quality of life as a concept is intrinsically appealing for many different parties involved in managing health and disease. Despite the taxonomic and conceptual vagaries, at a fundamental level, everyone understands HRQoL.

3.4.1 Quality of life and disability

The potential relevance of HRQoL measurement for people with disability comes from the various departures HRQoL measurement make from traditional health care measurement.

3.4.1.1 Quality of life is multi-faceted

Firstly, HRQoL measurement is multi-faceted. It encompasses *all* aspects of life (physical and mental health, social and role functioning and general well-being). This contrasts markedly with the narrow focus of most clinical measures previously employed to measure health and illness. This is relevant when considering conceptualising health in the context of living with a disability. Health status should not be separated from life when living with a health state that is not likely to change (be it acquired or congenital). Health status does affect how we are able to function, experience and perceive life, but it is also only one part of the life we lead. Living with a disability, is only one aspect of living. Having a disability will have differential effects on how someone lives and experiences her/his live. Equally as has been discussed, having a disability is one aspect of identity (Schlaff, 1993).

Living with a disability is about living, with all its facets be they social, economic, or physical. There is increasing evidence that people with disabilities are disadvantaged in every aspect of life that has been measured be it employment statistics, income levels, suitable housing and access to public transport, buildings, information and leisure facilities (Swain et al, 1993). HRQoL measurement has the potential to acknowledge this fact. HRQoL measurement has the possiblility to measure broad parameters, which are outside the medical model, to gauge these disadvantages. It has the potential, by setting up dialogue at this level, to disentangle the interrelationship between these parameters, and use this information to assist in positive action.

3.4.1.2 Quality of life is user focused

Secondly, the perspective measured in HRQoL is that of the user, not the professional. Again, the majority of health measures used in the past measure from the perspective of the clinician. When considering living with a disability, the 'expert' is the person living with the disability not the clinician, thus his/her opinion is the one being sought.

The individual nature of HRQoL measurement acknowledges the exclusive and distinct nature of this lived experience. The causal link between objective measurement of impairment and function, and perceived health is broken, by tapping the subjective experience of health status. This is potentially beneficial on several levels. It acknowledges the primacy of the views of the user, demonstrating that no-one else can assume the effects of disability on how a life is experienced. Addington-Hall & Kalra (2001) demonstrate that

> "There is no direct correspondence between objective functioning and an individual's quality of life nor between the perceptions of patients and healthy people, professionals, or others with similar disabilities. Patients may rate their quality of life highly despite obvious problems or may show significant improvements in scores that do not correlate with objective measures of disease or physical function" (p1421)

The subjective perspective in HRQoL measurement can also benefit the healthcare providers, because, as Gladis et al (1999) point out,

> "a number of studies have shown that it is patient's *subjective* well-being, rather than objective medical condition, that determines their treatment-seeking behaviour, their compliance, and their evaluation of treatment" (p320).

3.4.1.3 Quality of Life is subjective

As previously elucidated, subjective merely means that the information is opinion not fact. The acknowledgement that HRQoL information is a subjective perspective rather than an absolute reality is helpful. Perspectives are seen as preferable to facts. Opinions are seen as valid realities. The advantage of this, particularly for people with disability, is highlighted by Addington-Hall & Kalra (2001) who point out that

> "Clinicians may find it difficult to accept patient's ratings of quality of life. This can be an important issue when working with patients with severe disability...because clinicians may hold expectations about quality of life that are not supported by patients' assessments" (p1421)

The potential for dialogue (between the person with a disability and health care providers), education and attitudinal change (on the part of health care providers) is unlocked.

3.4.1.4 Quality of life is a positive perspective

HRQoL is a positive perspective on health. WHO (1996) state that health should be seen as

> "a state of complete physical, mental and social well being and not merely the absence of disease" (p2)

The positive perspective of health also has significant resonance for those who have disability. The medicalization of the lives of people with a disability is rejected by some (as will be discussed later in this chapter), but the positive focus on health and role fulfilment rather than disease and functional limitations, is welcome. As Mc Gee (1996) suggests discussion of an individual's status and aspirations

> "permits a more egalitarian relationship between and the person seeking or availing of health care. Both participants need to acknowledge that making healthcare decisions is not straightforward. A more cooperative, rather than authoritarian, approach to health consultations maybe the outcome of such HRQoL assessment in an increasingly consumer-orientated, and consequently litigious, society, addressing HRQoL concerns of individuals in an overt, systematic fashion may be the most appropriate strategy for consultations between the individual and health professional" (p167)

3.4.2 Limitations of HRQoL research

As exemplified above, HRQoL assessment is seen in some ways to depart from the medical model of health and disability, and offers potential benefits when investigating healthcare measurement. It is however, not without its critics. The criticisms levelled at it are practical, conceptual and ethical.

3.4.2.1 The remit of HRQoL measures

As has been mentioned, the definitions used and conceptualizations behind the definitions of HRQoL, are various. There is confusion about what is actually being measured. Williams (2000) suggests that there is closer agreement in disease-specific measures than generic measures. Carr & Higginson (2001) point out why it might be problematic.

> "many earlier questionnaires were based on health professionals' definitions of what was relevant...few researchers directly asked patients about which factors they thought constituted quality of life…there is some overlap in the generic factors included, there are factors that are important to patients that are not captured by these measures. Additionally some factors may be redundant or irrelevant to patients" (p1360)

There are however those who question whether *one* formulation of HRQoL is possible. Higginson & Carr (2001) describe how

> "Mount & Scott likened the assessment made (of HRQoL) to assessing the beauty of a rose: no matter how many measures are made (for example of colour, smell, and height), the full beauty of the rose is never captured. Quality of life measures will never capture all aspects of life that are important to an individual, although systems in which patients specify at least some of the qualities are likely to come closest" (p1298) (initial text in parenthesis added)

Gladis et al (1999) concur

> "Others worry that quality of life cannot be reduced to a single score or set of scores in that the unique and changeable set of everyday experiences that gives rise to feelings of well-being or discontent (like the companionship of a pet, a bad commute, or noisy neighbours) cannot be captured on a scale, no matter how comprehensive." (p328)

Even if all the definitive domains were selected, there is still the difficulty of weighting each domain. Individuals regard different areas of life as differentially important (Carr & Higginson, 2001). Any a priori weighting, intrinsic to the assessment not the individual being assessed, would override this important fact.

3.4.2.2 Expectations of HRQoL vary between individuals

Part of the difficulty with attempting to encapsulate HRQoL is this fact that expectations and values may vary between people. Carr et al (2001) point out that

> "people have different expectations…expectations are learnt from experiences and therefore highly specific. They vary between individuals and are subject to differences in social, psychological, socio-economic demographic and other

> cultural factors…existing measures of quality of life do not account for expectations of health; they do not incorporate the boundaries within which levels of expectation and experience are measured" (p1241)

McGee (1996) goes so far as to suggest that HRQoL measures that are based on consensus decisions, rather than on an individual's idiosyncratic HRQoL framework, are oppressive, as they fail to validate the individual nature of a person's perspective.

Williams et al (1999) demonstrated measurement insensitivity when using the SF-36 with people who had had a stroke. They postulate that the failure to discriminate patient-reported differences in overall HRQOL was due to the domains or items lacking specificity for this client-group.

Hatton (1998) working with people who have learning disabilities suggests another reason behind invalid or insensitive measurement within HRQoL instruments. He cites Edgerton (1996) who proposes that subjective well-being is largely influenced by personality or disposition rather than objective life circumstances. He suggests it, like personality, stays remarkably stable over the life span. Research has shown that income, years of education, health, changes in marital status, or changes in employment status appear to have little enduring impact on the subjective well being of individuals. Hatton (1998) proposes that life events may have short-term impact on the subjective well-being of a person (lasting less than 6 months), after which time the person adapts to the situation and reverts to their dispositional level of subjective well-being.

There is therefore uncertainty about the validity or sensitivity of HRQoL measures. Certain researchers have pointed out that entire social *groups* may have much lower expectations of HRQoL than others. Disabled people as group are recognised as one such group. As has previously been reported, Felce (1997) suggest this is due to the connection between experience and expectation. He suggests people whose circumstances, status and options make them particularly prone to having low expectations (due to reduced autonomy) will report satisfaction rather than dissatisfaction even under adverse life conditions.

Carr & Higginson (2001) agree, citing examples of people with moderate or severe disabilities reporting excellent or good quality of life despite experiencing significant barriers to performing daily tasks, being socially isolated, and having limited incomes and benefits. They report people with cancer rating their quality of life in the top quarter of the WHO's quality of life questionnaire across all life domains: this is better than all other groups of patients including those attending a family planning clinic. Carr et al (2001) conclude

> "A primary aim of treatment, particularly in chronic disease, is to enhance the quality of life by reducing the impact of the disease. Yet patients with severe disease do not necessarily report having a poor quality of life. Therefore the relation between symptoms and quality of life is neither simple nor direct. Considering quality of life as the discrepancy between our expectations and our experience provides a way of explaining how we evaluate it" (p1241)

3.4.2.3 Expectations of HRQoL can vary over time for the same individual.

So perception of HRQoL may be influenced by experience and expectations. If one has had negative experiences of health then perceived HRQoL may have been adjusted accordingly. Different groups of people with similar functional abilities in similar circumstances may have very different perceptions of HRQoL Associated with this, is the fact that the *same person,* whose circumstances change, may adjust their perceptions of HRQoL accordingly. This is known as the 'response shift' or 'intra-subject construct dynamism' (Allison et al, 1997) and (MacDuff & Russell, 1998). Contrary to expectations, as symptoms get worse, HRQoL does not always follow the same trend. Williams (2000) suggests that

> "Our points of view change subtly as we move through life experiences; self-assessment of functioning, activities, and feelings may well shift…as individuals encounter specific events, problems, or interventions, our perspective or frame of reference may well shift. Individuals redefine their points of view, expectations for performance and health status accordingly." (p16)

Ruta recognised response shift in people using the Patient Generated Index, (1998). He similarly pointed to individuals 'stabilising' their perceived HRQoL by adapting their expectations to suit their particular social or economic circumstances. The response shift has been documented in people who have cancer, diabetes, renal disease and dermatological conditions (Carr & Higginson, 2001).

Muldoon et al (1998) suggest why this might be. They describe how people with cancer reported an increased ability to appreciate every day, greater feelings of personal strength, self-assurance, and compassion. These benefits can outweigh having the disadvantages to such an extent that HRQoL scores can be higher in people with cancer than their healthy comparison groups.

Carr et al (2001) summarise

> "this illustrates three problems with measuring health related quality of life; people have different expectations; people may be at different points on their illness trajectory when their quality of life is measured; and the reference value of their expectation may change over time…existing measures of quality of life do not account for expectation" (p1245)

Given the limitations described above, there is disquiet relating to imposing a conceptual HRQoL framework onto an individual, without reference to that individual's life circumstances and biography. Carr & Higginson (2001) extend the argument making reference to reliability

> "standardised measures (in which the questions and range of answers are predetermined and the same for all patients) may measure something distinct from quality of life of individual patients…if such measures do not capture the quality of life of individual patients they are unlikely to be responsive to change after treatment because they may not be measuring what is important to the patient and their scores may be difficult to interpret" (p1359)

3.4.2.4 Responsiveness of HRQoL measures

These conceptual issues bring with them specific practical consequences. The difficulties of perceptions changing within the same person, obviously raises difficulties with responsiveness. Williams (2000) described the issue of responsiveness as the Achilles heel of measurement for general HRQoL measures. There is clearly a dilemma between the robustness of measurement and the call for measures that encapsulate HRQoL for the individual. HRQoL measures are useful if they represent an accurate summary of an individual or group of individual's perception on health status at one time. This can then be used to make decisions relating to treatment choices and service provision more generally. The value of subjective measurement has already been discussed. However, if *perceptions* of health status change for reasons other than change in health status, then the situation becomes complicated and decision-making based on these measures then becomes questionable.

3.4.2.5 Those who are at risk of exclusion

A further practical consideration with regard to HRQoL that stems from user-focused subjective measurement is that relating to people who have difficulty formulating or expressing their opinions, for whatever reason. For the same reasons that certain groups of people are disenfranchised from other forms of health care measurement, so those same groups of people can experience exclusion from HRQoL measurement. HRQoL measures bring with them the same restrictions as other measures that have been discussed in chapter 1.

3.4.2.6 The clinical utility of HRQoL measures

The vast majority of HRQoL measurement has been administered under the auspices of clinical research. However, there are authors who recommend the use of HRQoL measures as part of routine *clinical* practice. Both the MYMOP (Paterson, 1996), and the COOP charts (Nelson et al, 1987), described by others as HRQOL measures, are designed for use in clinical medical practice. Higginson & Carr (2001) point out the *potential* for HRQoL measures. They suggest that to ensure that HRQoL influence clinical decision making, they should be used as the *basis* for making choices about treatment by identify individual problems and priorities for treatment and then for negotiating treatment goals based on them.

Though this idea is initially appealing, clinical use of HRQoL measures is not extensive. Katschnig (1997) gives an example of the difficulty of using HRQoL measures in psychiatry. He suggests that widespread use in everyday clinical practice is uncommon, because the measures do not yet produce results that are specific enough to indicate requirements for specific health care intervention.

The user-generated measures discussed earlier, (the SEIQoL-DW, Hickey et al 1996) and the PGI (Ruta et al, 1994)) are seen by many as a viable option to overcome a number of these conceptual and practical issues mentioned above. They do encourage dialogue between the clinician and the user. They provide the basis for sharing clinical decision making between users and clinicians, identifying users' priorities for treatment, and facilitating the setting of realistic goals (Higginson & Carr, 2001). They do not, however, overcome the issues of response shift (though the discussion that ensues may identify reasons behind it). They do not help with the difficulties of responsiveness nor of accessing people who are at risk of exclusion. Higginson & Carr (2001) summarise by suggesting that

> "There are a number of questions about the clinical utility of quality of life measures that remain unanswered. Are existing measures appropriate and adequate for clinical practice?...how do existing measures take account of changes in expectations, adaptation, and normalisation when assessing

changes?…what constitutes an important change in quality of life? " (p1315) Hunt (1997) goes so far as to suggest that there is growing support for the view that the existential and dynamic experiences which would seem to fall under the rubric of HRQoL are unsuited to measurement for clinical situation.

3.4.2.7 Over-medicalisation and power relationships within HRQoL

There are further questions being asked of HRQoL measurement. One of the most relevant for those who have a long-term disability relates to the ethics of the whole HRQoL movement. The validity of the extending of assessment into every aspect of someone's life has been questioned. Those who suggest it may have a role propose that the broader perspective taken by HRQoL measures, focusing on issues such as relationships and social support, suits the investigation of chronic disease, as information on these aspects can influence treatment decisions and assessments of health care need (Higginson & Carr, 2001). These same authors also point out that this aspect potentially seen as advantageous can also be perceived as tyrannical, by extending 'clinical interference' in aspects of people's lives that should not be of concern to the clinician.

This issue has been raised particularly from within groups of people who are not 'ill' such as those with learning difficulties (Hatton, 1998) or who live with disability. Gladis et al (1999) when discussing the role of HRQoL measurement with those who have psychological and psychiatric conditions state that

> "some wonder whether we should be in the business of assessing aspects of life that bear no obvious connection to a disorder to its treatment, especially when managed care is demanding briefer and more focused interventions, with treatment rationed according to "medical necessity"" (p328)

In addition, HRQoL measurement has been criticised for producing what may be a more *direct* negative effect. Higginson & Carr (2001) suggest that by measuring areas, the clinician raises the expectation that this area can be influenced in some way. They suggest that to measure when there is no ability or intention to effect change could be damaging to that person. McGee (1996) suggests why it could be harmful. She proposes that HRQoL assessment involves in-depth consideration, requiring individuals to face and to answer questions about life which they would not usually engage in or wish to discuss. The danger is that individuals may find themselves facing issues which they might otherwise choose to ignore by various coping strategies.

Higginson & Carr (2001) highlight another of the potential dangers of the use of HRQoL measures in routine clinical practice. They suggest that because HRQoL measurement can be seen as so comprehensive, there is a danger that health care professionals will see them as a substitute for communicating with the health care user.

Addington-Hall & Kalra (2001) also suggest that healthcare providers may project their own feelings of helplessness and distress on to the person when assessing quality of life.

HRQoL measurement is therefore criticised for its *potentially* abusive role; by extending and consolidating power over an individual, by projecting the professionals own negative feelings onto the situation, by potentially threatening coping strategies around areas that the person does not wish to address, by possibly acting as a substitute for communication with the individual who is being measured, and by raising expectations of change when no attempt to effect change is intended, nor can any change be made. If HRQoL measurement does have a role in clinical practice then the way in which it is used needs constant and careful scrutiny.

Some authors feel that the conceptual base on which most HRQoL measures are based is so fundamentally flawed that they propose existing models need considerable modifications and that concepts need clarifying before new HRQoL instruments are developed (Carr et al, 2001), (Williams, 2000) and (Hunt, 1997) for example.

Other authors feel, however, that despite these limitations and difficulties, HRQoL measurement does have a role in healthcare. They point out the limitations and pitfalls but recommend further research into and use of HRQoL measures, particularly individualised measures (Gladis et al, 1999), (Higginson & Carr, 2001), (Muldoon et al, 1998) (Carr & Higginson, 2001). Such authors suggest that, if used sensitively and appropriately there are significant benefits to be had, particularly for those who might question its use, such as people with a disability.

> "data gained from quality of life measures could be used in positive ways to lobby for sufficient resources or to inform health and social policy" (p1300)

3.5 The relevance of these conceptual issues to aphasiology and the development of the DQ

So there are a number of complimentary conceptual, methodological and ethical challenges and themes converging from different sources. These issues have been influential within aphasiology affecting both those who receive and provide health care. This will now be discussed in combination with how they informed the development of the DQ.

3.5.1 The WHO classifications in aphasiology

Though the ICIDH-1, WHO (1980) had been published some 13 years previously, little use had been made of this in the world of SLT until the early 1990s. At this time SLTs became interested in both outcome measurement and the formal conceptualisation of the distinction between impairment on the one hand, and its consequence and significance on the other. One of the earliest references to the ICIDH-1 classification system within speech and language therapy was found in a major review article by Sarno in 1993. When discussing it Sarno describes the classification as a schema

> "which is not new to the medical speciality of rehabilitation medicine but may be new to aphasiology" (p323)

From then onwards however, the ICIDH-1 (1980) framework began to emerge within the aphasiology literature in a variety of contexts; Oxenham, et al (1995) used it when writing about spouse and SLT perception of comprehension difficulties, Parr (1995) cited it in relation to everyday literacy practices; and Simmons-Mackie & Damico (1996) discuss its relevance to communicative assessment from an authentic social perspective.

The first *measures* available to SLTs that used the ICIDH-1 classification as their conceptual base, were the TOMs, (Enderby, 1998) (described in chapter 1). More recently, authors within SLT have been highlighting the relevance of the revised ICIDH -2 (ICF, 2000). Worrall (2001) for example proposes that the ICF framework, be used by SLTs as *the* conceptual model within which to describe their practice. She poses the question

> "why is the WHO framework better than the simple medical versus social model? The simple answer is that the medical and social models are included in the WHO model but the concepts are expanded considerably into a 'biopsychosocial' approach, classification systems are detailed, qualifiers for each dimension are provided and the other factors are described in detail...the WHO model provides me with an overarching framework for my client's goals, but it also acts as a reminder that all dimensions are part of the disabling

> condition…we have used the WHO framework to frame our clients' goal and to provide a range of interventions that target the Body, Activity, and Participation dimensions." (p52-3)

3.5.1.1 The influence of the WHO classifications on the development of the DQ

The DQ was first drafted in 1996, conceived within a biomedical model framework. It was not deliberately based on the ICIDH-1 classification. However, the milieu within which it was conceived, including the discussions within the SLT profession surrounding the conceptualization and operationalization of impairment and disability distinctions, were influential in the choice of content and organisation of the DQ. From the original draft, the DQ was divided into sections that were in line with the ICIDH-1 classification. Draft 1 (shown in Appendix 2.2) has sections headed 'disability', 'handicap' and finally 'emotions'. The content of the items for each section broadly mirrored the content expected within this classification for people with language impairment. The 'emotions' section did not fit within the ICIDH-1 typology, but covers the emotional consequences of aphasia. The need for examination of emotions had been seen by other SLTs. Enderby (1998) for example when producing the Therapy Outcome Measures, which were explicitly based on ICIDH-1 typology, added a similar emotional section.

The subsequent drafts of the DQ maintained this typology, whilst increasing the content within the 'handicap' section to include specific questions relating to changes in self-image that might be associated with functional language difficulties. These included items relating to confidence, self-esteem and isolation. Development that was influenced by the ICF (2000) will be discussed in chapters 4 and 5.

3.5.2 Sociological perspectives in aphasiology and DQ development

The themes emanating from the sociological perspective have been rehearsed. They included

- an acknowledgment of the fact that influences on living with long-term illness or disability were likely to be social rather than medical (Conrad, 1990)
- an exploration into the role of language in perpetuating negative stereotypes (Phillips, 1990),
- discussion about the interaction of the social and personal meaning of living with disability (Nettleton, 1995), (Bury, 1991), and (Kleinman, 1988).

All these issues had significance when considering the impact of aphasia.

One additional concept that had emanating from sociological writing had been particularly influential within aphasiology, was that of identity. Brumfitt (1993a), for example, wrote extensively on self-image and the potentially damaging consequences that acquiring and living with aphasia might produce. She described what factors make self image vulnerable and what facets are supportive of self-image. She echoed Bury suggesting that

> "disabilities that form a central part of the self image are more difficult for the individual to accept" (p569)

She suggested that one's own communication is integral to personality and thus alterations to the ability to control this aspect of oneself can threaten sense of self. She described the effects of aphasia on someone's ability to complete activities dependent on communication, on the altered (or removal of) interaction with others and the effect this has on reformulating a new sense of self.

> "if the self is without experience, it cannot be a 'real self', because it is empty" (p570)

Elman (2000) describes some of the political and economic consequences of aphasia being invisible, under represented in the media of all types and so poorly understood by the general population (these issues will be examined later in this chapter). Brumfitt (1993a) expanded on why these characteristics make the reconstruction of self problematic. If someone has little previous knowledge of aphasia, representation of self can be difficult.

This difficulty with identity reconstruction is further hampered by the unpredictable nature of aphasia. Access to words can be inconsistent, one day a man can say his wife's name, the next day he can't. Additionally factors external to the person with aphasia influence communication performance. Conversation may flow when talking to one person, who is trusted and familiar. It may not do so if there are several people, if the one person is a stranger or if the topic of conversation is significant in some way. This inconsistency is perplexing for all concerned. It means that characterising a new identity can be difficult as behaviour, others and one's own reactions, cannot be predicated.

Brumfitt (1999) considered the factors that support the maintenance or development of a positive self-image, suggesting they relate largely to external social forces. Brumfitt discussed Charmaz' work (Charmaz 1995), when considering situations that discredit one's sense of self. She reported that the success with which a person withstands a discrediting incident is dependent on both the integrity of the individual's notion of self but also on the supportive context in which the individual lives, Brumfitt (1999). Clearly society has a significant role to play in both these areas. Nettleton (1995) also cited Charmaz' work on loss of self, describing how

> "the impact of cultural values, in that a society where 'doing' is privileged over 'being', those who cannot perform conventional tasks tend to lose the very means needed to sustain a meaningful social life" (p87)

The ideas emanating from sociological writings confirmed that the interaction between society and the individual is complex, and that having language impairment has the potential to make that relationship even more complicated, not least by threats to identity.

3.5.2.1 The influence of sociology on the development of the DQ

These ideas obviously had relevance when considering the development of the DQ, as they informed what resources a person might bring to navigating her/his way through acquiring and living with aphasia. They suggested that there is a need to explore the external influences on the impact of aphasia, and the personal resources and biography that an individual might bring to the situation.

In addition, with issues of identity and self-image being so important, there was a need seen to begin an investigation of how the identity of 'self-with-aphasia' is constructed. The influences that can make the world with aphasia seem chaotic could be identified, explained, and made predictable. This process of demystification could facilitate the reconstruction of identity as 'self-with-aphasia'. Expression and dialogue around changes in identity, status and circumstances are one very useful strategy to limit the challenges presented by altered identity (Pound et al, 2000). The need to explore barriers and facilitators within the DQ was beginning to emerge. The need for the tool to highlight how a world with aphasia operated for an individual was being confirmed.

3.5.3 HRQoL in aphasiology

What relevance did HRQoL issues have to aphasiology? As has been demonstrated above living with aphasia is complicated. It is an invisible, unfamiliar, pervasive, acquired, language disability that violates socially constructed codes of interaction that confer social competence. For all these reasons the concepts that will be relevant to living with aphasia are wide-ranging and multifarious, but not necessarily obvious or predictable. Thus to assume that the conceptual base of generic HRQoL measures will comprehensively capture the experience of living with aphasia may be optimistic. A disease-specific measure designed explicitly for people who have had a *stroke* may not be much better given the complex and all-pervading nature of aphasia (limitations of these measures for use with people who have aphasia has already been discussed in chapter 1).

A disease-specific measure that was designed exclusively for use with people who have aphasia could be more promising in terms of accessibility. In addition, if the conceptual complexity has been investigated and incorporated into the HRQoL measure the acceptability may be greater than generic or stroke-specific measures. The SA-QOL, Hilari (2002) described in chapter 1, has been designed specifically to be used with people who have aphasia, to overcome some of the problems relating to accessibility and acceptability. However, many of the issues explicated previously remain problematic. These include the ethical question of the level and nature of enquiry and involvement of healthcare providers in the lives of people who have a disability, the validity of results as there are two sources of instability of HRQoL measurement for someone who has aphasia; the person is *redefining him/herself* as a result of acquiring a language impairment, and the person may alter how s/he perceives the *aphasia and its consequences* in light of the situations s/he encounters. If the results are to be used to inform clinical decision-making or as a marker against which to judge intervention, then given the fluid nature of the situation, this could be misleading.

3.5.3.1 The influence of HRQoL issues on the development of the DQ

HRQoL literature was influential in the development of the DQ. The emphasis in the HRQoL literature focussed predominantly on developing measures and establishing their psychometric properties in terms of reliability and validity, rather than their value in clinical care (Eiser et al, 2000). It therefore focused my attention particularly on aspects of questionnaire construction and administration that helped consolidate the process of development. It highlighted issues relating to the need for accessibility within test design (for example Felce 1997, Mozley et al 1999). This literature also widened the debate towards more critical analysis of the conceptual basis behind HRQoL measurement (for example Higginson & Carr, 2001 Gladis et al, 1999, and Williams, 1998). This debate around the conceptual difficulties associated with

HRQoL measurement encouraged me to question the purpose, and therefore the nature and the scope of the tool that being was developed.

One question that arose related to whether the DQ was a HRQoL instrument? Bowling (1997a), as an example, summarises the components of HRQoL as functional ability including role functioning (e.g. domestic, return to work), the degree and quality of social and community interaction, psychological well-being, somatic sensation (e.g. pain) and life satisfaction. There was an acknowledgement that where possible the rating should be made by the subject of measurement. HRQoL measures were (and are) usually short.

3.5.3.1.1 Is the DQ a HRQoL measure?

The DQ had similarities with HRQoL instruments. When considering the DQ in the context of Bowling's definition of HRQoL, there was exploration of functional activities (in terms of functions associated with language tasks and their impact on role fulfilment), and it covered psychological well-being and life satisfaction (the DQ would go onto to be expanded to explore aspects of social and community interaction). It was also designed specifically to measure these from the perspective of the person with aphasia.

However, the DQ differed from HRQoL measures with regard to both the domains it explored, and how it sought to explore them. It explored only those domains that might be directly affected by communication change. It did not explore domains such as physical abilities, sexual functioning, pain, or energy levels. As has been discussed previously, HRQoL measures specifically investigate all areas of life regardless of whether the person administering the assessment has the intention or capability to alter these domains. The DQ did *not* seek to explore areas that could not be influenced by the future therapeutic process. The DQ deliberately considered only the domains that could be expected to be affected by the acquisition of language impairment, and were within the remit of a SLT. Though the content of the DQ needed checking with people who had aphasia, there was no need seen to expand the scope of enquiry beyond domains that could be altered by input from a SLT. Broadening the conceptual base with regard to other non-related life domains was seen to expand measurement beyond an SLT's area of expertise and realm of possible influence, and was not therefore seen as appropriate.

The DQ did not, and was not designed to provide a *concise* measure of expectations and experience associated with living with aphasia, as an aphasia-specific HRQoL measure might be expected to do. *The way* in which it examined the domains it explored was also intentionally different to the method traditionally used in HRQoL. HRQoL measures specifically aim to be brief. HRQoL measures frequently originate from research where time and budgetary constraints are different to those in clinical practice (Higginson & Carr, 2001). The DQ was not brief. (The length of the tool will be discussed in Chapter 5). It was intended to explore *in detail* aspects of how the person with aphasia perceive her/his life with aphasia. Thus the tool specifically aimed to cover the minutiae associated with living with aphasia.

The DQ differed from HRQoL instruments in another significant way. HRQoL measures seek to quantify. The DQ does facilitate enumeration through selection of a score, but it also attempted exploration and explanation.

It can be seen then that the DQ was not a HRQoL instrument. If the DQ were to be made into a HRQoL instrument, there would be a need to reduce its length, reduce the depth of exploration and expand its scope into areas that were beyond the remit of the SLT, and were not amenable to change.

The reason behind the lack of enthusiasm for this direction lay in the intended purpose for the DQ compared with HRQoL measures. The DQ's primary function was to inform decision-making and practice. It sought to do this by establishing a partnership between the person with aphasia and the administrator. The depth of exploration encouraged the beginning of identity-reconstruction for the person with aphasia, as a positive/expert role, and the confirmation of the authenticity of the administrator in the role of facilitator. It was felt that these processes would be threatened if the changes above were implemented.

3.5.3.1.2 Is a HRQoL measurement the only way forward?

Did this then jeopardise the DQ's validity as a tool for measuring health for someone with aphasia? Despite the support for HRQoL recently, departure from it is also recognised as legitimate within health care measurement. Hunt (1997) suggests

> "There is no particular reason why outcomes research should continue to focus on quality of life with all its attendant conceptual, technical and ethical problems...there seems to be no good reason why outcomes research should continue to include quality of life assessment, although the soliciting of patient's perceptions of their health status and functioning should continue to be an important component." (p210)

Further justification for methods other than HRQoL instruments, particularly with people who have a disability, was suggested by Kitchin (2000) who reported that respondents were wary of questionnaires and statistics generally. Questionnaires, the disabled respondents felt, were often poorly presented, poorly conceived, limited their responses, and led to a limited understanding of the subject which they seek to address. These respondents expressed very positive bias towards methodologies where they could

> "express and contextualise their true feelings, rather than having them pigeon-holed into boxes with no or little opportunity for contextual explanation" (p43)

Gill & Feinstein (1994) made a suggestion for overcoming conceptual rigidity. They proposed that instruments should be constructed to give participants the opportunity to list factors that they consider personally relevant that may have been omitted. Gladis et al (1999), however, pointed out it is difficult to know how to handle such 'write-in' responses in otherwise quantitative research. Despite this proviso, there was support for a methodology that can encompass the person's comments and input, beyond a simple rating, as was encouraged within the DQ.

HRQoL research within aphasiology has been limited. Previous sections have described those HRQoL measures which have been used and rehearsed the limitations of them for people with aphasia. Though recently several measures have emerged that have been specifically designed for people with aphasia (the SAQOL and the BOSS-CD as described earlier) there remains scepticism particularly relating to the purpose of measurement and what will be done with HRQoL information once it has been obtained. Clinically, HRQoL measures may lack the necessary depth of investigation and probe areas beyond the remit of SLTs.

The purpose of the DQ was also to acknowledge the situation that the person with aphasia found her/himself in. Kleinman (1988) suggested that this alone could be a powerful therapeutic process particularly for people who have chronic disability. Thus there is a role for measurement within aphasiology that does not necessarily fit neatly into the HRQoL framework. The DQ was not a HRQoL instrument, then or in the future. Issues raised by HRQoL literature however, were beneficial in challenging the purpose behind the development, in honing the process of developing the DQ and keeping the development true to its aims.

3.5.4 The social model in aphasiology

A major influence in the development of the DQ was that of the social model of disability. The debate challenging the medical model of disability and illness in favour of the social (and/or emancipatory) model began within aphasiology over the latter part of the last decade, when the DQ was being developed.

At the beginning of the last decade, the nature, rights and role of health care providers for people who were disabled were being contested. The initial challenges to the existing paradigm emanated from within the social work profession, from authors such as Finkelstein (1991) and Oliver (1990). Authors within other health-related professions began challenging traditional methods of health care provision and the conceptual bases behind them (French, 1993b, 1994a) for example within physiotherapy, and Schlaff (1993) within occupational therapy.

Up until the early 1990s speech and language therapy, in common with most mainstream therapies within the NHS of the UK, had traditionally assessed and treated people within the medical model of disability and health (Jordan & Kaiser, 1996). The review of assessment measures available in chapter 1 corroborates the fact that the emphasis in speech and language therapy assessment was on impairment and functional tests, in the absence of assessments of participation or environmental factors.

In 1988 Eastwood published a paper advocating the use of qualitative methodology within speech and language therapy. She proposed that conventional research methods did not meet SLTs needs or those of the people to whom we provided a service. She suggested that the application of scientific methods frequently required that situations be compromised and altered to meet the demands of methodology for identification and control of variables. She suggested that because communication is a social, interactive and complex field whose parameters may rarely be quantified, quantitative methods did not allow for the importance of context or creativity (essential characteristics of communication) to be taken into account.

Though she did not make reference to the social model of disability explicitly, Eastwood's article was the first to begin to question the existing medical paradigm within which speech and language therapy had traditionally been sited. It has been suggested that SLTs have often felt awkward within medical settings, and that this could be largely attributed to SLT's discomfort at working within a medical model paradigm (Jordan & Kaiser, 1996).

By 1993 the medical model conceptualisation of disability and health care delivery was being explicitly questioned within speech and language therapy. The British Aphasiology Society[1] hosted a number of study days for clinical SLTs entitled 'Power and Empowerment', largely organised by Carole Pound, a pioneer in this field. These study days were jointly hosted by BAS and ADA[2]. Their focus was to introduce alternative models of disability, and challenge, discuss and exemplify power relationships within the therapeutic discourse. The majority of the speakers had aphasia. SLTs speaking alongside people with aphasia, discussed how their practice had been challenged and changed by these particular people. These study days were followed up by two articles written for the most widely read of SLTs' journals (the College of SLTs 'Bulletin'). They discussed the principles of delivery of therapy to people with aphasia. The first was Parr et al (1995) who proposed that SLTs reconsider the core rehabilitation principles.

> "This is the assumption that the role of the aphasia therapist is to fix, or attempt to fix, the client's impairment, whether linguistic or psychological. However, current developments in the politics of disability demand the reappraisal of these assumptions – a process we may find uncomfortable" (p9)

The second was Pound (1996) who gave examples of how the City Dysphasic Group[3] was attempting to implement the social model of disability into both clinical practice and clinical teaching. It is relevant to note that Pound highlights the 'current absence of adequate outcome measures' capable of use within this arena. At around the same time Jordan & Kaiser (1996) published a thoughtful, revolutionary book that highlighted the difficulties with the traditional methods of assessment that were prevalent at the time within speech and language therapy. They suggest that aphasia therapy located in the individual pathology model 'may lack sensitivity to social barriers that limit communication'. They go on to point out that diagnostic testing

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[1] *The British Aphasiology Society (BAS) is a national interest group made of health care providers formed to foster the development of the study of aphasia.*

[2] *Action for Dysphasic Adults (ADA) is UK based charity for people with aphasia. It aims to provide support through information services, promote self-empowerment through networks of self-help groups, campaign for better services, greater recognition of the needs of people with aphasia and provides training and support to professionals working with people with aphasia.*

[3] *The City Dysphasic Group (CDG) was a charitably funded centre providing long-term therapy and support for people with acquired aphasia. The CDG was also responsible for clinical training of 30 students a year from London and beyond.*

(commonly practiced by SLTs) will be stressful for the person with aphasia, does not immediately benefit the person and will further strengthen the unequal power relationship between SLT and person with aphasia.

Through the work of authors such as those mentioned above, the role played by SLTs within the lives of people with aphasia, was being challenged. These were the beginnings of changes in how SLTs perceived their role.

Changing attitudes within aphasiology was not straightforward. Much of the impetus for change seen within the disability movement more widely had come from disabled people themselves. For example, Oliver, Finkelstein, French, Barnes, Morris, noted academics in the field of disability theory, rights and politics, all have a disability. Many of these authors made reference to their personal experiences within their papers on the conceptualising models of disability (e.g. Oliver, 1996), French, 1993a, and all the contributors to “Disability Discourse” Corker and French (1999)). In contrast, people who have communication impairments, by definition, will encounter barriers to fluent expression of their opinions and views (either verbally or in print). Challenges to the medical model were first articulated by SLTs, not people with aphasia. However, in 1999 Boazman, who does have aphasia, addressed questions relating to disability theory. This was the first paper where someone with aphasia gave a personal account of aphasia within the context of the role of the social model of disability.

Having communication impairment leads someone to be disabled in the way that all disabled people are oppressed, by social values, attitudes and prejudices. However, it further disadvantages the person by denying her/him the ability to state her/his needs, views, opinions and wishes. Given the nature of the impairment, it is not surprising that they are denied lobbying power and lack strong advocacy (Jordan & Kaiser, 1996).

As mentioned before, another barrier to empowerment for people with aphasia is the fact that aphasia is an invisible impairment. Paterson & Hughes (1999) discussed how impaired communication ‘makes one’s impaired body ‘dys-appear’’; the previously invisible body suddenly becomes the centre of attention, by the ‘violation’ of socially constructed codes of interaction. They went on to suggest that communication is socially codified particularly with respect to time. They suggested that each speech act has a socially defined type and time allocation. These allocations are informed by the experiences and needs of people without communication impairments and that violation of the codes confers social incompetence. They suggested

> "Embodied forms of communication (socially produced) are oppressive to people with speech impairment. Time is the primary criterion of exclusion and discrimination. A fact which the social model of disability with its emphasis on a politics of space is apt to neglect...the scripts for communication, timing and proprioception are, therefore, predisposed to the exclusion of people with impairments. It is not the exclusion from social space...which is at issue here, but ostracism from opportunities to participate in the everyday, mundane, sensate minutiae of the lifeworld" (p605)

Nettleton (1995) proposed that the invisibility of the impairment of aphasia compromises a person's ability to develop or maintain a positive self image.

> "Once diagnosed, people felt bound, or were encouraged by those close to them, to conceal their condition, and were consequently at the risk of being 'found out'. Stigma-bearers share the value system of those around them and thus experience a sense of shame." (p91)

French (1994b) discussed research findings that demonstrate that people with a less obvious or hidden disability have more social difficulties that those with a visible impairment. She also discussed the effect of comprehensibility of the impairment and disability to others. She discussed how functional ability can be markedly affected by differing situations but in a way that is not appreciated by the lay observer. French argued that the ambiguous nature of impairment and disability can lead to the behaviour of people being interpreted in terms of intellectual or personality deficits.

With regard to aphasia, the speed of the conversation partner's speech, the background noise, the frequency of topic switching can all affect the comprehension, and thus the ease of conversation dramatically. People are often met with bewilderment, uncertainty and embarrassment from others, who assume that the person with aphasia is drunk or intellectually impaired, or who have no idea what reason there could be behind the linguistic and thus conversational impairment. Block and Yuker (1979) presented evidence that the most rejected people are those with the most 'non-normal' appearance and behaviour because these appearances and behaviours may be hard to ignore and for people to adjust to. They included 'brain damage involving speech patterns' within this.

Elman et al (2000) discussed further consequences of aphasia being invisible and poorly understood. They demonstrated through a newspaper search that aphasia is underrepresented in print media in comparison with other neurological disabilities such as Parkinson's Disease, stuttering, autism, muscular dystrophy. They suggested that because aphasia is inadequately described, few people are aware of what it is. As a consequence not only is there a dramatic disparity for funding of aphasia-related programmes and research compared to other health conditions, but on an individual level, when someone acquires aphasia, this person mistakenly believes themselves to be affected by a rare condition, thus increasing her/his sense of isolation.

Given the nature of the impairment, there are barriers to people with aphasia being effective as their own vocal advocates. Thus they, as a group, are further disenfranchised as a result of their impairment (Elman et al, 2000).

Jordan & Kaiser (1996) demonstrated another level of disenfranchisement.

> "the literature considering services from disabled people's perspective includes little reference to speech and language therapy, and none to aphasia. This is not surprising given, for example the small size of the profession and the barriers aphasic people have to overcome to contribute in this arena" (p137)

So the impairment itself is disabling (by affecting the capacity to describe or lobby, by being invisible, misunderstood, and underrepresented), the impact can be compounded by the value system within which a person with aphasia operates, and having aphasia has disabling *political* consequences, beyond and including those shared with anyone who has a disability.

Despite the barriers inherent in having aphasia, self-advocacy has been gaining momentum within the community of people who have aphasia. It is interesting to note that here, again in contrast to some other arenas SLTs were involved as facilitators within this movement. Examples of self-help groups began to emerge in the early 1990s. In 1993, HASH (Harrow Aphasia Self-Help Group) was described at a British Aphasiology Society study day. One of its founder members describes HASH as 'a positive and creative environment to meet people, improve my communication, campaign and publicise and become independent from professionals'. In 1996, Pound published details of CASH (City Aphasia Self Help

Group). The activities listed included regular meetings and outings, and designing, developing and filming awareness–raising videos on aphasia and the needs of people with aphasia. In both cases these self-help groups were facilitated by SLTs, but the impetus for maintaining and developing the groups came from people with aphasia.

Three articles in the Royal College of Speech and Language Therpaists own publication (Bulletin) suggest that the issues relating to the social model are currently influencing diverse clinical and managerial practice for those with communication disability. Cameron (2001) describes how she set up a project to encourage people with aphasia to participate actively in making changes in their local communities. She and her colleagues facilitated the formation of action groups for people with aphasia to express and address different issues with the aim of improving their lives. Secondly, Chapman and Forshaw (2002) encourage SLTs to shift their focus towards helping service providers to increase accessibility. They give examples of where their service has increased awareness of communication disability, educated service providers on the ways to reduce barriers for people with communication disability, and provided this sort of input at local, regional and national levels. The service providers they have influenced include the care staff, dental services, the police, and government policy makers. They propose that it is acceptable to reallocate clinical time to broaden the remit of SLTs to include working with service providers. Finally, Young and Storer (2002) describe how they implemented a project that sought to introduce signs and symbols into mainstream school for *all* children. They aimed to ensure that signs and symbols (currently used by a minority of children with language impairment) were

> "attributed status, that they were accepted means of daily communication and that they were consistently and systematically used across the city and county local education authority " (p12)

By introducing signs and symbols they sought to break down the barriers to participation that existed for the children who routinely used alternative and augmentative methods to communicate.

Speech and language therapy has some vocal and respected advocates for moving practice away from the medical model towards models of empowerment and inclusion. Jordan & Kaiser (1996) conclude that

> "This is due partly to the assertiveness of a few aphasic individuals who have challenged the traditional assumptions about professional/client roles, and

> forged new relationships in which they (aphasic clients) set the agenda. No less important have been the responsiveness of the therapists, their openness to new ideas and their willingness to change established ways of working. There is a growing awareness among SLTs of the disability movement and considerable interest in promoting equal opportunities for communication-impaired people" (p180)

3.5.4.1 The influence of the social model on the development of the DQ

As can be seen from above, the social model has been a major, and increasingly powerful, influence in speech and language therapy. In 1996, the role of the social model of disability was beginning to enter the speech and language therapy arena in a more explicit way. It was at this point that stage 2, directly involving users through the use of the focus groups was in progress. The final stages of development of the tool stage 3 and 4 (to be discussed in the next chapter) have been strongly influenced by the social model.

So the next step in developing the DQ were informed by marrying the considerations of the HRQoL and WHO literature, the social and emancipatory models and the views of the user focus group. These all led to consideration of the purpose and nature of the tool. Its very existence was questioned. Though it sought to validate the experience of having aphasia, its emphasis on quantification felt inappropriate given the antipathy towards the medical model. There was a realisation that the DQ was based on professional constructs and that the validity of the conceptual base needed critical analysis by people with aphasia. Additionally, the processes operating around the person with aphasia needed to be incorporated.

This process of reflection in the light of these powerful conceptual influences led to an awareness that, though many of the constructs used were valid and acceptable (in the opinion of the focus groups), the involvement of the user, the person with aphasia, had up until that point been inadequate in the research process. The way forward lay with people with aphasia themselves. In an effort to ensure that the tool was acceptable at every level, and led by the conclusions emanating from the literature, people with aphasia needed to be involved in the next stage of development in a fundamental and powerful way.

Chapter 4

Development of the Communication Disability Profile

RATIONALE FOR THE DEVELOPMENT OF THE COMMUNICATION DISABILITY PROFILE

The various sources of evidence and inspiration elucidated in the preceding chapters motivated the further development of the tool. The tool was moving from one located within a medical-professional frame of reference towards an instrument located within a social model of disability, more in line with classifications of health and disability described by the ICF (WH0, 2000). Focus groups had highlighted some of the inadequacies of the tool. The literature had offered new frameworks and potential directions to guide the further development of the tool. The methodology employed after consideration of these issues also contrasts with that which had gone before. Both arenas strongly suggested that people with aphasia should be influential in the next stages of development. This chapter describes in detail the methods used in these next two stages of development.

The first modification that took place was a name change. The 'Disability Questionnaire' was changed to the 'Communication Disability Profile'. The name change highlighted that communication disability was the main focus, and reflected that the tool was as much about exploration as it was about measurement. The tensions that this dual function of quantification and exploration bring will be discussed later in this chapter. The 'Communication Disability Profile' will be referred to within this thesis as the CDP. Since this change happened at the start of this stage of the major re-development, the transforming DQ will, from now on, be referred to as the CDP.

4.1 Background to the development of the CDP

4.1.1 The purpose of the CDP

Before discussing the methods used in its subsequent development, it would be useful to reiterate the purposes of the CDP. As has been mentioned, reflection on the use of the tool hones the refinement of it. The CDP was aiming to do many things including:

- rate the experience of acquiring and living with aphasia from the perspective of the person who has aphasia
- systematically explore this experience
- order, and by so doing demystify, the experience for the person with aphasia
- validate the experience
- facilitate a shared understanding of the meaning and significance of aphasia between SLT and person with aphasia
- inform and facilitate discussion around priorities for goal-setting
- and provide a relevant, authentic outcome measure.

It might also be useful to catalogue what the CDP was *not* aiming to do. It was not trying to

- record 'misery'
- quantify at the exclusion of exploration
- explore areas that cannot be influenced by such things as intervention, greater understanding, or increased awareness
- reinforce traditional power relationships between SLTs and people with aphasia

4.1.2 The Communication Disability Profile (draft 1)

The tool had undergone a considerable amount of change within stages 1 and 2 as has been described in Chapter 2, including the validation process utilising the skills of the two user focus groups. The DQ went through 5 iterations during stages 1 and 2. The resultant tool, the CDP (draft 1), is shown in appendix 4.1. A review of the structure of the CDP will help inform the discussion of the modifications that took place during this next stage, stage 3. The CDP (draft 1) was structured as follows:

A. Disability self-rating.

Four sections (i-iv) relate to a domain of a language that is potential vulnerable to change following the acquisition of aphasia. They are rated using a one-stage rating method.

i. Talking
ii. Understanding
iii. Reading
iv. Writing

Each section has:

- 4 hierarchically ordered items relating to communication situations that might act as a barrier to someone with aphasia
- An open ended item for the respondent to supply situations relating to his/her personal experiences NOT mentioned in the items above
- An item that quantifies how the situations described affect participation in daily life
- Anxiety associated with any limitation to participation experienced by the respondent)
- The response is rated using a one-stage rating scale

B. Emotional consequences

This section chooses emotional states that are commonly reported in the presence of living with aphasia.

The response mode is a two-stage rating scale (initially rating frequency of emotion i.e. always-sometimes-never, and secondly intensity of the emotion i.e. a little-a lot). 7 items relate to constructs of confidence, competence, frustration, anger, control, sadness, and general life satisfaction (currently and in the future).

The CDP (draft 1) described above underwent changes during the subsequent development stages to be described in the next two chapters. 3 further iterations of the tool were produced. Revisiting table 2.1 will provide orientation to the processes of development.

METHODS USED IN THE DEVELOPMENT OF THE CDP

At the beginning of this stage, stage 3, the structure and presentation of the CDP (draft 1) were the result of implementing many of the suggestions made by the DQ user focus groups (as described in chapter 2). The major aspects to note relate to structure, concepts, and wording and have been detailed in table 2.11. The changes made between the end of stage 2 and the beginning of this stage 3 (moving the DQ to the CDP) were significant. The negativity of the instrument was addressed, procedural complications were ironed out increasing accessibility, rewording took place to increase accessibility, and concepts and how they were presented were discussed at length with both SLTs and people with aphasia. These changes were important in terms of increasing accessibility and acceptability of the measure for people with aphasia, *when carrying out the assessment.*

However, the conceptual and methodological influences described in chapter 3 suggested that a new approach to the *research process* needed to be implemented to move the tool into a social model framework, by enlisting the support and guidance of people with aphasia to inform future changes.

There were a number of processes that took place within this stage of development. The first was to implement the final suggestion of the focus groups, namely to introduce pictures into the CDP. The other processes were significantly different from what had gone before. They utilised qualitative research methods enabling people with aphasia to take control of aspects of the research process itself.

The qualitative methods used in stage 3 were two-fold; firstly interviewing approximately thirty people within both group and individual settings to explore with them their experience of living with aphasia and secondly setting up a panel of people with aphasia to advise on and oversee the development process. In contrast to the reporting of the development of the DQ, the development of the tool in this stage 3 will be structured along more traditional lines but the detail will be significantly more than is expected in traditional reporting. The methods and processes will be discussed in this chapter with the results and outcomes being described in chapter 5. This is due to the nature of the changes that took place as a consequence of the differing methods adopted for stages 1 and 2, as distinct from stages 3 and 4. Changes in the first two stages related only to the instrument itself and did not lead to examination of the research process itself. The methods and results could be reported in a relatively simple and efficient way. During stages 3 and 4 however, both the tool but also the process changed. The changes were significant but subtle. The level of detail brings out the subtlety of changes that took place. Therefore the level of detail of reporting for these stages 3 and 4, will be significantly greater than is the norm within reporting of instrument construction. The focus of interest of this thesis is on the rationale and relationships behind the processes involved, rather than on the process or the actual tool itself.

STAGE 3: Direct user consultation

4.2 The qualitative interviews

The first process that contributed to the development of the CDP was the use of qualitative interviews.

4.2.1 Rationale for in-depth interviews

General advantages of in-depth semi-structured interviewing for exploring people's attitudes and opinions have been discussed in the second chapter, and these were pertinent to this choice of methodology here. The information gained from these interviews about the range of experiences and life-stories that are associated with having aphasia informed the development of the instrument. This information was compared with suggestions from the advisory panel (discussion of which will follow in the next section). This method of data management validated the content of the CDP. It ensured that separate lines of enquiry were consistent with one another. It checked whether all the areas mentioned as relevant by the people with aphasia during in-depth interviews could be addressed when administering the CDP.

Additionally, given this controversy regarding non-disabled people undertaking research in disability, there was a strong need to achieve the necessary self-reflection, experience and knowledge that would enable me to validate my position as a non-disabled researcher with the necessary credentials. I had personal experience of being involved with many people with aphasia, assessing, treating, supporting, counselling, and sharing social situations through my role as a health care provider. Whenever I had consulted people in these contexts however, I had a professional, therapeutic agenda. I had not listened to their stories for listening sake. Though I had exposure to aspects of people's experience of having aphasia, I felt I needed to explore what it was like to have aphasia in a less constrained way, to listen openly, without an agenda other than to hear what it was like for that person. The first part of this process was to share the experiences of people with aphasia without the professional agenda, hence the in-depth interviews.

The in-depth interviewing therefore was to guide the development of the tool but also inform me as a non-disabled health care worker.

In-depth interviews took place in stage 3 with people in both group and individual settings. Previous interviews (in stage 2) had had a single focus; to investigate users' perspectives of the DQ. In contrast, the interviews conducted in stage 3 were much less targeted. They sought to explore the experience of living with aphasia. They were much more guided by the person being interviewed, and less analytical than the focus groups of stage 2.

4.2.2 Group interviews

Initially group interviews took place. These were useful in their own right but also served to act as a precursor to the individual in-depth interviews. The themes that arose from the group discussions were used to check the topic guides for the individual interviews. Topic guides (also called interview schedules) are loosely structured schedules that specify the main themes to be explored in a qualitative interview. They act as an *aide-memoir* to the interviewer to ensure that the key areas are covered whilst not restricting the responsiveness of the interaction.

4.2.2.1 Sampling issues for group interviews

Two focus groups were conducted. They were not sampled in a purposive way but simply represented those who volunteered. This is known as convenience sampling, Bowling (1997b). The common characteristic of all respondents was that they all lived with aphasia. The members of the two groups were drawn from slightly different backgrounds. The first consisted of six volunteers who attended a Stroke Association dysphasic support Group (SAG)[1]. The second consisted of seven people who attended City Dysphasic Group (CDG) (described in chapter 3). The sampling characteristics of the participants are shown in table 4.1.

4.2.2.2 Implementation of group interviews

Each interview took place where the group normally met. The interviews were conducted by me and recorded on audiotape. The topics included whether and how each type of impairment associated with aphasia (reading, writing, talking, understanding) interfered with daily life, whether people, situations, emotions affected daily life with aphasia (facilitators and barriers), how life had changed since acquiring aphasia, how the person with aphasia saw him/herself, how others would perceive him/her, and the positive and negative aspects of living with aphasia. Each focus group had the same topic guide to direct discussion.

Having transcribed the tapes, the information was then used to draw out themes relating to the experience of living with aphasia. These themes were used to confirm the relevance of topic guide that would be used to conduct the individual in-depth interviews.

4.2.3 Individual in-depth interviews

Individual in-depth interviews were also conducted. Individual interviewing (as opposed to group interviewing) can be useful to explore areas that people may be reluctant to voice in the more public arena of focus groups. They can also probe areas in greater depth than may be possible within the group setting.

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[1] *The Stroke Association is a national charity that describes itself as solely concerned with stroke. It supports people who have had a stroke, and campaigns, educates and informs to increase knowledge of stroke. The Dysphasic support groups are run to provide support and activities for people with a range of stroke-related communication impairments.*

4.2.3.1 Sampling issues for individual interviews

In contrast to the group interviews, theoretical (systematic non-probability) sampling was carried out to access a group of people with aphasia who would take part in individual in-depth interviews. The interviewees were selected to possess characteristics, or live in circumstances, relevant to the social phenomenon being studied. Respondents are identified because they will enable exploration of a particular aspect of behaviour relevant to the research (Mays & Pope, 1995) in this case living with aphasia. Sampling issues within qualitative research have been discussed in chapter 2. The issues discussed there, for the validation process, are pertinent to this context when discussing sampling for individual interviewing.

For the same reasons as were elucidated in the previous sections, the following features were identified as being relevant to selecting the sample group: gender, ethnicity, age, duration of having aphasia, type and extent of language impairment and whether the person with aphasia was living with alone or not. Table 4.2 shows the characteristics of the people selected for individual in-depth interviews. It should be noted that all the interviewees were known to me before I interviewed them. I had been involved with assessing the majority of them (11/13) as part of the recovery prediction project previously mentioned. I had seen them regularly (every three months) over the year since they had had their stroke. The remaining two people were known to me through my previous clinical work.

As has been discussed, there are advantages to knowing respondents prior to interviewing them (Cornwell, 1984) especially where situations were new or unfamiliar such as during research and where there is a power imbalance (Goffman, 1978). My role with the people who were to take part in individual in-depth interviews *had* been as a quantitative researcher. However, I had a personal relationship with all the respondents that, I believe, facilitated the process of in-depth interviewing, as a bond of familiarity (and I would hope, trust) already existed between us. All those interviewed had agreed to do so, knowing that the in-depth interview was separate to the quantitative research project that had gone before, and knowing that the tenor of the process would be wholly different.

4.2.3.2 Implementation of individual in-depth interviews

All the individual interviews took place in the participant's own home. The interviews were always conducted alone, with no-one other than the interviewer and the interviewee present. All interviews were audio-tape recorded. The themes covered during the interviews can be seen in the topic guide shown in appendix 4.2. The conversations were then transcribed. Having transcribed the individual interviews, specific situations and experiences were then extracted from the data. Instances of people with aphasia reporting changes in activities, participation or emotional reactions to these changes were noted. These data were then compared with the domains used in the CDP – draft 1. This was done to establish that the CDP covered the areas of most significance to a person with aphasia. Results are discussed in chapter 5.

4.3 The expert advisory panel

4.3.1 Rationale for advisory panel

The quotation below from the otherwise excellent reference book by Streiner & Norman (1995) demonstrates how disabled people can be viewed in a distorted fashion within some fields of research.

> "A point often overlooked in scale development is the fact that patients and potential research subjects are an excellent source of items." (p16)

There is little feeling of reciprocity in this description. 'Subjects' are there to serve a purpose, provide information.

In relation to this project, people with aphasia in stage 1 had been included in the project as 'subjects' not advisors. There was little feeling of reciprocity or dialogue in the interaction. People with aphasia had been involved in the validation exercise, using the DQ user focus groups in stage 2. However, this involvement felt inadequate.

There is a significant literature relating to power relationships within traditional models of research practice (this will be discussed in chapter 6). This literature demands that those doing research in the field of disability use participatory methods on the grounds of ethical practice (Oliver, 1992), and human rights (Bricher, 2000). On a practical level, also, there are seen to be significant advantages to including disabled people in the development process. Woolley (1993) reports on a study involving people who are deafened. She suggests deafened people hold far more appropriate analyses of their disability and solutions than any person in the medical profession they are likely to encounter. (The parallels with acquiring aphasia, also a communication disability, are apparent).

Stage 3 therefore saw the convening of an expert advisory panel. This time, in contrast to the previous 'expert panel', the *experts* were almost exclusively people with aphasia.

4.3.2 Sampling issues for the advisory panel

The group of people asked to be members of the expert advisory panel were sampled on the basis of convenience. All had connection with an organisation called Connect[2]. There were four people in the advisory group. Three had been living with aphasia for seven years or more. All four had regular contact with a wide cross section of people who had aphasia through their various roles within Connect. Three of the panel worked for Connect; two as counsellors, one as a family support worker. The fourth member was involved in setting up Connect and acts as a voluntary advisory in selection of staff, and development of the organisation. All but one knew each other well before the advisory panel started. Table 4.3 gives their biographical details.

One member of the panel did not have aphasia. This person was someone who worked for the last two years with relatives/carers of people who had aphasia, and prior to that for three years with people who had aphasia as a member of the Stroke Association. At the time, the reasoning for her inclusion was that she had a wealth of experience of working with people who had aphasia, and in particular supporting relatives and carers of people who have aphasia. Her background was not that of a health care professional. As such her inclusion was based on the assumption that she could legitimately represent views of carers and relatives of people with aphasia. In retrospect, the inclusion of someone who did not have aphasia could be questioned.

Apart from this member, all the panel members were chosen because they had personal experience of living with aphasia themselves, and each had a wide variety of vicarious experiences of living with aphasia through membership of groups, work at Connect or through work as counsellors.

4.3.3 Implementation of the expert advisory group

The advisory panel met on eight occasions over an eleven-month period within stage 3. Each meeting lasted approximately two hours, often with a break for coffee. The format was reasonably standardised. Their role throughout was to advice on how to make the CDP accessible and acceptable to people with aphasia. In chapter 2 the

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[2] *Connect – the communication disability network is a newly established charity. Its mission statement is to work in partnership with people who have a communication disability to provide practical, creative and lasting ways of living with communication disability. They suggest that they achieve this through an integrated programme of therapy, education and research.*

importance of including pictures was raised: both DQ user focus groups had suggested that pictorial information would greatly improve the accessibility of the tool. The use of pictures has been found to enhance comprehension for people with aphasia. Pictures are iconic and by definition therefore negate the need to process words as they are received, as the information about meaning is graphically and permanently represented, rather than being transiently and linguistically present when spoken, or linguistically represented when written.

Using pictures ensures that, if conceived and drawn correctly, the person with aphasia who has an impairment of comprehension will be less likely to be excluded. Similarly using a pictorial rating system ensures that those with little or no speech can express their views without dependence on speech, or comprehension of a rating system that relies on numbers or written words.

Beyond the impairment level, the whole look of the tool is softened by the introduction of pictures; they reduce the feeling of measurement, pictures can introduce points of humour and interest beyond what is being directly rated. They can have an undefined sense of friendliness. The pictures support and, in many cases could wholly replace the spoken or written information. They set the scene, exemplify and elaborate on each statement or question.

There are precedents for using pictures as a rating response mode. Nelson et al (1987) reports the use of pictorial information in the COOP charts (previously described) to aid comprehension and rating of functional abilities. They comment that the use of simple diagrams to illustrate the response scale for each chart appeared to be sensible and appealing to respondents. Similarly Brumfitt (1998) discusses the Self-Concept scale for Hearing Impaired, Oblowitz et al (1991) for use with children, which uses a scale of picture material. Brumfitt also cites how Anderson (1988) uses a pictorial scale to assess general satisfaction with life for people who have had a stroke (described previously). Brumfitt (1999a) herself employs pictorial images as a rating scale output mode to depict items in her tool exploring self image, the Visual Analogue Self Esteem Scale (VASES). She is a strong advocate for the necessity of using pictures when working with people who had aphasia.

So both focus groups suggested or agreed that pictorial information would aid the administration of the tool. Previous authors have demonstrated that their inclusion can be both valid and beneficial, especially when working with people who have had a stroke but specifically with those who have language impairment.

An artist was commissioned to draw pictures for all statements or questions that appeared in the CDP (draft 1). The artist received the item wordings. She and I then discussed suggestions for how these items and concepts were to be represented and she then drew her interpretation of them. All the resultant pictures were then considered by an advisory panel, as they were produced. However, the advisory panel scrutinized the pictures that were produced, and suggested amendments. Attaining nuance of meaning through evaluation, discussion within the advisory panel and numerous iterations of the pictures took place to refine the precise pictorial representations.

As the development process continued, the advisory panel began to suggest additional concepts or pictures that would enhance the CDP (details of these will be discussed later). These extra drawings were commissioned and then the same process of refinement took place. The outcome of this process of picture inclusion will be discussed in chapter 5.

At each meeting, the current version of the pictures (plus item wording) from the CDP would be presented, with changes that had been implemented since the previous meeting being highlighted for approval or rejection. Relevant issues that I had come across in the literature since previous meetings were also raised for discussion. The conversations were not taped and handwritten notes were kept to the bare minimum. This was done as it was felt that detailed documentation would detract from aim and tenor of the meetings. The aim was to examine the CDP and recommend modifications, but to do so within an atmosphere of collaboration and equality.

Records of these meetings were therefore kept in two ways. Decisions that were made that related to the pictures were noted down at the time on paper copies of the pictures themselves. These conclusions were then discussed with the artist for her to make the necessary changes. ‘Field notes’ were also kept. These were records of discussions that took place within the advisory group. They contained information relating to the process of the meetings rather than the outcomes. Summaries of the discussions were kept. These served to highlight the issues that needed to be returned or document *how* and *why* decisions made been arrived at, if this was not obvious. These field notes were not shown to the advisory group but acted as documentation of the process beyond the decisions that affected the modifications for the CDP itself.

The initial focus of the meetings was for the panel to act as advisors to facilitate inclusion of picture material within the CDP. As the process developed the group took on a wider influence. They advised me on how the CDP should be further developed, in terms of both concepts and accessibility to people who had aphasia. The remit of the group was to advice, offer ideas, comments, opinions, wordings, but also to challenge and force reconsideration of all aspects of the CDP. The topics discussed by the panel related to the following areas; acceptability of items in the CDP (draft 1), broadening the conceptual base of items or domains, ordering of items and domains, how to introduce and use pictures to depict the concepts described, issues relating to methods of rating, presentation and precise wording of the items on the CDP.

This collaborative process was not straightforward for these group members. I was requiring of them not only comprehension of the linguistic aspects of the process (the discussion, the verbal/written labels), production of exemplars (of situations, roles, emotions, etcetera) but also detailed thought and expression around semantic categorization and issues of test construction. These are complex issues for anyone to grapple with. The success of the discussions and the final outcome is testament to the panel's insight, skill, tenacity and commitment. The panel also played a significant role in my own personal experience of the research process.

The aim was for mutual exchange of ideas and opinions, to embed the new tool in the lived experience of the impact of aphasia but also to ensure that people with aphasia were in control of many aspects of the development process itself. With this new group came a shift in the social relationships of the research project. Results of this process which will be discussed in the next chapter, led to the CDP (draft 2) (This can be seen in appendix 4.3a with score sheet as appendix 4b).

STAGE 4: Clinical usability

4.4 Rationale for usability field-testing

Efforts had been made in Stage 3 to alter the CDP in a way that was acceptable to people who had aphasia. The final stage of development was to ensure this new iteration was usable and acceptable to the other group of users, namely SLTs. Having increasingly moved away from the professional perspective, this view was returned to, to establish the usability of the CDP, and the impact of using the CDP on influencing practitioners and clinical practice.

4.5.1 Sampling issues

SLTs were sought to carry out a clinical usability pilot study using the CDP (draft 2). They were not purposively sampled, but represented those who had volunteered to take part having been part of audiences where the CDP had been presented. This ensured that the pilot testers knew what the project and the CDP were about, and by volunteering demonstrated a commitment to both.

4.5.3 Implementation of usability field testing

In a similar fashion to the previous SLT training described in chapter 2, all the volunteer SLTs attended a training session together. The purpose of this was; to give the background to the CDP's development; to discuss the relevance of the CDP in terms of the social model of healthcare delivery; to advice the SLTs on the proposed method of CDP administration; to give the SLTs a copy of the CDP and recommended administration; and to discuss the logistics of feeding back opinions. The training included discussing the issues relating to administration of the CDP, playing a video of myself administering the CDP to exemplify the suggested administration, and role-play of administering illustrative sections of the CDP. I had chosen the people to be videoed to exemplify different aspects of the process of administration of the CDP. The videos exemplified; using the CDP with someone where comprehension impairment might be a barrier to completion of other instruments; where someone has no speech at all and finally someone I knew well who would have lots to say about the process.

The volunteers were then requested to administer the CDP with as many people with aphasia as possible, with whom they considered it appropriate. They were given a three month time period. They were requested to give written feedback on two feedback forms. Form 1 (appendix 4.4) was to be completed after each administration of the CDP to capture immediate overall impressions of content and format of the CDP, with brief details about the person with whom they had administered the CDP. Form 2 (appendix 4.5) was to be completed at the end of the trial period and probed reasons for exclusion of people with aphasia, perceptions of content and format of the CDP and reflections of whether administering had influenced them or their practice. Results of these questionnaires (summarised in the next chapter) were then summarised, modified and taken back to the advisory panel for discussion.

Chapter 5

Development of the CDP; results and outcomes

The previous chapter documented the various developmental processes that were undertaken as a result of direct user involvement and consultation (stage 3) and the final stage of returning to health care workers to gauge reaction of those who might use the CDP (stage 4).

This chapter will describe, in detail, how these different processes contributed to the development of the CDP. These two stages will be discussed separately. When discussing stage 3 the methods employed have previously been described sequentially. However, the contributions from all the processes influenced the CDP simultaneously rather than separately. Therefore, the modifications that resulted as a consequence of the information and experience gained from direct user engagement will be discussed in general themes under the following headings;

- issues relating to the use of pictures
- modifications to structure,
- modifications to concepts,
- modifications to wording and
- the role of the advisory panel.

RESULTS AND OUTCOMES OF STAGE 3

5.1 Issues relating to the use of pictures

At the beginning of this stage 3 the CDP did not include pictures. The rationale and overview of methods used to introduce pictures have been discussed in chapter 4. This section will consider the details of introducing pictures. The primary aim of using pictures was to support concepts, questions and rating scales thereby making the CDP more accessible for people with aphasia. The advisory panel, and the individual and groups interviews influenced how pictures were introduced and modified. The majority of time and effort within the advisory panel was spent discussing and perfecting the details of depiction[1].

Depicting concepts was not always straightforward and there are a number of issues raised by depiction that do not necessarily have to be addressed if items are presented verbally.

The first issue relates to difficulty depicting abstract concepts. By definition depiction requires representation. The aim of using pictures within the CDP was to increase accessibility so the pictures used needed to be clear and representative. Depicting concepts that were abstract, such as time concepts, emotional constructs or constructs such as 'aphasia', could become problematic.

Secondly, within a picture, a context and the protagonists (if needed) must be specified, which raises consideration of culture, race, age and gender. So depiction forces a decision on these issues, which means striking a balance between representation and prescription.

Finally, specifying the details of the picture forces reflection and clarification of constructs that lie behind the items included. It highlighted constructs or items that had been omitted. It required detailed consideration of item wording, and nuances of meaning that are expressed through pictures.

5.1.1 Interaction of influences

The introduction of pictures often caused the issues above to interact with one another. The development of the participation section highlighted how these issues collided creatively when introducing pictures. Table 5.1 summarises the changes to the concepts, wording and structure of this section brought about by the introduction of pictures and the issues highlighted by the inadequacies of the pictures. This table is supported by a detailed description of the process of expansion and refinement of this section to exemplify the process.

At the start of the process of introducing pictures into the participation section, the artist was commissioned to produce a drawing that supported the question 'how does that get in the way of everyday life for you?' (see appendix 5.1). As with all the subsequent pictures, this drawing was then discussed with the advisory panel in terms of how accessible the picture and item wording was, how acceptable the concept was, and whether the picture supported the concept (see table 5.1, version 1).

Discussions revealed that the panel had reservations. There was real difficulty

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[1] *When discussing the advisory panel, it should be noted that I include myself as a member of this group, as the panel functioned in a collaborative way. This will be discussed in depth in the final chapter.*

agreeing on how 'everyday life' should be depicted; the picture presented was seen as inadequate. Discussion around alternatives highlighted that the overall conceptualisation of 'everyday life' was ill-defined, meaning different things to different people, and being affected by influences external to the person in question. Equally the ability of people (including those who have aphasia) to rate such a diverse concept without an examination of what lay behind it, was questioned. The concept of participation was therefore refined to include external influences, particularly people, as these were seen by the panel as being the most influential with regard to how someone could participate.

Further drawings were commissioned (version 2 in table 5.1). These were drawing that supporting first introducing the concepts of 'what makes it worse?' and 'what makes talking easier?' then 'how is talking in everyday life?', and 'are there people who make things easier?' These are represented by the appendices 5.2, 5.3, 5.4 and 5.5 respectively. These pictures were then discussed.

The picture that supposedly supported 'how is talking in everyday life?' was seen as obscure, esoteric and inaccessible. Additionally, the discussion around this set of pictures led to the following conclusions;

- that there was a need to expand this section to depict different specified areas of participation that might be affected by having aphasia

  (Conceptual issues relating to this area will be discussed in section 5.4)
- participation should be divided into three overlapping areas (things you *have* to do, things you *want* to do, at *home*), and that the pictures shown could stand alone

  (concepts that were included will be discussed in section 5.4)
- given the expansion of the section, the need to depict 'everyday life' was actually redundant
- the concepts of barriers and facilitators were helpful,
- but there was a need to introduce the *concepts* of facilitators and barriers before attempting to identify what those might be for that person
- that barriers and facilitators should to be identified separately from participation
- not all these items would be rated.

The following items were therefore written as a consequence of these conclusions. Pictures were commissioned to support them (see version 3 in table 5.1); 'how are things you WANT to do?' (shown in appendix 5.6), 'how are things you HAVE to do?' (shown in appendix 5.7), 'how are things at HOME?' (shown in appendix 5.8), 'what HELPS?' (introducing the concept) (shown in appendix 5.4), 'WHO helps your talking?' (identifying who acts as facilitators) (shown in appendix 5.9), 'What THINGS help your talking?' (identifying specific facilitators) (shown in appendix 5.10), 'what makes talking HARDER?' (introducing the concept) (shown in appendix 5.11), 'WHO makes talking harder?' (identifying who acts as a barrier) (shown in appendix 5.12) and finally 'what THINGS makes talking harder?' (identifying specific barriers) (shown in appendix 5.13, 5.14 and 5.15)

Consideration of these pictures led to the following conclusions, which are summarised in table 5.1;

- participation should not be married to individual modalities but should be scored as a separate expanded section. It was unrealistic to expect people with aphasia to be able to relate the effect of ONE modality (e.g. talking) to how easily they were able to participate in life. The new expanded section would therefore relate to the effects of aphasia overall on participation.
- three-way division of participation was accessible and acceptable (things you have to do, want to do and at home)
- it was useful to separate 'who' from 'what' acted as barriers and facilitators
- participation would be rated but the barriers and facilitators would not (rationale for this will be discussed within the section 5.4).

So pictures were presented for consideration. Discussions about the inadequacies of the pictures led to refinement of the concepts, wording and structure under investigation. This in turn led to further drafts of pictures as both concepts and depiction were clarified and refined.

5.1.2 How the advisory panel worked

The depth of analysis of the pictures by the advisory panel was considerable. For example, within the development of the participation section described above the picture seen in appendix 5.4, where a woman offers a hand across the water, was very popular. It was seen as being suggestive of facilitation rather than dependence, guidance rather than control. It also helped to suggest the alternative to the original barrier picture (appendix 5.1). The new picture that was used to depict how things were made *harder*, showed our central 'character' on a broken bridge.

A further example was seen when the panel were shown the draft for the 'talking under pressure' (appendix 5.16). The responses suggested alterations were needed. "She (lady with aphasia) doesn't look under pressure...needs a clock, or phone", "she shouldn't be smiling", "he (the doctor/listener) too nice, look down and writing". These suggestions were subsequently all included (see appendix 4.3a page 10).

So these examples demonstrate how the advisory panel considered the pictures, reflected on the use and context of them and made suggestions to increase clarity for people with aphasia.

5.1.3 Depiction of abstract concepts

Depicting abstract concepts was challenging. Abstract concepts within the CDP included constructs such as 'aphasia', 'what helps/makes it worse?', time constructs such as 'since your stroke-during the last week', 'always-sometimes-never', 'looking to the future', 'how are things today?', and finally all the emotional constructs including 'how does that makes you feel' 'valued', 'determined', 'embarrassed'. Each of these items required considerable deliberation and numerous redraws.

Concepts relating to time will be described to exemplify the nature of the discussion and the level of consideration achieved by the panel when discussing abstract concepts.

When discussing the depiction of 'when you look to the future, how do things look?' the subtleties behind the depictions were exemplified. The picture originally showed a man with a sad expression, pointing over the distance, with a sun half covered by the horizon (see appendix 5.17). There was no other detail.

The group discussed how successful the imagery was. They felt the man was "very sad – no good". We discussed the success of conveying 'future time'; "He's looking to his horizons", "new dawns", "no, it's the end of an era", "sun setting on the future" (because the sun was partially occluded). Suggestions to enhance it were made; "it's a beautiful day" (suggesting the sun should be fully visible), "should he have his hand up above his eyebrows, maybe a road sign – direction", "maybe a road – a path" to signify that he's searching for "a way forward", "the road to recovery", "going on a journey", "maybe a road to nowhere!" "that road – you know – yellow – and witch!", and when discussing what kind of road or path would be depicted, "the long and winding road", "a straight and narrow" , "but recovery isn't from here to there (showing a straight line) its ... (indicating twisting and turning would be better)".

So after discussing these various points the conclusions were that the man needed a neutral expression to ensure no presumptions were made regarding optimism or pessimism for the future, that the sun needed to be in the sky fully, his pointing posture should remain, there should be a road, straight and narrow, but that there should be no other 'props' as they might mislead towards 'being lost or not knowing your own direction'. Appendix 5.18 resulted.

Pictures depicting emotions were equally problematic due to their abstract nature. A similar process of discussions and redraws ensured the pictures and concepts were accessible and acceptable to the advisory panel, to reflect the precise emotional tone.

For the emotions pictures, the actual manner of presenting the pictures was as important as each actual picture itself. The way the pictures were presented on the page, and the way the person was able to rate the pictures were all discussed at the same time as the detail of the individual pictures. Altering the structure of the emotions section to take account of this will be described later. There is an acceptance of the fact that all the pictures that represent more abstract concepts are potentially (and in some cases actually) less successful than pictures depicting specific situations or people. By definition, these representations cannot depict defined situations. They must be generalised and broad. To be of use they must be suggestive of a state and their utility rests or falls on how successfully they are able to depict generality in a way that denotes a state of being. Pages 52-55 in appendix 4.3a show the pictorial representations of these abstract emotional constructs at the end of stage 3.

5.1.4 Accessibility versus inclusion and acceptability

Another challenge when introducing pictures was balancing the need to maximise acceptability and inclusion against the need to have a pictorial representation that was accessible. To maximize accessibility, pictures must be clear and unambiguous, usually therefore making all referents in the picture obvious, with the situation and characters specified. To maximize acceptability *and* inclusion, however, a *range* of social, cultural, racial and gender images should be presented. The marrying of these two seemingly opposing influences exercised our thinking considerably.

The first part of the process was discussion with the artist about who the 'subject' would be. For example when depicting 'how easy is it for you to talk to the person closest to you', there needed to be a picture of someone talking to someone else, in a relaxed context. Who would that person be? Would they be male or female, how old would they be, what would the cultural and/or racial and/or socio-economic background be?

The conclusion reached was that despite the concerns for inclusion, there would be one central character who would be most representative in terms of statistical representation of 'a person with aphasia' in the Britain – an older, white, person. To try to counterbalance this degree of prescription, the artist attempted to make situations that this character was put in as general as possible with respect to socio-economic and racial considerations. We discussed incorporating images of people from other more diverse backgrounds throughout the tool, around the central subject character. With the expansion of the participation section this became a lot easier, as there were many more situations where non-white younger people, for example, could be included in the pictures.

The artist and I also made the decision that the central character would remain the same throughout the activities section. Field testing the DQ had shown that it was not always easy to ensure that the person with aphasia had understood that the topic of the questions had changed when moving from 'talking activities' to 'understanding activities' for example. If the central character changed between sections as well as the situation this potential for confusion might be exacerbated. If the central character remained the same, the only thing that changed was the situation (from a 'talking' situation to a 'listening' situation), and that was precisely what the focus should be.

The central character also remained the same throughout the emotional section, but a decision was taken to make this central character different from the one seen in the activities section. It was felt that after completing all 28 items within the activity section, the idea of rating would be established and that a change of character would not be intrusive. The central character for the emotions section therefore changed to be male. He remained white and older as this was the most representative of the majority client group with whom it would be used.

The introduction of the 'external influences' section brought the issue of inclusion even more sharply into focus with regard to the subject of race. In this new section, there were a number of questions that required the person completing the CDP to identify specific people within their social circle 'who helps?' and 'who makes it worse?' If the person completing the CDP was non-white, identifying members of his/her family from a white social group might be both unacceptable and confusing. For the external influences section 'who helps' or 'who hinders', the person rating *must* locate him/herself within the picture, to then identify people within her/his immediate social network. With other sections they can rate by using the scenario depicted as an exemplar rather than needing to locate themselves personally.

The decision was taken therefore to have three versions of this picture representing the three racial groups; social circles of people who were white, then another similar picture but where the people were black (Afro-Caribbean) and a third where the social circle were Asian (final pictures are shown on pages 44-46 of the appendix 4.3a).

The issues of race, gender, age and socio-economic background were at the forefront of our minds when vetting all the other pictures. On several occasions pictures were revised where situations might be made more inclusive. Queues and groups were presented to be multi-cultural and multi-racial.

Though all these changes make the pictures more inclusive than they were originally, the CDP remained located in a predominantly white Anglo-Saxon cultural context. This mono-cultural bias was seen as particularly distracting in relation to the pictures used for rating scales. The CDP (draft 1) utilised two rating scales (a one-stage rating scale used for ‘communication activities’ and ‘participation’ and a two stage rating scale for rating ‘emotional impact’). If the scales were to represent men, women, Asian, white and black racial backgrounds, with younger and older people all represented then there would be a need for 12 different scales. At the time of discussion, there was a perception that if the rating scales should be representative then so should the items themselves, therefore requiring 12 versions of the entire CDP. The decision *not* to have multiple rating scales to foster greater representation on the grounds of race, age and gender was logistical, practical and financial. The discussion also revolved around which racial groups should be represented and whether cultural issues should be explored. In light of all of these discussions, the task of making the CDP truly representative seemed impossible. It was felt that tokenism should be avoided. Therefore, at this stage, the decision was made to focus the representation of different racial background only to the areas where the respondent had to identify members of their family and social network (as discussed above).

Latterly however, after presenting the CDP (draft 2) within health care provider peer group meetings, the inadequacy of the rating scales was again highlighted. It was again stressed that it would be beneficial for the person to identify him/herself in the scales by having scales that were more inclusive. There is no necessary connection between the items and the scale. It was, therefore, possible to make the rating scales more representative without having to make multiple versions of the *entire* CDP. Extra funds had also become available and a set of 12 rating scales was produced that were more representative in terms of age, gender and race and can be seen in appendix 4.3a 59-71.

All the considerations described above have been presented separately. The complexity of introducing pictures into the CDP came from the reality that these issues were not considered in isolation. The advisory panel had to consider all these issues simultaneously.

Situations where the use of pictures interacted with other aspects of the development process to modify structure, concepts and wording of the tool will be discussed in the remainder of this chapter.

5.2 Modifications to the structure of the CDP

Modifications to the *structure* of the CDP were influenced primarily by comments and reflections made by the advisory panel. Table 5.2 compares the structures of CDP drafts 1 and 2. Table 5.3 demonstrates that the effect of these changes on the tool was considerable. The changes to structure will be discussed in the order in which the sections appear in the CDP.

5.2.1 Changes to the structure of the 'communication activity' section

The main changes to the structure of this section related firstly to which items were included, and secondly to the ordering of those items.

5.2.1.1 Item inclusion

Table 5.3 summarises the details of the changes between CDP drafts 1 and 2 with respect to item inclusion. New items were introduced as a consequence of a new 'expressing yourself' category. This category was introduced at the suggestion of the SLT user field trail group. There are people with aphasia who rely on various forms of non-verbal communication to supplement or replace speech. People who communicate better than they speak would be enabled to demonstrate this, and reveal potentially masked competence through using this new section. The section was also an attempt to validate the experience of those who use non-verbal means as the primary method of communicating.

5.2.1.2 Ordering of items

The hierarchical ordering of items within the communication activity sections originated from the DQ. It was informed by my clinical experience. I wanted to establish that the hierarchy was appropriate from the perspective of people who had aphasia. I took summary information about endorsement frequencies to the panel. These would be presented as a different source of information to inform the discussion relating to item order.

Endorsement frequencies are sets of figures that note the frequency with which a particular score (0-4 in the case of the CDP) is selected on administration. They reflect the popularity of a score within an item, and difficulty of an item. These figures had been calculated for DQ (draft 4) scores taken from 35 people with aphasia who had their stroke a year ago. The results can be seen in table 5.4. The results show that each response option for each item is selected at some point.

The advisory panel discussed the order in which items should appear, initially without seeing the endorsement frequencies. This discussion led to the following conclusions: the ordering of items for the reading and writing communication situations were acceptable to the panel. The panel felt that for both the ‘talking’ and the ‘understanding’ situations, the two extreme items were appropriately placed. However, they felt there was no ‘correct’ hierarchy for the other two intermediate items; for different people, different situations would present different challenges. Thus the hierarchy would vary from person to person, from time to time. At this point, the endorsement frequencies were presented to add to the debate. They were not presented as being ‘right’, but merely as another source of information.

The panel decided to order the items to correspond with the endorsement frequencies; the item that had the lowest mean frequency should be presented first, up through the items ending in the item with the highest mean rating being the final item in the section, for all communication situations. The endorsement frequencies confirmed their views of the hierarchy and offered clarity when they were undecided about the positioning of the intermediate items.

5.2.2 Changes to the structure of the participation section

On both a theoretical and clinical level, participation is seen as crucial to the investigation of the experience of living with a disability or illness. Issues that were raised in HRQoL, sociology and those promoting the social model of disability all advocate the primacy of considering participation when investigating perceptions of health. As has been discussed previously, the role *communication* plays in participation is significant. It enriches lives by its interactional dimension (Simmons-Mackie, 2000).

However, the participation section in the first draft of the CDP seemed inadequate. In CDP (draft 1) there was only one item relating to participation. ‘What’s that like on a day to day basis?’ was repeated four times, once in each ‘communication activity’ section. It was sandwiched between the ‘communication activities’ questions and the ‘anxiety’ question. This ordering was a suggestion from the SLT DQ user focus group.

It should be noted that the discussions in the advisory panel concerning this participation section were wide-ranging. The majority of the discussion related to concepts and situations associated with participation and how these could be categorised (this will be covered in section 5.4). Once the categorisation was decided on, there was debate on how to present and rate the items. The discussion concerning the structure of this section (in terms of item location) was subsumed within these discussions. Table 5.1 details the expansion of the participation section.

5.2.2.1 Ordering of items

Discussion of concepts relating to participation led to this domain being investigated using three items rather than one. As discussed before ‘What’s that like on a day to day basis?’ became

- ‘how is that for things you *want* to do’,
- ‘how is that for things you *have* to do’ and
- ‘how is that for *at home’*.

Each item was supported by a composite picture that depicted groups of situations or activities that would fall within the category described. So for example the picture to support ‘things you *have* to do’ showed pictures of situation relating to ‘work’, ‘money’, ‘health’, ‘transport’, ‘business’, ‘shopping’ with written labels below each one (see page 32 appendix 4.3a).

Discussion took place in the advisory panel about where these three new items should be placed. Option 1 was for the items to remain in the same place as in CDP (draft 1) i.e. following on from the ‘communication activity’ questions, and be repeated for each modality. Alternatively these questions could be asked *only once*, having asked all the ‘communication activity’ questions. The panel felt that presenting the participation questions after each communication activity would be unhelpfully repetitive. They also felt that it may well be difficult for people with aphasia to disentangle the separate effects of different modality impairments on something as cohesive and overarching as participation. Participation was given a separate section that followed after all the activities section had been completed.

5.2.2.2 Rating issues

At the same time as ordering of the participation items was being discussed, decisions relating to rating of these items were being made. Conceptual issues for this area will be discussed later in this section.

The first option for rating was to have one rating for each of the three items. The person with aphasia would give one rating in response to each of the three participation questions ('How are things you have to do?', 'how are the things you want to do?' and 'how are things at home?'). The process necessary to arrive at this rating was recognised by the panel as being complex and potentially unacceptable, as it required the person to summarise different areas of life into one rating (e.g. one rating to subsume perceptions across all six domains of 'things you have to do').

The alternative option was to produce a separate rating for each of the domains depicted. So in the example above 'things you have to do', would generate *six* ratings, one for 'work', 'money', 'health', 'transport', 'business', and 'shopping'. This was obviously a more straightforward process.

However, its perceived disadvantage was with regard to reliability and length. The components chosen to represent the items in the support pictures had been produced by me taking ideas to the advisory panel. The advisory panel had commented and extended some of these areas. The categories (e.g 'work', 'money', 'health', etc.) did not represent a recognised typology such as the WHO ICF nor a HRQoL instrument classification. I was wary of stating that all areas of life participation could be represented within the supported pictures. There was also an open-ended 'anything else' question included at the end of each of the three questions. Lastly the three items were not mutually exclusive, as 'at home' overlapped with many of the domains in the other two items. This felt acceptable if one rating was to be made (option one), with the support picture acting only as a reference to guide discussion and consolidate the concept of 'things you have to do'. If the components used in the support pictures were to be used as items in their own right (option two), then the use of an open-ended 'anything else' question raised concerns with regard to reliability. If the person with aphasia could bring one feature to the rating on one occasion, and a different feature on other occasions, as could be the case with open-ended items, then consistency of rating could be compromised. Additionally by having 6 ratings for each question the length of the tool would have been significantly increased. This was felt to be unfeasible. The decision was to adopt option one.

Thus participation was rated using three items ('have to', 'want to' and 'at home'), producing three ratings only and presented once only after presentation of all the 'communication activities' sections.

5.2.3 Changes to the structure of the external influences section

A significant change to the structure of the CDP was the inclusion of a new section that explored external influences on the impact of living with aphasia. In the CDP (draft 1) external influences were touched on by asking 'Are there any *other people or situations* that are difficult?'

Conceptual issues discussed in chapter 3 highlighted the significance of external influences beyond the individual. Comments made by some of the SLT user focus group had also suggested that the tool was too prescriptive, because it did not allow for these influences. Additionally, many of the individual interview respondents had discussed the influence of external factors on self-perception and participation in everyday life.

The aim of developing the new external influences section was to highlight (to both SLT and person with aphasia) the barriers and facilitators, external to the person, that affected the impact of the aphasia. Manipulation of these external influences could not take place without identifying and acknowledging what they were. Exploring these influences would also facilitate the process of creating understanding in the seemingly chaotic new world of life with aphasia. These issues will be returned to later.

After the user focus group, the researcher who had facilitated the user focus groups and I had discussed the changes that could be made as a result of the groups. Together we agreed that the exploration of external influences needed to be expanded. The sole question in CDP (draft 1) that tapped external influences needed to be broken down into its component parts, expanded to include facilitators, and a way found to explore each issue through the use of examplars.

The individual in-depth interviews were reviewed. Each person, or group of people, who had been interviewed had been asked about things that helped or hindered everyday life. The situations and people they described were collated and divided into groups that corresponded with the questions that had been identified as being relevant to this external influences section (see table 5.5). An abridged version of this information was taken to the advisory panel for discussion.

The decision reached by the advisory panel was that this expanded external influences section should follow on from the participation items, and should conceptually be part of the participation section. This was felt to be appropriate to ensure that the focus stayed on the *detail* of the individual's life and experiences of living with aphasia.

The panel ratified the expansion of the one original question into four ('WHO helps?', 'What THINGS help?', 'WHO makes it harder?' and finally 'WHAT makes it harder?'). The discussions about how this was done appear later.

There was discussion relating to rating of this external influences section. However, we were unable to see how this individualised information could be usefully and reliably rated. It was decided therefore that in contrast with the rest of the CDP, this section would not be rated. This section will be further discussed when referring to feedback given by the clinical usability field testers.

5.2.4 Changes to the structure of the emotional consequences section

There were two main changes to the structure of the emotional consequences section. The first related to the relocation of items. A list of 14 emotions was selected (conceptual issues relating to this area will be discussed in section 5.3). During the process of selection, the advisory panel grouped the items into those that explored issues relating to self image, those that dealt with emotional states and the remaining two looked at issues associated with satisfaction. The panel chose to subsume the self-image items into the newly reconfiguring emotions section. The order of the items can be seen in table 5.3.

The second change in structure related to the *presentation* of the emotional constructs through pictures (these changes are summarised in table 5.2). For the purpose of this discussion which focuses on structure and presentation, it is necessary to know only that fourteen emotions were selected, four of which were expressed positively, eight negatively and two neutrally (the description of the process is presented in section 5.3).

There were two options for how these pictures could be presented. Pictures could be presented singly (one emotion depicted per page), to be rated one after the other. The panel felt this would maximise accessibility but might feel prescriptive and potentially unacceptable; a list of mainly negative emotions being put up for rating in succession.

A second possibility was to put three of the emotional pictures on the same page (an example of which can be seen on page 54 appendix 4.3a). There was a suggestion to have two emotions which were negative expressions of the emotional construct and a third emotional construct expressed positively e.g. frustration, anger, determination. The person with aphasia would then be asked which of those emotions they felt represented how aphasia made them feel. They would then make a rating for that emotional state, choose another and then finally rate the remaining picture of the page.

Discussion took place over the relative merits of each possibility. The conclusion was to select the option that seemed to offer some degree of control for the person with aphasia, i.e. the three-picture presentation. The panel felt this method made fewer assumptions about emotions associated with having aphasia always being negative. They felt it enabled the person with aphasia to choose those emotions that were most pertinent to him/her, whilst still rating all emotions. They liked the fact that the three pictures together conveyed the message that emotions did not exist in isolation but were related.

However, it was acknowledged that though this three-per page presentation might be more acceptable to people with aphasia, it was not yet *accessible*. Appendix 5.19 shows that the presentation of the three pictures closely together was cluttered. Suggestions were made by the panel as to how to make the presentation less visually confusing. Circles were drawn around the pictures that framed and so separated them, facilitating clearer presentation. So when redrawn at the same time as the detail of each picture was changed, these suggestions were also incorporated (see appendix 4.3a page 53).

So a three-picture presentation, with each picture delineated by a circle was chosen as it was perceived as be being more acceptable and accessible.

This outcome was significant for the following reasons. The panel initially made the decision that the element of choice in this case had supremacy over accessibility, leading to the three-picture presentation being favoured. They then suggested ways to maximise accessibility for the procedure, having made their choice about the priorities for the presentation of the items in this section. Without this input I would have had great difficulty deciding which option to choose. The help given to me by the panel ensured that I had confidence in the manner of presentation for each emotional picture and the rating scales to be used. This area will be further discussed however, when considering feedback from the field testers.

5.3 Modifications to concepts

Table 5.3 highlights the changes made between drafts 1 and 2 of the CDP in relation to the modifications of the concepts underpinning the CDP. As with the changes to structure, different sources of information combined to inform how the modification of the concepts took place. Items were depicted and shown to the advisory panel. This often led to the realisation that concepts were ill-defined and needed revisiting. This reconsideration was influenced by examining ideas articulated during the interviews. I also contributed pertinent ideas from the literature to add to the discussion.

5.3.1 Modifications to concepts in the participation section

Discussion previously has highlighted that participation is, arguably, the most important domain in the whole tool. The inadequacy of the exploration of this domain has been highlighted. Modifications made to the structure of this section have been described. This section will examine changes based on conceptual considerations.

5.3.1.1 Item inclusion

As discussed the CDP (draft 1) explored participation through one question 'what's that like in everyday life for you?' The advisory panel needed to break this concept down into smaller more manageable and meaningful areas. The panel and I set about dividing participation in life into areas. As with all discussion within the advisory group, the starting point was for me to summarise and present options to the panel for discussion, in a form that was accessible.

I was aware of the WHO ICIDH-2 classification and did look at that as a possible typology for this participation section. However, I was unable to reduce the coding into manageable groupings that would be meaningful and accessible to the advisory group. This was mainly because the typology used *combines* activities and participation.

We began the discussion with a summary of situations affected by aphasia that had been identified through the in-depth interviews. The exemplars that appear in the qualitative interviews are shown in appendix 5.20. We brainstormed how aphasia affected people on a daily basis, using the information obtained from the interviews as a guide. With the resultant list of activities, situations, roles and emotions, we then deleted those already covered by items from other sections of the CDP, and set about categorising the remaining areas. This was a complex process.

The section was complex for several reasons. We were attempting to develop a way of rating the impact of aphasia on people's daily lives. We were also considering the information provided by the interviews. The following questions, paraphrased and asked of the panel, show the complexities that needed to be tackled.

- (as discussed) Should participation be divided into modalities i.e. should there be a participation item after each set of communication activity questions or should participation be a section in its own right?
- Should life domains be divided on the basis of activities, roles, situations or emotions (for example should 'how talking/aphasia affects being a mother' come within a 'role' section, a 'children' section, a 'relationship' section, or an 'at home' section?)?
- Do the sections need to be mutually exclusive?
- Was it acceptable to 'pre-select' items relevant to living with aphasia, or were people's life circumstances so individual that pre-selection would be too prescriptive?
- Could we incorporate open questions (e.g. what else gets in the way?) to reduce the prescriptive nature of the section? How would this section be rated?
- How would open questions be rated?
- Was rating going to be possible at all?

The conclusions from discussions around these sorts of questions and issues were as follows:

1. There was to be only one participation section, not one for each modality.
2. It would be divided into 3 categories; 'things you want to do', 'things you have to do' and 'at home'.
3. Within each of these categories, domains would be specified. They would be predetermined (and, some might argue, prescriptive) but general enough to be as inclusive as possible. The domains within each category were selected with reference to the in-depth interviews. Individual interviews were particularly influential in domains that needed to be included. They established that the CDP already tapped many of the areas raised by people with aphasia as being relevant or significant to them in their daily lives. However, as can be seen from appendix 5.21 (participation section) and 5.22, there were areas that the panel felt had been missed that were of significance. Before the introduction of this participation section, none of the exemplars listed under the participation headings were specifically investigated in the CDP. The domains investigated

within each item can be seen in appendices 5.6, 5.7 and 5.8.

The participation categories were not mutually exclusive, as certain activities that someone would want or have to do would take place at home. However, it was agreed that this was a meaningful and accessible typology. The panel strongly advocated for the 'at home' category to remain despite the overlap its inclusion caused. They felt that home was so fundamental to living with aphasia that it necessitated a category in its own right.

4. Each category would be rated, rather than attempting to rate each domain (i.e. one rating for 'how are things you want to do' rather than six (hobbies, clubs, holidays etc.)).
5. A further set of items investigated external influences (what things/people help or hinder participation) would follow the participation items. This set of external influence items would not be rated. Details of the external influences section will be discussed later.

When discussing 'things you want to do' there was much debate around whether to include things *not* likely to be affected by aphasia. Gardening and art were brought into the discussion as examples of things people often take up after acquiring aphasia precisely because they are activities that are less language-dependent. However, discussion clarified the fact that the main purpose of the CDP was to enable people with aphasia to change things that were problematic. Space and time were limited. If attention was paid to things that were relatively easy for people with aphasia to access and participate in, areas that were less accessible might be overlooked and missed in terms of therapy planning or addressing barriers in external agencies.

The novelty of this section, (and perhaps why it was so complex to develop), lies in the fact that though using predetermined categories, and mostly closed questions, it allows the person with aphasia to bring to the assessment the areas of life they are personally relevant.

5.3.1.2 Rating issues

Having redefined the typology and items to be included in the participation section, and realising that external influences were to be separate, the one stage rating scale used for the activities section and shown in appendix 4.3a pages 59-71 was decided on as being suitable for this section also.

5.3.2 Modifications to concepts in the external influences section

One aim of this 'external influences' section was to raise awareness of people with aphasia and the SLT, of the barriers and facilitators external to the person that affected the impact of the aphasia for that person. Through this awareness they could identify what needed to change, to enhance participation as they would like it. Examples of such therapy might include conversation partner training, or altering the physical environment in which people communicated, education of workers in shops frequented by the person with aphasia. As Bury (1991) suggests without knowledge of the things that influence the internal and external environment, development of 'coping strategies' is compromised. People are unable to weigh up alternative forms of action if the options of which strategy to employ are unknown.

As has been mentioned when the structure of this section was considered, the original one question within the CDP (draft 1) was expanded using the individual in-depth interviews as a guide on how the domains could be categorised. The acceptability of the actual items themselves was discussed. Which barriers and facilitators should be included?

As an example, the item 'speaking books' will be discussed. This item was included under 'things that help your reading?' This item had originated from other people with aphasia being asked 'what is it that helps your reading?' during interviews. The controversy centred on the fact that speaking books didn't *help* reading, they bypassed it. Initially the panel did not want to include this item. The origin of the item was reiterated, and the purposes of the section (identifying facilitators, raising awareness, validating 'self-with-aphasia' (useful strategies being part of that)). After discussion it was decided to include it.

5.3.3 Modifications to concepts in the emotional consequences section

Reviewing the literature had confirmed that many of the emotions included in the CDP were reported elsewhere as being experienced by someone soon after having a stroke and finding they have aphasia. Parr et al (1997) for example mention helplessness, anxiety, uncertainty, confusion, fear, anger, frustration, sense of loss and isolation. Simmons-Mackie (2000) and Brumfitt (1999) talk of stigma and feelings of low self worth being associated with aphasia.

The emotional impact of the aphasia needs to be explored in a systematic, accessible yet sensitive fashion. As with other sections within the CDP, comments that had originating from the DQ field trial user focus groups, and were supplemented with suggestions gleaned from the qualitative interviews, formed the basis for discussion with the advisory panel. The focus groups had highlighted a number of areas for deliberation: the items selected needed to be validated further with subtleties of meaning being considered (when discussing *which* items to include and *how* they should be depicted), the section had been criticised by the SLT focus group for being negative, and the method of rating needed scrutinizing.

5.3.3.1 Item inclusion

As with the participation section, a brainstorming activity took place around the current CDP items and the additional emotions suggested within in-depth interviews. During this activity other emotional constructs were suggested including fear, pride, embarrassment, determination, dependence, energy/fatigue, clarity/confusion, respect/being valued, certainty/uncertainty, loss and spontaneity. As can be seen from the list, many of the emotions are very close in meaning (certainty/clarity, respect/being valued, pride/respect, and embarrassment/confusion). Discussion focused on clarifying what each one meant, examples of what might engender each and their relative significance. The final set of emotional constructs from which to select are shown in table 5.6.

The emotions fell broadly into two areas; emotional states that emerge immediately in situations of communication breakdown (termed 'emotional states'), and secondly the feelings of loss and threat to self image as a consequence of those breakdowns and the repeated experience of communication breakdown and social exclusion (termed 'self image').

For practical reasons, the panel were asked to select 14 emotions from the list shown in table 5.6. Whether these were to be expressed and presented in the negative or positive will be discussed in next section. The panel selected those they felt should be considered for inclusion in the CDP.

An illustration of how the emotional constructs were modified by the advisory panel will be exemplified by detailing the process of talking about the item 'do you ever feel a bit stupid'. The reason for its inclusion in the DQ originally was to enable expression of the fact that competence might in some ways be being masked by the presence of aphasia. There was never a suggestion that someone with aphasia was stupid, nor did anyone signal that there had been any evidence that had been taken as such during the DQ user field testing. Comments from the SLT focus group demonstrated that different SLTs held different views about this concept; "asking that one made me feel uncomfortable", "easy to ask about stupidity, concrete gave them the opportunity to say "I'm not thick"". Interestingly, none of the people with aphasia mentioned this item as being problematic despite attempts to elicit this reaction from the interviewer during the DQ user focus group. However, as SLTs had raised it as being potentially problematic, it was discussed with the advisory panel.

The advisory group agreed that the concept was important. When discussing the wording it became clear that the *concept* of stupidity itself was not necessarily the one that the group felt was most pertinent. Discussion took place around what its opposite would be, around the similarity and differences between stupidity/sense, competence/incompetence, inability/ability and finally the *consequences* of being perceived as being stupid or incompetent; embarrassment and shame versus being perceived as self assured, able, or proud. It was noted that one could be embarrassed for reasons other than having being perceived as stupid or incompetent. A decision was taken to include the positive pole of competence, 'able', along with the consequential emotion of being perceived as being stupid or incompetent; 'embarrassed'.

So through discussion such as these emotional constructs were clarified and modified. The panel then choose which they felt should be included in the CDP draft 2. The final choice is shown in italics within table 5.6.

5.3.3.2 Negativity of items

A second conceptual issue for this emotional section was whether these chosen items were expressed positively or negatively. The assumption that aphasia is a negative experience was prominent in the original tool. The DQ was conceived within the medical model. One of the assumptions made about disability in this framework is the inevitable negative influence of disability on a person's life. As Morris (1992) reports, a lack of disability is treated as both a positive, and the universal experience; while the experience of disability represents only the negative, defined by limiting criteria. Phillips (1990) elucidates further suggesting that negative words and images not only reflect but also reinforce condescending attitudes towards disabled persons. Such words and images effectively penetrate the cultural consciousness, predicting social interactions.

If this negative attitude extends to the health care provider further harm can be done. Jordan & Kaiser (1996) suggest that if SLTs hold a negative attitude to disability it impedes the potential of the person with aphasia to take more control over their response to the consequences of the stroke on their life.

From a psychometric perspective, Streiner & Norman (1995) point out that

> "as a general rule, scale developers should avoid negatively worded items. Such items tend to have lower validity coefficients than positively worded ones (Holden et al 1985)" (p57).

So for a variety of reasons, negativity in wording or premise was to be avoided where possible, to make the tool more acceptable and more robust.

This section had been singled out by the DQ user focus group of SLTs as being disproportionately negative. They had suggested having positive expressions of emotions alongside the negative ones. The negativity of the section had to be addressed with the panel.

I discussed both the reservations of the SLT focus groups, and the literature on disability politics (elements of which were familiar to some in the group already) with the advisory panel. Despite these concerns the panel advised me that, in line with the perceptions and experiences of the respondents in the qualitative interviews, the overwhelming emotional tone associated with living with aphasia *was* negative, particularly in the early days. The panel wished the majority of constructs to be expressed negatively, as they felt to do otherwise was to deny the reality of the situation.

As a consequence, when selecting the final items, 14 emotional constructs were to be chosen; 6 for self image, 6 for emotional state, one third were worded positively and two thirds were worded to represent that negative aspect of the emotional construct. The final two emotional constructs related to states of satisfaction and were worded neutrally.

5.3.3.3 Rating issues

There was parallel discussion about how to rate these emotional constructs. Emotional states do not lend themselves easily to being described along one dimension. They can be described in terms of intensity (for example feeling very angry or a little angry) and/or in terms of frequency (for example feeling angry all the time or never).

When piloting the original version of the DQ (draft 1), a number of people with aphasia had expressed dissatisfaction with having to rate on one-dimension (based on intensity of emotion - a lot, a little, none). The scale had been changed to incorporate the two-phase/two-dimensional rating system that included the temporal aspect (all the time, sometimes or never). Using a two-stage system, acceptability to the users appeared to be greatly increased; the two-stage rating system had been used successfully with subsequent iterations of the tool throughout the rest of stage 1.

However, both DQ user focus groups expressed dissatisfaction with using so many scales (at that point the DQ had three different scales; one for ‘communication activities’, one for ‘participation’ and one for ‘emotions’). Certainly the simple one-dimensional rating scale appeared more accessible at first glance. It is also the most commonly used means of rating in other scales.

This background and these competing issues were discussed with the panel with a view to discussing whether a one or two-stage rating system should be used to rate the emotions section. The decision was made to keep the two-dimensional scale but again make the procedure as accessible as possible, by having clear pictures and precise wording (the scales used for this two-stage rating can be on page 72 & 73 appendix 4.3a). This decision was revisited after feedback from clinical usability field testers.

Alongside these discussions came consideration of how to translate the pictorial output mode into numerical values for the positively worded items. The suggestion was made to simply reverse the rating. Usefully there are precedents for this in the literature. Barker (1990) for example when assessing the validity of a patient satisfaction measure in general practice suggests, “In scoring replies, the one to five scale was reversed when appropriate” (p488). Reversed scoring was therefore adopted.

5.4 Modifications to wording

Whenever pictures were presented to the advisory panel for consideration, the words accompanying them to frame the question would also be presented.

5.4.1 Issues of accessibility and acceptability of wording

Given that our aim was to make the CDP as inclusive as possible, we wanted the language used to be as accessible as possible, for as many people with aphasia as possible. Making language accessible to people with aphasia is not always easy. Understanding the factors that increase accessibility of language for people with aphasia, will contribute to appreciating why certain choices were made with respect to development of the CDP.

People with aphasia, more than those without, often benefit from language that is structured in a simple, though not simplistic, way. It may be helpful to keep words and phrases short, with repetition of task procedure often being an advantage. If the words used are high frequency, concrete words, within simple linguistic structures (be that spoken or written or both), supported with pictures, this will usually facilitate better comprehension for people with aphasia (Nickels & Howard, 1995). People with aphasia can find pointing an easy response mode, as it bypasses the need for speech.

All the panel members contributed to discussions on wording as pictures were presented. However, I felt that the person who found verbal comprehension most challenging, John, might be best placed to advice me on this aspect of the questionnaire design. The social relations of this interchange are discussed in chapter 6. I set up separate groups with John alone to discuss options for wording. The options were presented in both written and spoken form. He was asked to give his opinion of wording options such as ‘How is talking *day to day?’* versus ‘How is talking in your *daily life?’* versus ‘How is talking in your *everyday life?’* or ‘Competent’ versus ‘Know what you are doing’ versus ‘Able’. Once decisions had been made by John, the preferred option was shown to the other panel members for ratification. They always concurred.

Discussions about wording often led to discussions about conceptual and practical issues that lay behind the selection of an item. One example of this was in the use of the ‘aphasia’. Several items in the DQ refer to ‘communication difficulties’. The advisory panel were unanimous in their dislike of the term ‘communication’. It was seen as inaccessible because of its length, complexity and potential for referring to other things (like telephonic communications). The panel immediately suggested ‘your aphasia’ as an alternative. I reflected back that in contrast to the panel, many people for whom the CDP was intended may never have heard the term ‘aphasia’, nor would they have a sense of ‘having aphasia’. The term would be meaningless to them and as such potentially make those items that included it inaccessible; they would essentially contain a nonexistent word for many people who had recently acquired aphasia.

After much discussion, we concluded that ‘aphasia’ should be the wording used. The word and concept would be introduced at the beginning of the tool, with pictures to support what it was (Appendix 4.3a page 2). Whenever it was next mentioned the same pictures would be shown reminding the person with aphasia that the things that might be restricting them, were the impairment ‘aphasia’. The panel’s motivation was as follows; firstly ‘naming the demon’ was a useful process (this was a phrase used by one of the panel members), secondly giving a name to the condition suggested that it was recognised, legitimate, and that there were others who had similar experiences; the advantages of including people in the collective body of people who have aphasia and of demystifying the condition, outweighed the potential for less transparency of meaning and that introduced the term began raising awareness of ‘a self-with-aphasia’ identity; and finally the pictures would aid comprehension (the panel then came up with suggestions about how to present this concept in an accessible, acceptable way and this is exemplified by referring to page 2 of appendix 4.3a).

5.4.2 Issues of negativity of wording

As has been discussed there was an effort to avoid the assumption of negativity. Efforts in all areas were made to phrase questions in a neutral or positive way where possible.

An example where debate enabled negativity to be reduced was one of the exemplars used in the external influences section, that of 'help cards'. Several people who had been interviewed in depth mentioned how communication improved if they told people about their aphasia. They specifically mentioned showing a card such as a Speakability[2] or Stroke Association card that gives a brief written description of aphasia, stroke and ways to facilitate conversation. This idea was incorporated into the 'facilitator' exemplars of the external influences section using the word 'help card' and a picture. The discussion in the advisory panel suggested that the word 'help card' denoted helplessness, dependence, and a searching for sympathy, 'please look after this bear' was the phrase used by one panel member. After discussion about why these cards helped, confirming that letting people know about aphasia often helped a situation, the wording was changed to include a broadened and positive definition of 'telling people'.

5.4.3 Issues of reliability

When wording the sentence that would accompany each emotion item, however, there were occasions where altering the wording to make it accessible and reduce negativity, put reliability in jeopardy. The panel saw the CDP (draft 1) wording as negative and overly complicated (e.g. 'since your stroke does your communication make you angry?')

An obvious solution seemed to be to keep the wording simple and make no reference (other than in the introduction of the emotions section) to aphasia (e.g. 'do you feel frustrated' or 'are you worried'). The problem with these accessible sentences

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[2] *Speakability is UK based charity for people with aphasia formerly known as Action for Dysphasic Adults (ADA). It aims to provide support through information services, promote self-empowerment through networks of self-help groups, campaign for better services, greater recognition of the needs of people with aphasia and provides training and support to professionals working with people with aphasia.*

is that they do not refer to aphasia at all and therefore are not exclusive to the experience of living with aphasia. One can be angry, unhappy, determined, isolated, valued for many reasons (including as a consequence of stroke more generally), whether you have aphasia or not. With the issue of reliability in mind I raised the question of needing to marry the emotion with the experience of living with aphasia.

The example of 'being able' highlights the point. If the question was the accessible version 'do you feel able?' the person completing the test might rate this with reference to his experience of making a successful phone call, difficulties writing a letter to the bank, or talking to a stranger for example. He might also rate it with reference to his experience as a person with a hemiplegia being unable to get up stairs or carry his child. More worryingly in terms of reliability, on one occasion he might rate it from his experiences of having aphasia and on a subsequent occasion rate his experience with reference to living with a hemiplegia. One of the cornerstones of reliability and 'test construction' is the clarity of the question – that there is no confusion about what the item refers to. Without marrying the emotion with the aphasia this could not be guaranteed. This point was discussed.

The conclusion was to link emotion to impairment to ensure maximum reliability but to alter the wording to 'living with aphasia' rather than 'because of aphasia' which felt some way distant from the impairment itself. The tensions between measurement and inclusive practice highlighted by this example are further discussed in 5.7. Further changes took place as a result of field testing.

RESULTS AND OUTCOMES OF STAGE 4

5.5 Clinical usability field testing results

Discussion so far in this chapter has focused on the efforts made to ensure the CDP was acceptable to people with aphasia. Changes to facilitate this goal have been documented. The final stage of the development process was to return the CDP to SLTs to test for clinical utility. Despite the rigorous efforts documented so far, if the CDP did not find favour with SLTs it would not be used, and its part in the goal of social model practice could not be realised.

The methods used for this stage have been described in chapter 4. Table 5.7 shows sampling characteristics of those involved in the clinical usability field study. The only major omission was that of a male SLT. Table 5.8 shows the characteristics of the people with whom the CDP was administered. This group appears to be reasonably representative of the British population of people with aphasia being weighted towards people over 50, with most being over 60. They come predominantly from a white British background though people from other racial backgrounds are represented. Men and women are equally represented.

Tables 5.9 and 5.10 describe the experience of both sets of users in the clinical usability study. From the perspective of the people with aphasia (shown in table 5.9) the experience was positive for the majority with people. Most of those who commented suggested that they found the pictures engaging and relevant. A significant number wanted to explore the areas raised in even more depth. People welcomed what was seen as a fresh, holistic approach that centred on their views and perspectives.

From the perspective of the SLT users (summary in table 5.10), the experience of administering the CDP was felt to be appropriate and useful for the majority of respondents. Content was felt to be appropriate for most clinical situations, though field testers were sceptical about its use in some acute settings. The majority of SLTs felt the CDP was easy to use, though there were a number of suggestions for how it could be improved (these suggestions are catalogued in table 5.11). Those who had only been able to administer the CDP on one occasion were less positive than those who had used it repeatedly, and (in their eyes) become accustomed to its format and style.

A summary of the comments made by the field testers was taken back to the advisory panel (see appendices 5.23 and 5.24). The suggestions for improvement were also taken to the advisory panel. Appendix 5.25 gives an example of how these ideas were presented to the panel for discussion. A similar consultation process with the same panel members was undertaken to consider the suggestions made by the field testers, and decisions were made about the CDP (draft 3).

The most noteworthy conclusions were the revisiting of issues relating to how the emotional pictures should be depicted, and the rating of the participation section. The details of which are documented in table 5.12. As can be seen these represented a reversal of previous decisions made by the advisory panel. The panel felt that the strength of feeling exhibited by both person with aphasia and SLT field testers demanded that our previous decisions be scrutinised. For the most part changes then occurred. One occasion when this did not happen was with the emotional rating section. Though a second rating scale was commissioned that is intended to be simpler, the other source of complexity (the three-picture-per-page presentation of the emotions) was not changed. Discussion around this point was vociferous and lengthy. The alternative was to present each emotion singly on one page, one after another. However, ultimately the panel decided that the advantages of the three-picture-per-page presentation outweighed what was lost in terms of accessibility. The panel felt strongly that this method of presentation conveyed that emotions co-existed and could not be considered in isolation from one another. They felt that it gave the person with aphasia some degree of choice within this section, and that this was important given that this section was taxing (emotionally and logistically).

A further example of where suggestions from the field testers were not ratified by the advisory panel was that of whether to amend the CDP to increase its accessibility for people in the acute medical setting. Several SLTs had deliberately chosen not to use it in this setting. Others had and had found areas (particularly the participation section) inappropriate. A suggestion was made to add three extra participation pictures that would be designed to be used in the acute setting.

It would be possible to produce three participation pictures that could be used within this setting (for 'things you have to do' there may be pictures of completing menu cards, calling the nurse, coping with self care for example). We all agreed that the use of the CDP with people who had recently acquired aphasia was NOT appropriate (reasons for this will be explored when considering how to introduce the CDP into clinical practice). Field testing had shown that the level of reflection and flexibility with which the CDP was used by SLTs varied enormously. It also demonstrated that despite having been trained in the use of CDP and having detailed written instructions, SLTs did not always use it in the way it was intended. Though there were advantages to having a version that could be used with people in hospital (particularly for those who had moved on from this initial stage but for other reasons remained in hospital for protracted lengths of time). Despite this, the panel agreed that the potential for abusive use of the CDP with someone in this difficult stage was too high. It was felt that including a picture may signal to SLTs that use in a hospital setting was *expected*. The decision not to amend it for the acute setting was therefore taken. Discussion about how this issue could be addressed will take place later when considering how the CDP should be introduced to clinical practice.

So the field testing led to modifications of the CDP (draft 2) into the CDP (draft 3). The pictures that will form the final version are currently being drawn, the pre-final score sheet can be seen in appendix 5.26. The field testing confirmed the advantages and limitations of the CDP. These will now be discussed in detail.

5.6 Advantages of the CDP

The resultant CDP is qualitatively different from what has gone before in measuring the effect of acquiring and living with aphasia. The innovation stems from several sources, which have been highlighted during the field testing. (It should be noted that the people with aphasia who took part in the field testing were not *specifically* asked to comment on their perceptions of the CDP as involvement of the advisory group had sought views of people with aphasia directly. Therefore the reporting of this phase of the process is weighted towards comments made by the SLTs. The feedback sheets did however, encourage the SLTs to summarize the opinions of the person with aphasia).

5.6.1 The primacy of the perspective of the person with aphasia

Many authors have noted the importance of listening to the client's perspective (Simmons-Mackie, 2000). She suggests the process of aphasia management should start with the respectful consideration of the individual and family's social and communicative perspective, then work to building communication and quality of life within that perspective. The CDP offers domains of experience to facilitate the 'respectful consideration' that Simmons-Mackie mentioned. It is wholly focused on the views and experiences of the person with aphasia.

The CDP, through the participatory methods used in its development, ensures that the concepts presented are those that are likely to be relevant to the person with aphasia. Table 5.13 demonstrates that many of the changes to the CDP are directly attributable to the contribution of people with aphasia, ensuring that the tool will focus on the areas that are likely to be most relevant to them. The person with aphasia has an opinion, which is treated as fact and valued. The person with aphasia becomes the expert. Field testers commented on the novelty and utility of this.

> *"Felt it really focussed on her as a person and overtly respected her point of view"*
>
> *"useful to get an immediate and emphatic reaction. Shows you what is really important"*
>
> *"so much better to have information about what helps and hinders directly from him (person with aphasia)"*
>
> *"Identified several issues that were not previously recognised by the SLT to be important for client (therefore very beneficial)"*

5.6.2 The accessibility and acceptability of the CDP

The CDP has been designed to be maximally accessible. Efforts have been made to ensure that people with aphasia can understand the items presented and that they can express their views easily despite their impairment.

Equally, the CDP has been developed to ensure that the items presented are meaningful. Items focus on social participation including the identification of external influences, areas often neglected from assessment within aphasiology. Comments made by people with aphasia involved in clinical usability testing reported confirm this has been achieved for the most part

> *"Identified with the emotions illustrated"*
>
> *"Content good and relevant as shown by strong reaction to some of the pictures and questions"*
>
> *"Content was relevant"*
>
> *"Wanted to rate each of the participation areas"*
>
> *"Put (us) on the right track "*

There were, however, situations and people for whom the CDP proved less successful. The CDP has not been designed to be directly relevant to people when they are in the early stages of acquiring aphasia nor for when people are in acute medical setting. These were the situations where field testers experienced unease.

The overall levels of acceptability and accessibility have been achieved as a result of the participatory research methods used, ensuring that the CDP would become an 'enabled instrument'. The research method used was unusual. Very few measures in speech and language therapy have used such an inclusive approach. Even Le Dorze & Brassard (1995) in their seminal paper reporting on the consequences of living with aphasia did not include people with aphasia in the design of the questionnaire. They propose that researcher-designed problems may not be very real for the person with aphasia and spouses, because the experience of aphasia from the point of view of those affected differs from the ones researchers can imagine when designing questionnaires. This area will be discussed further in the final chapter.

5.6.3 Challenging traditional relations and roles within the therapeutic context

Assessment and therapy for a communication disability that has been acquired, can be disempowering for an individual. Woolley (1994) describes how newly deafened people can experience feelings of incompetence as a result of opinion and action of the healthcare provider. She highlights how a newly deafened person in the early stages can feel that everyone knows more about deafness than the person experiencing it does, that there is the potential to feel dependent on professionals and other hearing people.

The CDP, in contrast, validates the experiences of the person with aphasia, and facilitates them to make choices about their future in the therapeutic context. Its central assumption is that the person with aphasia is the expert. The SLT's role when using the CDP is seen as different from traditional assessment of aphasia. The SLT is there to facilitate, glean knowledge relating to the impact of acquiring and living with aphasia, and then to offer suggestions for the way forward for the person with aphasia. Jordan & Kaiser (1996) discuss social model practice when working with people who live with aphasia. They underline the *mutual* expertise that each party has to offer, and the changes that need to be made to facilitate change within the power relations of therapy.

> "By virtue of their technical knowledge, aphasia therapists offer people their best chance to maximise both language and other communication skills…in many instances it is not the *content* of the services that would need to change with the adoption of the social model, as the *relationship* between the service provider and the aphasic person" (p145)

The dynamics of this partnership should continue throughout therapy, with the SLT making their skills and resources available to ensure that therapy confirms and develops the competence, confident identity and behaviour of the person with aphasia. Some of the field testers show evidence of beginning this process through having used the CDP

> *"the CDP enabled him to be more assertive in expressing his views. We couldn't have covered the ground without this format/these pictures"*
>
> *"Gave me specific ideas re; advice to family based on HIS experiences rather than my viewpoint as a therapist"*
>
> *"Recognising that what you see as a clinician to be the area of difficulty may not be what is important for this person"*
>
> *"Someone's perceptions of their skills can be very different to their actual skills"*

5.6.4 Validating and comprehending the experience of having aphasia

People with aphasia can have positive attitudes towards living with aphasia, and it appears that for some people the CDP enabled them to reflect on, and express this.

> *"Don't know how much he had articulated or reflected on the positives before. This was a good opportunity"*
>
> *"Says life has never been better, people give him more time and he sees the*

> *good side of human nature"*
>
> *"Says feels more valued with aphasia"*

Though one can have aphasia and have a positive life, for many people who acquire and live with aphasia, it can have enormous negative consequences. People with aphasia may have held negative attitudes to disability, as such attitudes are commonly held within society. Finding themselves with a disability of any kind can therefore be challenging on top of any restriction they may experience as a result of living with language loss.

The process of administering the CDP seeks to validate both positive and negative experiences for the person with aphasia. Woolley (1994) suggests that if a loss (due to acquired communication disability) is fully expressed, the necessary grieving period can be relatively short and the person can more rapidly adjust to the changes in her/his life. S/he can meet the changes as a stronger and more confident person than if s/he were still suppressing the initial trauma. People with aphasia seem to concur.

> *"She liked the fact that it addressed areas of her life that weren't usually addressed"*

It is clear however that therapists had differing views on how comfortable they were with this area of work, possibly for legitimate reasons of a lack of time available, training, knowledge or skill.

> *"Opens up several other issues for client that SLT not necessarily able to deal with"*
>
> *"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"*

The CDP encourages people with aphasia to understand their aphasia and reflect on it. Brumfitt (1999) suggests a process of reflection gives people the opportunity to make changes to their own attitudes. She concludes that attitude change is facilitated if based on that information being personally meaningful and easy to understand, and suggests therefore that understanding and remembering the information is critical. The CDP begins this process of reflection, comprehension and identity formation.

> *"Helped to bring out the positives and for the person to reflect on them"*
>
> *"Participation section was really important section for him"*
>
> *"Identified with the emotions illustrated"*

> *"Rated situations that he hadn't tried but could anticipate how he would manage"*

5.6.5 Rating impact of aphasia

Clinical usability results suggest that the CDP enables SLTs to explore and rate the impact of acquiring and living with aphasia in a systematic fashion. As has been discussed the impact of aphasia has been acknowledged, with much work done, within therapy to reduce the impact. However, there has not been a tool that enables the impact to be measured before. The advantages of measurement in this context have been rehearsed previously. Field testers appreciated that this was useful for feeding back progress in a concrete form

> *"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"*

5.6.6 Guiding therapy

Many field testers suggested the CDP guided their future management for the people with whom it was administered.

> *"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"*
>
> *"He expressed an interest in working on writing which he had not articulated before despite me knowing him well over a long period of time"*
>
> *"Definitely useful in the community setting to highlight areas which client themselves was concerned about/wanted to work on"*
>
> *"It was a gentleman I know quite well but there were still a few surprises"*

The CDP does not dictate what type of therapy should be offered. It highlights where there are barriers to participation for the individual. It leaves how these barriers are to be reduced, removed or avoided to the SLT and person with aphasia to negotiate. Impairment-based therapy, for example, is seen as a potential avenue leading from the CDP, to eliminate a particular barrier by reducing a specific aspect of impairment (this will be discussed further in chapter 6).

Equally, there will be instances where impairment-based work is not the best way forward. Focusing on impairment may merely confirm a person's feelings of altered competence. It may be that concentration on aspects of interaction with the communication or the social environment will effect more immediate and relevant change.

> *"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"*
>
> *"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"*

The partnership of the SLT and the person with aphasia can negotiate the best way forward. Conrad (1990) discusses the notion of illness as work. He highlights areas that he feels are potential candidates to be worked on. These include addressing uncertainty, stigma, work on biography and reconstruction of self, managing regimens, the role of information, awareness and sharing, family relationships. The CDP is a way of beginning the process and represents a means of opening up the dialogue to enable this type of 'work' to begin.

> *"Recognising that what you see as a clinician to be the area of difficulty may not be what is important for this person"*
>
> *"Identified several issues that were not previously recognised by the SLT to be important for client (therefore very beneficial)"*
>
> *"Gave me specific ideas re; advice to family based on HIS experiences rather than my viewpoint as a therapist"*

5.6.7 Encouraging reflective practice

The CDP represents a break with traditional assessment in aphasia. It is designed to measure, as many traditional tools are, but in contrast to conventional measures its focus is centrally on the wider context of the person with aphasia and his or her life. This broader outlook encourages therapists to reflect on previous practice and examine the relevance of their current practice. There was evidence of reflection from some of the field testers.

> *"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"*

5.7 Limitations of the CDP

Though many SLTs and person with aphasia involved in the field testing were positive about the CDP this was not universal and it is confirmed that the CDP is not without its problems. These fall broadly into two categories; practical and epistemological.

On the practical side the CDP is long. It continues to be mono-cultural and mono-racial. The CDP's psychometric qualities are as yet unknown. Finally, it remains inaccessible to people who have significant comprehension impairment.

In terms of the theory behind the method and knowledge, there are issues relating to how much of someone's life SLTs should be exploring, the degree to which any measure can truly reflect constructs akin to satisfaction, the tension between being precise and specifying situations and being over-prescriptive and finally the lack of relative or carer information in the equation.

5.7.1 Length issues

The CDP had its conceptual roots in the DQ, a screening instrument whose focus was more firmly on measurement alone. The DQ was necessarily brief. The use of participatory methods highlighted large gaps in the DQ. Addressing these omissions and expansion of the remit of the tool has led to an increase in the length of the tool. The tool therefore is now no longer brief or superficial. It explores *in detail* aspects of how the person with aphasia perceives her/his life with aphasia. Though the enumeration through selection of a score is important, the content of the minutiae informs how the therapeutic dialogue would continue. MacDuff (2000), when reviewing the SEIQoL (O'Boyle et al, 1992), commented on the length and complexity of the administration of this tool, pointing to a new version that reduced the administration time to 5-10 minutes. He says that

> "Testing the two version in healthy populations, Browne et al (1997) found that the new version proved stable and valid but concluded that it should not be preferred over the old one, *if time is available*" (p379). (italics added)

The length of the CDP is akin to an in-depth interview rather than a screening procedure, though it has the advantage of not requiring the time consuming analysis required for in-depth interviews. Many studies have successfully carried out research using guided or indeed unstructured in-depth interviewing of people who have aphasia (Parr, 1994 and LeDorze & Brassard, 1995). Though these examples are taken from research situations, it does demonstrates that lengthy procedures for people with aphasia are possible and not necessarily to be avoided.

The length of time taken to complete assessments within SLT varies. Language screening tests such as the FAST are similarly designed to be brief. However, most SLT measures are not usually so concise. Functional communication assessments reviewed by Crockford & Lesser (1994) varied from 30 minutes using the CETI (which they report as being of limited value for planning appropriate intervention), to 90 minutes for the ANELT and 120-185 minutes for conversation analysis. Standardised measures of linguistic impairment, with people who have aphasia, often take well over an hour to administer, and when assessing using the PALPA, testing routinely extends over many sessions.

The length of time seems to be related to the level of detail of investigation. This in turn is related to the purpose of the assessment. If the purpose of measurement is simply to document a state of being (presence/absence of aphasia as in screening tests) then the duration will be short. If however, the information is to be used to understand the nature of the situation, and plan intervention, the level of detail needed is greater as is the time taken to obtain this information.

As has been mentioned, a method of reducing the length of questionnaires, one favoured by psychometricians is to delete all items that are universally (or very frequently) selected. As Streiner and Norman (1995) say

> "Since we can predict what the answer will be with greater than 95 percent accuracy, we learn very little by knowing how a person actually responded. Such questions do not improve a scale's psychometric qualities, and may actually detract from them by making the test longer" (p59).

There are a number of these in the CDP (talking under pressure, understanding in a group, reading a newspaper) repeatedly score highly. Does this make them 'redundant' items? If the purposes of the CDP are borne in mind, then the answer must be 'no', as the expression and validation of these difficulties for each individual is paramount.

In contrast, if a research outcome measure for pre-post therapy was needed, then it is possible that the CDP would not be used. In this instance, the CDP might well be too long, especially if the CDP is used to explore rather than simply rate and document.

However, the main function of the CDP is in the clinical setting. In this setting the benefits of using the CDP to obtain an understanding of the impact of aphasia through exploration as well as rating are obvious. In this setting also the process of administering the CDP should benefit the interrelationship between SLT and the respondent. Brevity would not necessarily be paramount in this situation. Views among field testers with regard to length were varied. Some comment that

"I think the CDP is an appropriate length" (SLT)

"Not too long" (person with aphasia)

where as others reported that

"my client found the assessment exhausting" (this was from someone assessing people who have brain tumours)

Several SLTs commented on wanting to spend more time discussing the issues raised in the CDP especially the participation and emotional sections. A number of SLTS reported spending several sessions completing the CDP. Many did not comment on its length at all. One recommended highlighting the length it takes in the manual.

The difficulty this highlights is that the CDP might begin a shift in the culture of SLT assessment procedures (as had been confirmed by field tester comments). The focus of the CDP is on partnership, relationship building, and more holistic exploration, rather than on information gathering. These things cannot be hurried. When discussing this issue in the final advisory group, looking of potential areas for deletion, Sue commented that *"everything is needed, its bare bones - it takes as long as it takes."* How easily SLTs can or how ready SLTs are to engage in this shift of culture will vary. However, for some people and for some SLTs, at certain stages in their journey the CDP will remain an unhelpfully lengthy instrument.

5.7.2 Cultural and racial considerations

One of the major changes from developing the DQ to the CDP was the utilisation of picture material. Though of undoubted value, this process has brought with it the issue of requiring a racial and cultural context to be chosen. Every effort was made to ensure racial and cultural acceptability. However, the CDP remains mono-cultural and mono-racial. It is a white, Anglo-Saxon context.

It may be presumptuous to make assumptions about using a tool developed within one cultural context with a separate cultural or racial context (Stewart & Napoles-Springer, 2000). Gladis et al (1999) comment on why this might be, suggesting that the subjective factors (psychological states and emotional experiences) rather than the objective ones, are most problematic from the design of cross-cultural measures because of the powerful effect of culture on the labelling and expression of emotions. The final section of the CDP may well be the one most at risk of being unrepresentative when the CDP is administered outside the cultural context in which it was developed. The final section of this chapter will address what can be done to remedy this. As can be seen from table 5.7 field testers were able to administer the CDP across a range of racial groups. No-one mentioned feelings of exclusion. However, the possibility of alienation due to mono-cultural bias cannot be excluded.

5.7.3 Lack of psychometric validation

The psychometric qualities of the CDP are untested. However, limited statistical testing *has* been carried out on a small sample of people who completed the DQ. As part of the validation exercise carried out to standardise the CAT, factor analysis (n=60) and test-retest reliability (n=15-18) correlations were carried out by an independent statistical expert. When beginning to develop the CDP, raw data from the DQ was analysed to produce a Cronbach's alpha score (and the endorsement frequencies previously mentioned) (n=41-51), Tables 5.14, 5.15 and 5.16 summarise the results. Numbers are small but tentative conclusions about the psychometric qualities of the DQ can be seen to be encouraging. They demonstrate that there are good correlations between individual item scores and the overall total suggesting that the items and the overall instrument are measuring the same conceptual domain. The results obtained suggest that test-retest reliability and internal consistency for the DQ were promising. However, the DQ is not the CDP. Psychometric information on one does not confer validity or reliability on the other. The positive results shown for the DQ are encouraging for the CDP, as they contain similar domains, but no more than this.

Throughout the development of the tool, efforts have been made to ensure both the potential psychometric robustness of the tool and also the meaningfulness, social validity and clinical utility of the instrument. This appears unusual in test construction. Eiser et al (2000) suggest that the emphasis within HRQoL research for example has been disproportionately on reliability and validity, rather than on their acceptability or utility. They suggest that

> "the focus on reliability and validity as reflected in Cronbach's alpha or correlations with other measures of QoL may be an essential part of the development of a measure, but does not address issues of acceptability to

> children. There are few reports to show that questionnaires have been evaluated to ensure that children really understand them." (p406)

However, the development of questionnaires is not complete without investigation of its psychometric properties. Full investigation of the reliability and validity of the CDP is warranted, and this will be discussed later in this chapter.

There are precedents, nonetheless, for the widespread use of tools within SLT that are non-standardised or validated using small sample sizes. The PALPA for example, has been a huge influence in the past decade within clinical SLT. However, of its 60 subtests, 17 have no statistical information available at all. Those that do give statistical information, give descriptive statistics only (means, standard deviations and/or ranges for people with non-aphasic language), often with sample sizes of as little as 15. There is no attempt to establish or document internal consistency, reliability or validity. The Code and Müller Protocols (1992) do not report any information relating to the psychometric qualities of the scales in their test manual. Lyon et al (1997) reports the use of two non-standardised measures consisting of two investigator-constructed questionnaires aimed at capturing key constructs not assessed by standardised measures. Thompson (1998) similarly describes the use of two unpublished tests to contrast lexical and sentence comprehension.

So there are precedents for tools used in clinical practice with people who have aphasia that have not demonstrated their psychometric robustness.

In the world of rehabilitation, the FIM/FAM, (Stineman et al, 1994) has been widely used, e.g. Béthoux et al (1999) despite its lacking insufficient evidence of the reliability and validity (Bowling, 1998). As has been discussed, user-generated measures have been receiving increasing positive attention, despite the obvious difficulty they pose for establishing reliability.

Therefore though lack of psychometric information is seen as a limitation for the CDP currently, it does not necessarily preclude its use in clinical or research arenas.

5.7.4 Inaccessibility issues

Every effort was made to make the CDP as accessible as possible. However, there is an acknowledgement that there will still be people for whom participation in the process of the administration of the CDP will not be possible. This was documented as being the case for a number of field testers, who chose not to administer the CDP or abandoned administration (see table 5.10). In the training it had been stressed that if the field testers had any suspicion that administering the CDP would have be a negative experience for the person with aphasia then they were to stop or not attempt it in the first place.

As with other groups of people at risk of exclusion (for example, Brod et al 1999), there are those for whom we were unable to think of ways to make the tool inclusive. Significant comprehension loss or major cognitive impairment affecting task maintenance, concentration, reasoning, memory or decision-making will all present barriers to the successful completion of the CDP. The main reason reported by field testers was that people were in the early stages of recovering from stroke, or that cognitive, comprehension difficulties or anxiety were intruding.

5.7.5 The remit of the CDP

There are a number of issues relating to the remit of the CDP. The first relates to expectations or assumptions that may be made as a result of measurement. The second relates to the relevance and ease of dividing disability as a consequence of communication impairment from disability stemming from other sources.

Aphasia will be a life-long experience for the majority of people who acquire it. There is an argument that exploration in so broad a manner as the CDP invites the assumption of 'cure' or change in all the areas explored. Kleinman, (1988), suggests that

> "treatment assessed solely through the rhetoric of improvement in disease processes may confound the patient's (and family's) assessments of care in the rhetoric of illness problems. Hence at the heart of the clinical care for the chronically ill – those who cannot be cured but must continue to live with illness – there is a potential (and, in many cases, actual) source of conflict" (p7).

The main focus of the CDP is indeed to identify things that are amenable to change, and the items have been selected accordingly. It has been designed to guide therapy.

However, the CDP has other functions. The CDP aims to facilitate the person with aphasia towards a new 'self-with-aphasia' identity to enable greater participation. This 'self-with-aphasia' identity is also encouraged by the actual process of administration, where the person has his/her experiences and feelings associated with living with aphasia validated. It serves simply to share the experience of living with aphasia, and let the person with aphasia know that someone else has 'heard' his/her perceptions from the inside.

However, Higginson and Carr (2001) suggest that

"some pressure groups...have opposed the clinical measurement of quality of

> life on the grounds that it represents the 'over-medicalisation' of life and clinical interference in aspects of patients lives that should not be of concern to the clinician" (p1299).

This criticism has resonance with a debate that took place previously within the SLT profession, which centred on whether or not counselling was within the remit of speech and language therapy. Recognising this dilemma, I asked the members of my advisory panel directly whether they felt the use of the CDP felt intrusive or inappropriate. No-one did. In fact, the panel were rather horrified at the suggestion that these areas would not be covered. However, as discussed there were a few field testers who had reservations about how it could be used.

McGee (1996), after reviewing research that reported positive or negative effects of the actual procedure of HRQoL assessment, suggests that

> "the net effect of research intervention (completing the interviews or questionnaires) appears positive although a small number of people are distressed by such interviews...the dilemma (is) of being unable to predict an individual's reaction in advance " (p164)

I believe this to be the case with the CDP as well. I believe also that the way in which the CDP is presented could be open to abuse. If it is perceived and administered as a 'test', then the supportive function it sets out to perform may be in jeopardy. As discussed there are situations where the CDP would be abusive (such as early on in someone's aphasic journey). Section 5.9.3 will discuss suggestions to minimize this risk.

A second issue relating to the remit of the CDP is that of locating the source of disability. There was one person who had aphasia who commented that she had difficulty differentiating the effects of hearing loss from effects of comprehension loss, and the difficulties of writing due to letter selection or physical coordination problems. For other field testers the CDP enabled them to *highlight* that limitations on life were as a result of physical disability rather than language impairments. Locating the source of disability can be difficult. As discussions relating to participation and emotions has highlighted, this dilemma challenged us considerably. Traditional SLT has tended to focus in a rather myopic fashion on impairment. Certain sections lend themselves to being focused specifically on the effects of language impairment (activities section). In others sections, such as the emotions section separating the effect of language from stroke or other factors that contribute to feeling of frustration or competence, seems counterproductive. (The dilemma this causes with regard to reliability will be discussed later in this chapter).

Additionally, the CDP, by broadening the remit of investigation, opens up the possibility for therapists to move beyond their traditional role. The degree to which SLTs choose to do so and how comfortable they are doing so will vary.

5.7.6 Clinical measurement issues

The CDP is a clinical measurement tool. As such it shares the limitations associated with other such tools or procedures that have been rehearsed in chapter 1, including such issues as ability to introspect, social expectations, responsiveness, response shift, desire to please, and effect of mood state (Hetu et al, 1988).

In the case of the CDP, a degree of introspection is necessary on the part of the person with aphasia. The advantage the CDP has over other briefer measures (such as HRQoL instruments) is the degree to which the process of administration guides both participants (the SLT and the person with aphasia), through this process of introspection systematically.

> *"We couldn't have covered the ground without this format"*
>
> *"Liked that it addressed aspects of their lives that they felt had not been done in such a structured way"*
>
> *"Made me feel quite positive about previous practice as it appears the areas have been covered though not in such a structured way"*

This structure may overcome some of the difficulties around self report, but it will not eradicate them in the absence of an ability to reflect on the situation the respondent finds her/himself in.

Another potential limitation of the CDP is the fact that it is likely to be administered within the clinical setting. For valid responses to be gained beyond the desire to please or be acceptable, a relationship of trust and support must exist. The way the administrator introduces and uses the CDP it therefore seen as crucial. This will be returned to in the context of recommendations for clinical use of the CDP.

A further issue common to all self-rated tool is that of response shift. In general terms there is a debate about the responsiveness of clinical tools (Williams, 2000). Williams points out that our perspectives change subtly as we move through life experiences; self-assessment of functioning, activities, and feelings may well shift as individuals encounter specific events, problems, or interventions, our perspective or frame of reference may well shift. We then redefine our point of view, our expectations of performance and our health status accordingly.

The CDP is designed to highlight the direction of future development for the person with aphasia. For this role Williams' criticism is not relevant. However, the CDP is also designed to measure an individual's view of how life with aphasia is at one point in time, and compare this against that same person's view at another point in time. Williams' observation then may present a problem. If an individual's frame of reference changes subtly then 'real changes' may be masked or diluted as the frame of reference shifts. It is difficult to see how this can be overcome. Note should be taken of the comments that accompany the ratings. These may be illuminating with respect to how ratings compare and whether there have been real changes despite any altered frame of reference.

Wu and Rabin (1992) present another reservation about the use of self-report tools in clinical settings. They question whether different types of data can be successfully combined.

> "can physiological or mortality data be combined with self-reported quality of life measures?...the utility and feasibility of combining self-reported and physiological data has yet to be explored " (p261).

The original motivation for the CDP was to do just that; to combine the client's perception of the situation with quantitative data obtained through clinical testing. The DQ has been used on over 120 occasions. On most of these occasions, the results were combined with those of impairment data, the CAT, to give an overview of the clinical situation, from both participants' perspective and the SLT's. My personal opinion is that the combining of the two sources of information enriched the analysis of the situation and benefited both the person with aphasia and the SLT, by the partnership that was established as a result of broadening the remit of investigation. There is reason to believe this process would be even more productive given the improvements to the tool. One field tester mentioned combining information gained from the CDP with other assessment data.

> *"Assessment will be useful as adjunct to other areas of assessment"*

It does raise the question of how SLTs use the information that results from the CDP. Again this will issue will be returned to in section 6.2.3.

The final issue that is relevant to the CDP in common with all self-report measures is the degree to which mood state could influence rating. Hanita (2000) suggests that

> "the effect of a negative mood on the evaluation is hard to predict. Whereas positive moods are mostly identical to one another (happy), negative moods are more differentiated (e.g., sad, angry, fearful). This complexity of negative moods may be partly responsible for the unpredictability of their effects. In short, research suggests that positive mood may bias measures...positively, and negative mood may bias these measures in unpredictable ways" (p472)

Hanita proposes that research suggests that measures are susceptible to biases introduced by people's transient mood states. This is particularly difficult if the CDP is to be used as an outcome measure, less so when being used to guide intervention. There is evidence from the DQ user focus group interviews that mood state does influence ratings on the CDP. Three different people made the following comments when asked about perceptions of the self esteem questions.

> *"On your mood at the moment...because of your mood at the moment you are very happy...you are going out with friends...but sometimes your not happy at all"*
>
> *"When you get up in the morning, in the afternoon, in the evening, everything is different..."*
>
> *"I think the way it affects us if the sun's shining we feel better"*

However, though mood states may be transient and affected by fluctuating influences, it is my contention that comparisons between sections which highlight an individual's areas of concern will not be so fickle. It is also likely that external influences and areas of reduced participation are also less affected by transient alterations of mood. So though the overall severity may be affected by transient mood states, comparison between sections, priorities expressed and qualitative information that is obtained should still be meaningful. As a gesture towards this limitation, an additional question relating to mood has been added to the CDP (see table 5.12). It is not rated but merely seeks to record the mood of someone as they complete the CDP.

5.7.7 Prescription issues

Within the CDP, the same questions are asked of each person with aphasia, regardless of the individual circumstances and characteristics. Each situation or emotion has been confirmed as being one that is relevant and meaningful to people with aphasia, through completing the in-depth interview process, and through consideration by the advisory panel

The expansion of the participation section was motivated, to a large degree, by the desire to facilitate the person with aphasia to bring her/his own situation to the assessment. The way it has been structured is such that though the domains are predetermined, the actual facets within the domain are left to the individual. For example, in the 'things you want to do' section, 'going out' and 'relationships' are specified but the details of these are left up to the individual. The person with aphasia will bring to this the information and interpretation of her/his own biography, within the spheres specified by the areas described. Similarly, the wording that accompanies the pictures has also been chosen with care, to attempt to reduce the prescription of the depictions. All these features are attempts to reduce the prescriptive nature of the CDP.

However, each situation, domain or feeling that is described is depicted. As has been discussed the very act of depiction necessitates pinning down the situation to something concrete and definable. By doing so, latitude of interpretation may be compromised. The wording has been chosen as carefully as possible to reduce the degree of prescription. The domains of investigation have been rigorous established and ratified. However, there is no doubt that situations, domains and feelings are specified within the CDP. Feedback from the field testers suggests that for some the level of prescription is not intrusive.

> *"Identified with the emotions illustrated"*
>
> *"Content was relevant"*
>
> *"Wanted to rate each participation picture and show the contrast"*
>
> *"Put (us) on the right track"*
>
> *"Very thought-provoking – enabled her to discuss concerns re: future, think in structured way about impact of aphasia in different settings"*
>
> *"She liked the fact that it addressed areas of her life that weren't usually addressed"*

For other people the CDP contained aspects that were too prescriptive.

> *"Commented that some situations were not appropriate to him (didn't ever do the shopping or go to the bank)"*
>
> *"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"*

Therefore it appears that there is varying acceptance of the level of prescription. All the people quoted above still rated the experience as positive, and the comments above are certainly said within the context of the CDP being acceptable as a tool *overall.*

However, it remains an issue.

5.7.8 The assumption of negativity

The CDP deliberately depicts communication situations, domains and feelings that have been chosen to potentially be vulnerable to negative change as a result of acquiring aphasia. By selecting these factors the CDP is at risk of being criticised for being biased towards a negative conceptualisation of living with aphasia.

There is no doubt that the DQ was framed within this conceptualisation. Efforts were made in stage 3 and 4 to move away from this framework. During the individual interviews people with aphasia were specifically asked to report any positive experiences or feelings associated with having aphasia. A few were able to, and are discussed in the final chapter. The majority were not. Indeed most interviewees were rather perturbed at the suggestion that the experience of living with aphasia could be anything other than negative.

During the DQ user focus group, the facilitator encouraged the participants to concur with the view that aspects of the DQ were unnecessarily negative. Despite repeated attempts the group would not confirm this.

Facilitator	*"we were asking whether the words were very negative or whether they were helpful"*
1st person with aphasia	*"yes all quite good yes they are all quite good"*
2nd person with aphasia	*"I didn't mind doing this there's no problem doing this"*
Facilitator	*"did it upset you at all to talk about these things?"*
3rd person with aphasia	*"no no"*
Facilitator	*"we were wondering whether people would feel upset talking about these things"*
4th person with aphasia	*"no no"*

They agreed that to have a way of rating positive aspects would be beneficial but they would not reject the negative emotions. There are many reasons why individuals who have acquired a disability might have difficulty construing their altered state as positive, and these will be explored in the final chapter. The same was true within the advisory group. When asked specifically about the negative bias, particularly of the emotions section, I was unable to elicit any feelings of dissatisfaction. One field tester commented on aspects of the CDP being negative.

> *"Content mostly appropriate apart from emotional factors; patient insight heightened by the negative changes"*

No other field testers (SLT or person with aphasia) made any reference to negativity. The advisory group commented on the fact that they could imagine SLTs having trouble with the expression of negative emotions by the person with aphasia. Their view was that this was a limitation of the SLT not the CDP.

The tenor of the CDP seems to be appropriate to people with experience of living with aphasia. However, any investigation of issues that are this powerful needs great care and sensitivity as will be discussed with reference to how the CDP should be used in clinical practice.

5.7.9 Relative and carer considerations.

Chronic illness or disability is not an individual concern. The consequences of acquiring and living with disability have ramifications beyond the individual who has acquired impairment. Kleinman (1988) when discussing chronic illness suggests illness refers to

> "how the sick person and *members of the family or wider social network* perceive, live with and respond to symptoms and disability'" (p78) (emphasis added)

Parr (1994) discusses how aphasia can affect partnerships in terms of physical, emotional and role changes. Brumfitt (1999) discusses the interplay between an individual and the attitudes of the family. She suggests that the amount of incapacity and symptom visibility will influence how the family copes. If the person is obviously disabled, there are many issues to do with how the family members feel about going out into society with the person. Jordan & Kaiser (1996) suggest that

> "A*ttitudes of other family members* in the household and how they attempt to cope with the disability are of considerable importance" (p164) (emphasis added)

All these authors highlight the fact that a person with aphasia is not in a social or familial vacuum. Family attitudes, roles and emotions affect the experience of living with aphasia. The participation section of the CDP explores whether family members facilitate or act as barriers to the person with aphasia. However, this view is one-sided, from the perspective of the person with aphasia.

Hart & Chesson (1998) when discussing child-centred assessment approaches discuss the relationship between the view of the client and the views of the carers.

> "To suggest that service providers should consult children does not mean that parent's views should be ignored. Parents need to have the opportunity to

> express their expectations, which are likely to differ from children and will be based on many years experience of health services...parents need to be encouraged to stand back and enable children's voices to be heard. " (p323)

Several authors have called for the inclusion of the families' perspective in the evaluation and therapy process within the field of aphasiology. Lyon (1999) for example advocates that aphasia treatment should not be about a process of a person, but of people. Finally, Le Dorze & Brassard (1995) compare the impact of living with aphasia from the perspective of both the relative and the person with aphasia. They conclude that the degree of disability may well be different for each of the people involved in the relationship. They suggest that it would be warranted to consider each person's perspective.

Does this then present a problem for the CDP? The CDP is a tool that enables the person with aphasia to express her/his perception of aphasia. There are several opportunities within it to encourage the individual to discuss the effect of family relationships, attitudes and behaviours on her/his experience of having aphasia. This may lead to working in partnership with those close to the person with aphasia. There is no specific mechanism for doing so within the CDP; that is beyond its remit. However, by the nature of the level of investigation used in the CDP, the way is made clear for open and constructive dialogue to take place between person with aphasia, her/his relatives or carers and the SLT. In fact a number of field testers reported that the CDP did just that.

> *"Communicate results to wife – brainstorm ways to increase independence and opportunity to express himself"*
>
> *"Thought there were sections that were very pertinent and certainly provides fodder for further discussion with family re: needing extra time for him to achieve some independence in the home"*
>
> *"Liked the fact that it enabled him to give HIS perspective – he surprised his wife"*

5.8 Future developments

There are evidently a number of outstanding issues relating to the overall use of the CDP.

5.8.1 Field trials to establish psychometric validity

Field trials would aim to gather large numbers of repeat administrations of the CDP to enable statistical analysis to establish aspects of the CDP's psychometric robustness.

SLTs would be recruited to undertake repeated administrations of the CDP (draft 3). These repeated administrations would provide information that could be used to calculate internal consistency ratings.

For a sub-group of the people with aphasia who volunteer for this part of the project, the CDP would be administered twice, within two weeks of one another. 30 people providing this information would enable the calculation of test-retest reliability.

It may be possible to attempt an exploration of one aspect of criterion validity, concurrent validity. Though this tool is unique in its aims and construction (and therefore has no obvious comparator available for concurrent validation), the emotional section shares certain features with VASES (Brumfitt & Sheeran, 1999b). Both seek to rate aspects of the emotional impact of becoming aphasic and living with aphasia. Both use pictorial rating scales. Both have been specifically designed to be maximally accessible for people who have aphasia. It might therefore be useful to compare the two tools. This would be done by selecting a sub group of people from the pool of volunteers, to undergo administration of the CDP but also the VASES, with statistical comparisons made between the two.

5.8.2 Maximising inclusion

There is also a suggestion that the CDP draft 2 could be taken to a group of people who are not significantly represented within it, such as a group of black or Asian people who live with aphasia. The idea of showing the CDP to a group of people who could give a perspective from the multi-cultural society of Britain today is seen as a possible option to establish the acceptability (or not) of the current CDP, and seek suggestions for modifying it. The option of making 12 versions of the CDP, each one culturally, age and gender specific is likely to be financially and practically unfeasible, but information on the current CDP's acceptability with different cultural groups could be helpful.

A second consideration of inclusion relates to the fact that there remain several groups of people for whom the CDP will not be useful. Despite efforts to make the tool maximally accessible, certain people may be unable to comprehend the CDP. Field testers reported a few instances of people who they choose not to administer the CDP because of 'significantly reduced comprehension levels'. People who have recently acquired aphasia are also excluded from participation in the CDP (as previously discussed).

Though the CDP may not be accessible in its unabridged form to certain people, the SLT could use the pictures within the CDP but use them outside the framework suggested. The pictures can be used to explore the issues raised within the CDP. Quantification, however, is likely to be difficult. Other pictorial resources exist that could supplement this process such as *Pictographic Communication Resources Manual*, (Kagan et al, 1996).

The Pragmatics Profile of Everyday Communication Skills in Adults (Dewart & Summers, 1996) can be used to elicit information relating to the changes experienced by someone as a result of communication impairment. It is descriptive and does not attempt rating. There is a self-report version and a proxy version. Both set out to identify behaviours of communicative functions, response to communication, interaction and communication and contextual variation.

Addington-Hall & Kalra (2001) when discussing working with people who have dementia sufficient to negate the possibility of formal assessment, suggest that rather than lose all information on that person who is unable to report her/himself, proxy ratings should be considered. They suggest that there is sufficient agreement between their assessments of quality of life to make information that proxies provide useful when the person cannot give it directly.

The CETI is another tool that could help elicit information in this situation. It relies on the information obtained from proxies. As discussed its psychometric properties have been shown to be good and it has been used internationally (Penn et al, 1992 and Pedersen et al, 2001). The CETI has recently been successfully used to document statistically significant positive change in people who have aphasia who attended for therapy based on social model philosophies at Connect (an organisation to be discussed later).

Interestingly, when field testing the DQ one spouse of someone with aphasia whom I saw over the course of a year, repeatedly asked whether there was a carer version of the DQ that could be administered with her. The possibility of a parallel version of the CDP for carers is open.

5.8.3 Ensuring valid use of the CDP

I believe there is a need to guard against abusive use of the CDP. An instrument constructed within an inclusive framework, with emancipatory aims can still be used in an abusive way if administrators are not sensitive to the principles associated with its use. It felt necessary therefore to ensure that, as much as possible, the people who use the CDP will do so in an empowering fashion, challenging their own perspectives on power relationships within the therapeutic relationship (should they need challenging).

The ideology behind the CDP must be appreciated and translated into the administration process.

To facilitate this it is likely that the CDP will be administered only after the administrator has undergone some form of training in the context of its inception and purpose. There are precedents for training prior to use of healthcare measures (the most commonly used examples being the interviewer-administered version of the Sickness Impact Profile (Bergner, 1993), and the Hamilton Depression Scale, (Hamilton, 1960)).

To facilitate valid use of the CDP, a specified system of dissemination is envisaged. Rather than publicising and selling the CDP in a traditional way, more control would be exercised over the distribution process. The CDP would be introduced to those wishing to use it, through participation in a workshop. The training for the CDP would centre on consideration of the use of the medical and social models within aphasiology, challenging the role of the administrator as 'expert', as was done during the clinical usability field test training. It would cite the CDP within the context of the social model of disability, questioning how the administrator would use the information that results from the CDP in an effort to ensure that the CDP will be used in the way it was intended. It would emphasis that the goal of all therapy is to facilitate positive healthy living with aphasia. Anything, including the administration of such tools as the CDP, which interferes with that aim, should not take place.

The way in which it is presented, therefore, is vital in minimising the impression of detachment in the clinical setting. A manual is being written to accompany the CDP that will set out recommendations for how it should be presented and used. These things will focus on ensuring respectful, empowering use of the CDP rather than its use as a blunt instrument for measurement.

The timing of the administration needs very careful thought. As has been discussed administration of the CDP with someone who has only recently acquired aphasia is to be avoided. Administration of the CDP when someone is hospitalised and has only recently acquired aphasia would be problematic on a number of levels. The person may be confused, shocked and vulnerable. They may be denied the support of their social network. They will lack experience of having aphasia in their normal daily life, so external influences and communication scenarios discussed will relate only to the institutional setting in which they temporarily find themselves. Beginning the process of identity exploration and investigation of emotional issues and in these early stages when someone is in a potentially vulnerable situation does not seem appropriate.

The CDP could act as a useful resource of pictures from which to choose. The SLT in the acute setting might choose to use parts of the emotional section, or the 'who helps' picture, with someone who they felt might benefit. However, it should not be used in its entirety nor should it be used as a measurement tool in those early days. There are other priorities for SLT in their role with the person with aphasia at that time.

It should be noted that though the tool was originally intended for use by SLTs alone, this position could be questioned. The person administering the CDP needs to have an awareness of the consequences of aphasia in terms of life and communication skills. The administrator needs proficiency and experience in talking with, facilitating and listening to people with aphasia. The person needs an appreciation of issues relating to the social model of disability (as discussed above). The administrator would need a valid person-centred reason for administering the CDP. The person does not, however, need to be a SLT.

5.9 Attention to psychometric qualities

The previous discussion has considered the development within stages 3 and 4, as a result of the use of qualitative, inclusive methods of research. Psychometric qualities have been mentioned. This section will describe the tensions that exist between these two influences.

5.9.1 To measure or not to measure?

Patton (1990) advocates

> "a paradigm of choices approach that rejects methodological orthodoxy in favour of methodological *appropriateness* as the primary criterion for judging methodological quality" (p39) (emphasis original)

When this tool was first conceived, it was developed to measure the disability associated with living with aphasia. It was conceived within a project that was utterly quantitative. For all the iterations of the DQ, this was unquestioned. With the introduction of participatory research methods through the operation of the advisory panel, the central motivation for the tool's development was queried. Participatory methods seek to include users centrally within the research process. As a result, actions, suppositions, attitudes, motivations about the research process and the tool itself were all questioned.

Similarly the medical and social models of disability bring different perspectives to how exploration of a phenomenon should be executed. Within a medical model framework, quantification is the cornerstone of investigation. The social model, by contrast, often utilises qualitative research methods that lend themselves to explanation rather than measurement (Damico et al, 1999). The aim of investigation within the two paradigms is often different. The methodological assumptions within qualitative research, for example, revolve around the objectives of descriptiveness and explanatory adequacy, not predictability.

As the DQ turned into the CDP, and qualitative methods were employed, there was a feeling of unease about whether the CDP should be aiming to *measure at all.* The more exploratory aspects of the tool were emphasised, the more tempting it became to reject measurement, in favour of discussion and exploration. When discussing methodology associated with investigation of the impact of aphasia, Simmons-Mackie (2000) suggests that

> "behaviours are viewed relative to the individual's own abilities and purposes rather than in relation to an objective norm. Because the emphasis is upon quality of life and social membership, measurement does not fit well into traditional quantitative paradigms" (p170).

Similarly, Damico et al (1999) suggest that

> "due to the complexity of the phenomenon under investigation, the reliance on numerical data, predetermined categories or classificatory schemes, or even reduced summaries of behaviour is often insufficient by itself " (p654).

So some authors question the role of measurement within the realm of investigation of aphasia in a social model perspective. The difficulties they have seem to stem from assumptions about the origins or philosophical underpinning of such measures. Simmon-Mackie, for example, suggests that measurement will, by necessity, be based on 'objective norms' and as such, cannot take into account individual perspectives on the situation. As can be seen, the CDP measures but does not compare a person against an average performance. It measures by enabling the person with aphasia to express his/her opinion about his/her unique situation.

Damico et al base their dissatisfaction with quantification on a view that "numerical data, predetermined categories or classificatory schemes" will be "inadequate". The people with aphasia who advised me on the CDP do not seem to share this view. They ratified the classification of participation, suggesting that all areas of life could be brought to the discussion and rating within the classifications that had been devised. The comparison of domains and situations described by people with aphasia during their in-depth interviews, and whether those could be covered in the

CDP adds weight to this contention. Comparison of appendices 5.21 and 5.22 demonstrate that there were very few constructs of relevance to the impact of aphasia that cannot be explored using the CDP.

Through the use of all the participatory research methods used during stages 3 and 4, I was able to be confident that the items themselves, the way they were presented and the ratings had all been agreed as as accessible and acceptable as possible, by a sample of people with aphasia. I had discussed the role of rating with the panel. Their conclusion was that the ratings had use for demonstrating change in a concrete way, for example when people had forgotten how things had been for them in earlier stages. I also felt that in these days of evidence-based practice, a tool investigating disability that could produce scores could make a contribution. CDP field test data supports this contention.

The CDP (including its rating scales) has been scrutinised, justified and ultimately approved by a group of people with aphasia as being a legitimate means to explore the impact of aphasia on people's lives. Simmons-Mackie (2000) discusses the importance of the social model for people with aphasia and suggests that SLTs must assist clients in maximising communication and participation *as defined by the client.* If these areas are to be assessed rigorously as is being postulated, instruments are needed that can do so. Very few measures exist that do this, as has been exemplified in chapter 1, apart from the CDP. The CDP has always aimed to facilitate a view from the inside. From the beginning, the ratings were those of the person with aphasia.

Maybe one reason for the feeling of unease about measurement in aphasiology is the realisation that this is heading into slightly uncharted, potentially hazardous, waters. Streiner & Norman (1995) suggest that

> "there is an increasing awareness of the impact of health and health care on the *quality* of human life. Therapeutic efforts in many disciplines of medicine...are directed equally if not primarily to the improvement of quality, not quantity of life. If efforts of these disciplines are to be placed on a sound scientific basis, methods must be devised to measure what was previously thought to be unmeasurable, and assess in a reproducible and valid fashion those subjective states which cannot easily be converted into the position of a needle on a dial. Researchers in health sciences are frequently faced with the desire to measure something which has not been approached previously (such as) the **speech difficulties of aphasic stroke patients**...the difficulties and questions raised in

> developing such instruments range from the straightforward to the complex ... the answers ... are frequently difficult to access" (p1-2). (italics original, bold and parenthesis added).

The alternative methods for exploring these areas might include qualitative interviews or observational methods. However, with these methods there is a heavy reliance on detailed analysis. It is questionable whether SLTs would have the necessary experience, skill and time to pursue such methods within routine clinical practice. Though it is possible to conduct qualitative interviews with people with severely impaired language, there is a question as to the accessibility of in-depth interviews for people in the clinical setting to guide intervention.

Qualitative approaches have their place for exploration and description, quantitative approaches have their place when measurement and evidence of change is needed. When discussing methodological difficulties in rehabilitation research, Pollock et al (1993) ask

> "do the measures reflect the range of dimensions relevant to rehabilitation and can changes in the measurement scale be translated into clinically and socially meaningful terms?"

When using the CDP, the answer is 'yes'. As can be seen from the following section, the CDP enables clinically and socially relevant information to be gathered. This can then be used to guide intervention that has direct relevance to the life of the person with aphasia. Again CDP field test data reported supports this aim as being achieved.

This, however, does not mean that measurement per se should always be attempted. Within the CDP there was a deliberation decision not to measure the external influences. The focus for this section was on *explanation* of the impact, with a view to modification and enablement. Quantification was not seen as relevant. Equally, it is envisaged that there will be people for whom administration of the CDP in its entirety will not be relevant and *measurement* would not be attempted. This has been discussed previously.

Therefore I would argue that socially valid measurement is possible using the CDP. However, it should only be attempted if its inclusion fits within the ethical and philosophical framework of empowering and enabling the person with aphasia.

5.9.2 Psychometric considerations *with* participatory research methods.

The issue of psychometric integrity has been alluded to on several occasions within the discussion about the development of the CDP. Stage 3 and 4 attempted to utilise methods that were participatory. There were occasions where the two methodologies complemented each other.

Bowling (1997b) suggests that there is a basic assumption underlying the use of structured questionnaires, that researchers and respondents share the same theoretical frame of reference and interpret the words, phrases and concepts used in the same way. Therefore, many of the changes that were made in consultation with the advisory panel were likely to improve the psychometric quality of the CDP; the advisory group were ensuring that I, as researcher, understood the same framework as they, as potential respondents, did. Pictures were included in the CDP to ensure this assumption could be made when using this tool with people who had an impairment that might impede comprehension. The use of pictures reduces ambiguity about the frame of reference and interpretation of concepts used, and by so doing increases face and content validity.

There was discussion at one point within the advisory panel of making the participation section *client-specific*, a user generated instrument, similar to those reviewed in chapter 1. This method would involve requiring the client to choose their most challenging situations and rate those, rather than having prescribed sections as was ultimately chosen. This idea was mooted in an attempt to overcome any potential lack of concordance between the constructs within the CDP and the personal frame of reference of a respondent. This was seen as problematic by the panel (including myself) on a number of levels; communicating the idea to the person with aphasia could be difficult, expressing their views may also be complicated for the person with aphasia, and consistent rating could be problematic.

If domains were not specified and respondents gave different type of responses on retesting, it would be difficult to argue that the change was a reliable finding, the respondent may be calling different things to mind on each occasion. The review of other user-generated tools seen in chapter 1 confirms that reliability of such tools has been questioned. It also confirmed that there was a perception that those who could not readily provide items themselves (such as people with aphasia) were dependent or at least influences in their choices by cueing devices.

Equally when deciding on whether to use open or closed questions in the participation section, the panel decided that specifying the domains and using closed questions was the way forward. User-generated items including the use of open questions were therefore not pursued, thereby avoiding what could well have been a process that would reduce the reliability of the participation section.

Some open-ended questions however, are still seen as useful. Jacobsen et al (1996) suggest that almost half of their respondent's added invaluable comments in response to open questions. Similarly, Carrick (2001) suggests that qualitative methodologies can allow more opportunity for individual comment in a way that fixed response format questionnaires do not, which she suggests as being helpful when trying to empower users. The use of open-ended questions was not completely abandoned within the CDP. In the emotions section for example, the person with aphasia is encouraged after rating to discuss situations that exacerbate or mollify a particular emotional state. There are several instances where the person with aphasia is encouraged to bring anything that they feel is relevant to the discussion, before moving on for example in the external influences section. The administrator of the CDP is advised to encourage the respondent to add whatever information they feel would support the rating on *all* items. This additional information is seen as crucial to the understanding of the impact of aphasia, despite not be rated.

Psychometric considerations working with decisions made by the advisory panel was again seen when discussing rating options. There were two issues; midpoint ratings and number of response category options. When the DQ was first used, midpoint ratings were allowed. A discussion with a psychometrician highlighted the fact that if midpoint ratings are used on a 5-point scale the scale was actually then a 9-point scale. Discussion with the advisory panel, with the five picture rating scale in front of them, came to the conclusion that a 9-picture scale was unnecessary, and potentially confusing. Given received wisdom on test construction this decision was welcome. Streiner & Norman (1995) confirm that many varied studies, suggest that the minimum number of categories used by raters should be in the region of five to seven. They cite such diverse studies as judging pitch of a sound, the saltiness of a solution, the position of a point on a line, or judgements of sadness and suggest that for all, the upper limits of the number of categories which could be discriminated was remarkably near seven (plus or minus two). They conclude that

> "there is good evidence that...people are unable to discriminate much beyond seven levels...when a large number of individual items are designed to be summed to create a scale score,*(as in the CDP)* it is unlikely that reducing the number of levels to five or three will result in significant loss of information" (p35). (text in parenthesis added)

Interestingly, in the study by Cruice et al (2000b) cited in chapter 1, where HRQoL instruments were examined for clinical utility with people who have aphasia, the authors concluded that the way forward was to reduce the number of item responses to 5 (and in the case of 'How I Feel About Myself' (Thelander et al 1994) to yes/no response options).

Therefore the observations and decision of the advisory panel to keep the scale to five choices seemed to be endorsed and as with other decisions explored within this section, concur with received psychometric wisdom.

5.9.3 Psychometric considerations *versus* participatory research methods.

In contrast to the situations cited above, there were instances where there was tension between psychometric considerations and the use of participatory research methods.

Making language and concepts accessible to people who have aphasia takes time. Each concept has to be explained and exemplified. Simplifying language often involves breaking up a sentence into several short linguistically simple sentences. This leads to an increase in the length of time taken to convey a concept.

Additionally the CDP is a tool for measuring domains but its purpose is also to explore these domains. Thus, as has been described, examining the effect of aphasia on participation in life (for example) is a detailed process. These two aspects combine to make the CDP a very lengthy tool. The CDP draft 3 contained 56 separate items.

As previously discussed, one way of reducing the length of the test would be to eliminate 'redundant' items, to keep the tool as brief as possible. The advisory panel reviewed the CDP in light of its length and its purpose (including legitimising the experience of the impact of aphasia for each person who completes the tool) and were unable to see ways of restricting it without losing relevant insights into the impact of aphasia on someone's life.

Accessibility also appeared to conflict with psychometric rigour on the question of rating scale descriptors. Received wisdom supports the use of descriptors for rating scales (be they numbers or words). Streiner & Norman (1995) report that

> "although proponents of the visual analogue scale eschew the use of descriptors, an opposite position is taken by psychometricians regarding rating scales. Guilford (1954) states 'nothing should be left undone to give the rater a clear, unequivocal conception of the continuum along which he is to evaluate objects'" (p33).

The original DQ rating scale had numbers (0-4) marking the response options. It also had a large tick and cross representing good and bad at opposite ends of the score-sheet. When help-sheets were introduced written descriptors and symbols were introduced (see appendix 2.3).

When pictures were introduced this scale was redrafted to include head and shoulder images that depicted varying levels of satisfaction/happiness, with a variety of additional alternative descriptors (symbols or numbers as can be seen in appendix 5.27). The panel were adamant that the pictures should stand alone. They felt that accessibility and clarity were paramount. All verbal, numerical or symbolic labels within the scales was seen as distracting and were rejected. The picture only scale shown in appendix (final one stage rating scale appendix 4.3a pages 59-71) was adopted. The conclusion was repeated when, during stage 4 (after field testing), a new more accessible scale for rating emotions was designed. The advisory group again chose not to use descriptors. This had the added advantage for them of the possibility of this picture then conveying both intensity of emotion and frequency without having to specify either (an original draft of this picture can be seen in appendix 4.3a page 74). It could be argued that pictures are by definition iconic and as such the most unequivocal conception, negating the need for descriptors. However, the final choice, devoid of descriptors could be questioned in terms of traditional psychometric rigour.

Precision of meaning clashed with simplicity of presentation in two further instances. When discussing the depiction of 'since your stroke'. When the pictures for 'since your stroke' were first drawn, specifying a time frame was rejected on the grounds of being unnecessarily complicated. The wording of the rubric was to be as simple and short as possible. However, later in the process of development, the issue was reconsidered. Streiner & Norman (1995) point out that

> "drawing on cognitive theory Means et al (1989) hypothesize that, especially for chronic conditions which result in recurring events, people have a 'generic memory' for the group of events and medical contacts, and therefore have difficulty recalling specific instances. Thus replies to questions like, 'Compared to how you felt a year ago …' should be viewed with a degree of scepticism" (p56).

The group discussed that one of the proposed purposes of the CDP was as an outcome measure. If the CDP was to be used to measure change, then a specific time frame had to be included in the rubric. As the quotation above suggests, a question such as 'since your stroke' with no specified time frame can be ambiguous. Unless the question is specific, the information gained is open to interpretation. The panel therefore decided to include a specified time frame choosing 'during the last week'. The panel then came up with suggestions as to how to depict and present this item in the most accessible way to overcome the reservations they had initially about reducing the clarity of the message. Initially to convey the concept 'since your stroke, during the last week' we had three pages containing four separate pictures (see appendix 5.28-5.30). Ultimately it was reduced to just one (appendix 4.3a page 4).

The second occasion when precision of meaning clashed with simplicity of presentation was when the wording of the emotional section was finalised. As discussed previously, to make the rating reliable across serial administrations, the wording should highlight the emotional state as being a consequence of the language impairment.

However, particularly when discussing positive emotions this becomes problematic. Take the emotion of 'confidence' as an example. To say 'does your aphasia ever make you feel confident?' would be probably patronising and illogical. A person with aphasia may feel confident *despite* or *as well as* having aphasia, but is unlikely to feel confident *because* of her/his aphasia. If, however, the wording is simply 'do you feel confident?' then the association between living with aphasia and the emotion would be lost. With regard to psychometric rigour this opened up the possibility for reduced reliability due to misinterpretation, as these questions could be answered in relation to some other parameter, say physical impairment or other sequelae of a stroke or indeed mood state per se. Additionally the panel felt it could be difficult for people to abstract themselves sufficiently to analyse where their feelings of 'competence', 'determination' etc might come from. They may be able to rate those feelings but not be able to differentiate competence associated with living with aphasia as opposed to competence in other areas of life.

The interplay between psychometric considerations and participatory research methods is intricate. On many occasions they will lead in the same direction, for example, ensuring and maximising accessibility and accessibility. If a tool is not psychometrically robust, then quantitative information obtained from it might be suspect. Given that quantification of disability in its broadest sense might, at some level beyond the personal, affect policy-making or service provision, the need for robustness should not be underplayed. However, if the design of the tool rendered it inaccessible or unacceptable to people with aphasia or SLTs, or if tools are constructed from wholly professional constructs, then compliance could be compromised and/or it could be viewed as oppressive (by people with aphasia) and redundant (by SLTs). Meyers & Andresen (2000) discussed balancing these two influences.

> "we recognise that there also may be considerable methodological costs related to the differences between the psychometric properties of standard and 'enabled' research instruments...there is a substantial research agenda associated with the process of enablement" (pS8)

This chapter has detailed how people with aphasia became an integral part of the research process, to move the CDP through to its conclusion. The next chapter will draw on this experience to inform discussion about social roles within the research process. The next chapter will reflect on the challenges and benefits of participatory working in the context of relevant conceptual issues.

Chapter 6

Social relationships of research applied to people with aphasia

The previous chapters have documented the development of a tool to explore and quantify living with aphasia, from the perspective of the person who has aphasia. There has been reflection on the evolution of methods and concepts used during this process. Much of this development process has involved people who have aphasia. This partnership has made the tool a more valid and robust instrument. Beyond that, however, it has raised a number of challenging questions for me, as a non-disabled, health professional. These related to; the role of those who have aphasia in the research I had undertaken; the social validity of the tool itself with respect to empowering or oppressing people with aphasia; my personal views relating to disability, disability politics, researching disability; and the direction my future work would take.

This chapter begins by reviewing conceptual issues pertinent to the social relations of research. It then examines these issues in light of their relevance to this project, reflecting on the legitimacy and success of the processes that were undertaken. It ends with reflection on the personal outcome of consideration of these issues and how the reflections will influence future practice.

6.1 Conceptual issues of social relationships of research

Social relations of research production relate to the individual practice of the researcher, and the relationships developed with disabled people and their organisations (Zarb, 1992). They contrast with the *material* relations of research production, which relate to the practice of, and relationship with, establishments responsible for the research, such as funding institutions and policy makers.

6.1.1 Disability politics

As has been discussed in chapters 3 and 5, various authors within the disability movement have seen traditional research involving people with disabilities as oppressive. The process and structural organisations supporting research are seen as being rooted in the traditional positivist paradigm, by being heavily weighted in favour of the researcher at the expense of people with disabilities (for example Oliver, 1992, Zarb 1992, Morris 1992, and more recently Bricher, 2000).

There was a call for new inclusive models of research production; 'emancipatory' and 'participatory' research (Barnes and Mercer 1997, Oliver 1992, & 1996, Stone & Priestly 1996, and Zarb 1992 & 1997). These two new research models, if practiced appropriately, are seen as contributing to empowering people with disabilities rather than oppressing them. Both models emphasise the importance of reciprocity within research. Both advocate gain and power being with those who have a disability rather than with the researcher. Both stress the importance of including people with disabilities at all stages of the research process (French, 1994c).

Participatory research seeks to promote participation of oppressed groups in all stages of the research process (Zarb, 1992 and Northway, 2000). This would involve altering the social relations of research production. Disabled people would be empowered through inclusion in a two way research process where their involvement went beyond consultation or information provision.

Emancipatory research is also characterised by empowerment, gain and reciprocity, but requires people to *exert control over* (not merely to participate in) research production (Zarb 1992, Oliver 1992, and Walmsley 2001). The importance of this distinction lies in the fact that by exerting control over the process of research, the traditional power structures are transformed. It involves changing the social relations of research production. However, it is seen as altering the dynamics of power relating to the material relations of research production, the financial and institutional influences on research production.

Zarb (1992), who was one of the first to discuss these new models of research delivery, sees participatory research as playing a potentially useful role in moving towards emancipatory working. He suggests that altering social relations of research may be a prerequisite to emancipatory research, in the sense that the researchers can learn from disabled people and vice versa, making themselves available to people with disabilities, as a resource. Participatory research seeks to be flexible, inclusive and empowering by recognising the expertise of those previously at the receiving end of research 'experts'.

Oliver (1996) suggests that though participatory research may change the rules of the 'game', the 'game' itself is essentially unaltered. He and others (Finkelstein, 1999 and Northway, 2000 for example), propose that participatory research alone leaves the agenda being set by people other than those with disabilities (the government or professionals (including, in some cases, disabled professionals and academics)). They believe that *emancipatory* research, however, breaks the mould. They suggest that emancipatory research enables control to be taken by those with disabilities. This ensures positive change for those with disabilities and the permanent setting of new agendas within disability research.

6.1.1.1 Power relationships

One of the fundamental principles of all inclusive research is the emphasis on altering power relations between the researched and the researcher. As has been discussed the balance of power is seen as unequally, and oppressively weighted in favour of the researcher (Oliver, 1992 and Bricher 2000). This asymmetry of power has been seen to contribute in a major way to the alienation of disabled people from the research process (Barnes & Mercer, 1997).

So what can be done to redress this imbalance? The first theme is that power is not something that can be given, but must be taken (Oliver, 1992). Macaulay et al (1998) suggest that

> "the use of the term empower is contradictory in the literature, however. Power, by its very nature, is gained or lost, not given. Power that is given is actually a subtle form of control" (p10).

Authors suggest that there must be a change in roles within research practice. There is a belief that the social relations of research production should be not so much reversed, as equalised (Priestley, 1997). Zarb suggests that researchers should strive to go beyond consulting disabled people and be directly accountable to them, as a resource (Zarb, 1992). Once disabled people have decided to empower themselves, the researcher must learn how to put her/his knowledge and skills at the disposal of the research subjects (Oliver, 1992). This is seen as preventing exploitation and providing an atmosphere where further empowerment can take then place (Macaulay et al, 1998).

The challenge then is to identify the processes necessary for this empowerment to take place. Zarb (1992) is at pains to point out that the process goes beyond consultation. Researchers must be accountable to disabled people. There is an acknowledgement that the process of altering social relations, through empowerment, begins with establishing a partnership. By doing so the expertise of the person with a disability can be recognised (Kitchen, 2000).

6.1.1.2 Role of healthcare providers in disability research

The idea of partnership between the researcher and the researched raises the question of who can be seen as a legitimate partner within this enterprise. Opponents of the medical model are particularly critical of those they see as initiating and perpetuating the oppression of disabled people; the medical profession (and by association, all health care professions). They are seen as having considerable power over people with disabilities. They are seen as acting as gatekeepers to scarce resources, (Oliver, 1990), as reinforcing the medical model and unequal power relationships in both research and practice (French, 1994b and Bricher, 2000), as constructing 'dependent relationships' (Oliver, 1990), and as being 'professional disability parasites' who

> "having gained a satisfactory career path are unwilling to help disabled people in their struggle for equity and social change as this may challenge their role" (Bricher, 2000, p783).

Given this history and perception, the question of whether health professionals can legitimately be involved in disability research has been asked (Bricher 2000, Scullion 1995, and Gradwell 1999). Scullion (1995) and Mason (1992) suggest that there are advantages to having an 'ally' who is an 'insider', as they can be a powerful campaigner against oppression.

For those whose impairment denies them access to active participation in the research process, health professionals can be seen to act as an advocate, ensuring participation where otherwise there would be disenfranchisement. As Carrick et al (2001) suggest

> "Representing the views of a group we must realise that there is likely to be dissent, confusion and contradiction within that group. What is presented will be filtered through the experiences of the representative, be that a 'professional' or a relative or a group member. Any of these is preferable to the group's views not being heard, and there may be situations where group members are not best placed to present the views of the whole group" (p221)

There is agreement that for health professionals to be legitimate partners, there must be fundamental changes in attitudes and behaviour. French (1994b), suggests that health professionals must relinquish power and control, and work under the direction of disabled people. Finkelstein agrees and suggests that rehabilitation providers should see themselves as a resource, to be tapped by disabled clients, rather than as professionals trained to make specialised assessments of what is appropriate for individual disabled people (Finkelstein. 1991). Many authors talk of partnership, but with the health professionals recognising and addressing the inequality of power that historically exists between the researcher and those who are researched (Scullion 1995, Schlaff 1993 and Bricher 2000).

There is also an acknowledgement that the health provider cannot remain independent within their new role. Barnes (1996) suggests that researchers must

> "join (disabled people) in their struggles to confront and overcome oppression. Researchers should be espousing commitment not value freedom, engagement not objectivity, and solidarity not independence...academics and researchers can only be with the oppressors or with the oppressed." (p110) (text in parenthesis added)

6.1.1.3 Role of a non-disabled researcher in disability research

Just as the role of health professionals undertaking disability research has been subject to scrutiny, so the role of non-disabled researchers has also been questioned. The stumbling block again being that it is those who have power putting themselves in a position to gain yet more, at the expense of those who are disenfranchised. Non-disabled people have been seen to set the research agenda for, and do research on, disabled people (Disability, Handicap and Society 1992). There are those who suggest you must be a member of a group to research on that group (Fatimilehin & Coleman, 1999) and therefore non-disabled people have no right to participate in disability research.

However, if representing the views of people with disability was the sole right of those with disabilities, then there are a number of issues to resolve. The first is who can legitimately be the representative? Can someone with a physical impairment, be said necessarily to accurately represent views of those with learning disabilities, just because both consider themselves to have a disability? Can a man with a disability be said to be representative of the views of women who have disabilities, or an academic be representative of a manual worker, simply on the basis of shared disability status? As Schlaff (1993) has pointed out disability does not have to be central to the disabled person's self-concept, self-definition, social comparisons and reference groups. There are other aspects of a person's identity that will be used for this purpose and may be more significant than their disability status.

Additionally, if only those who are members of a group can legitimately participate in research activities, it is possible that little work would be done with groups such as people with learning difficulties or severe long-standing mental illness, as significant barriers exist to their participation in the research process. Warmsley (2001) points out that for people with such impairments, change is difficult without allies. She discusses this issue in relation to normalisation; the principle of making available to people with learning disabilities, patterns of life and conditions of everyday life which are as close as possible to the regular circumstances and ways of life of society. Warmsley (2001) cites Campbell & Oliver (1996) who highlight that, in contrast to other civil rights movements by black and disabled people, the impetus for change which normalisation represented came from people who were *not* themselves labelled as having a learning disability. She addresses the issue of non-disabled researchers acting as research advocates and concludes that

> "unless and until research can be changed in ways which make it possible for people with learning difficulties to engage as equal partners, it may be that the role of advocate is a necessary one." (p203)

Kitchen (2000) interviewed a number of people with disabilities about their views on research into disability. His respondents supported the view of inclusion of non-disabled researchers in disability research. Kitchen reports that exclusion of non-disabled researchers was seen by his respondents as reproducing discrimination, albeit with disabled people in power. As they advocated emancipatory research that empowered, so they felt exclusion of this kind was inappropriate and benefited nobody. Thus, as with health professionals, non-disabled researchers can be seen as potential allies, whose alienation is counter-productive to the disability movement's cause.

Again in parallel with the inclusion of health professionals who undertake disability research, it is imperative that before non-disabled people can participate in disability research, they must address their attitudes to disability and acknowledge that their own role may be oppressive (Gradwell, 1999). They must also be honest about the benefits that accrue to them as a result of their involvement; professional, academic, career development and financial (Zarb, 1992). This is necessary to ensure that there is a lack of exploitation when they execute their research.

There are examples of non-disabled people, who act as advocates for those seen as compromised in voicing their own opinions, for example those with severe mental health impairments (Kerruish, 1995), and severe learning or behavioural difficulties (Booth & Booth 1994 and Notting Hill Trust 1994).

Advocacy is seen as supporting those whose impairment makes active participation in research activities problematic. However, there are those who urge caution with regard to advocacy. Warmsley (2001) suggests that there may be fundamental ethical difficulties associated with assuming advocacy.

> "the fact that people with learning difficulties usually need allies and supporters to enable them to undertake research means that they are extremely vulnerable to having their interests misinterpreted by others…I would suggest that given the continuing power imbalance between people with learning difficulties and their allies, the position of research advocacy is less straightforward than debates in the disability studies literature would suggest…the convenient rationale of advocacy allows researchers to occupy their often powerful roles with a clear conscience" (p200-3)

So, as with the involvement of health professionals, the view seems to be that non-disabled researchers may have a role to offer within disability research. But any involvement must be cautious and considered, constantly bearing in mind the potential for oppression and abuse of power.

6.1.2 User involvement

The disability movement is a powerful voice challenging traditional ideology and delivery of health care research. However, it is only one example of where consumer views have been receiving greater attention. Consumers/users more widely within health care, including research (be they disabled or non-disabled), have become increasingly influential in the latter part of last century.

6.1.2.1 Background to user involvement

The principle of user involvement is now well established as being a key feature of quality service in health provision (Pilgrim & Waldron, 1998). Within the NHS in 1990-1, quasi-markets were created in health and social services (Jordan & Kaiser, 1996). Contractual relationships were created between 'purchaser' and 'provider' health care units, and a rise of 'managerialism' was seen. Pilgrim & Waldron (1998) propose that managerialism places a value upon consumer feedback to increase service efficiency, and the development of quasi-markets encouraged a shift of accountability and involvement. A new climate began to exist where, in theory, the traditional primacy of health care professionals could be questioned and the voice of the consumer could be seen as being legitimate, valued and influential. Within the fields of learning disability and mental illness, this consumerism was further strengthened by the process of 'de-institutionalisation', where the residents of large institutions were relocated into the community. As Pilgrim & Waldron (1998) suggest, previously

> "this question of citizenship was obscured by mass segregation of psychiatric patients. With greater citizenship has come increased expectations of rights to good quality state-provided services." (p98)

There was, however, an acknowledgment that though there was a good deal of rhetoric about patient choice, the resulting organisational arrangements contained no mechanisms for promoting or implementing this choice (Harrison & Mort, 1998). The purchasers and providers were still institutions, not individuals, and debates about the emptiness of the discussions ensued. As Jordan and Kaiser (1996) suggest

> "Therefore money follows the contracts and the patients follow the money. Despite the apparent concern for user involvement, the role of patients in health care services is rather limited...the power to make key decisions about health care provision rests with the purchasers." (p94)

6.1.2.2 User involvement in research

The disability movement makes its position on research and user involvement very clear;

> "no participation without representation" (Finkelstein 1985)

and more recently

> "nothing about us without us" (Charlton 1998)

This position is belatedly being espoused by the more traditional institutions responsible for health care research; namely the Government and the medical establishment. The NHS plan, (Department of Health, 2000) proposes that

> "the involvement of consumers in the research process leads to research that is more relevant and more likely to be used. If research reflects the needs and views of consumers, it is more likely to produce results that can be used to improve practice" (p5)

This new emphasis is welcomed as there is evidence to suggest that involving users in medical research has been lacking up until now. Liberati (1997) suggests that even amongst progressive scientists and health professionals involved in research, paternalistic attitudes still prevail (where the doctor has the information, retains it and makes the decision). He suggests there is evidence that doctors do not believe that patients and consumers can improve the decision making process because of lack of knowledge and skill to contribute on equal terms with doctors.

There were calls for consumer involvement in medical research in the mid 1990s, (Chalmers 1995, Goodare & Smith 1995 and Oliver 1995). A recent study investigating the involvement of consumers in designing, controlling, conducting and interpreting one form of medical research concluded that consumer involvement in medical research may be beginning. Hanley et al (2001) surveyed all the centres in the UK who were coordinating randomised controlled trials. They analysed how many of the centres actively involved users in their research projects. Of those who replied, 37% were involving users in areas such as setting the research questions, drafting information to participants of the trials and participating on steering committees. The final conclusion from this report is that, though user involvement appears to be becoming more prevalent, it is still comparatively uncommon, often because investigators simply did not even consider involving users in research other than as information providers.

It is interesting to note that despite this, the material relations of research are also beginning to be called into question.

> "Sufficient evidence now exists to show that the involvement of consumers in all aspects of research benefits both researchers and consumers and that such endeavours are achievable. We believe for widespread adoption of consumer involvement to occur, pressure will have to be brought to bear by journal editors and research councils." (Tallon, Chard & Dieppe 2000, p380)

Goodare & Lockwood (1999) concur and suggest that where there has been no consumer input in the original research study design then journals should seek consumer's commentaries on the papers submitted for publication.

6.1.2.3 Complexities of implementing user involvement in research

> "Being in favour of better public consultation or more user involvement if rather like being against sin; at a rhetorical level, it is hard to find disagreement. Yet our studies have shown that there is disagreement" (Harrison & Mort, 1998 p 66)

This quotation highlights the fact that the idea of more user involvement is clearly a good one but that the devil is in the detail in terms of implementation; how can true participation be effected? The process of genuine user involvement is complex.

6.1.2.3.1 The need for authentic involvement

There are numerous examples of research that involves users in a wide variety of health service arenas. However, there appear to be few where the involvement has been anything other than tokenisitic. Liberati, as recently as 2001, suggests that the presence of lay people on research ethics committees is common but there is widespread belief that it is rarely influential. Jakubowska & Crossley (1999) suggest that this is partly due to entrenched attitudes on the part of the researchers.

Harrison & Mort (1998) interviewed professionals and managers responsible for health services in one geographical location. They demonstrated that their respondents were highly selective about how they used information gleaned from users. The health and social service managers reported positive attitudes towards increased user involvement and public consultation but gave themselves 'ammunition' to ignore the outcomes of such information. They report that

> "Many respondents described how they *used* such groups in both short-term tactics and longer-term strategies. The former is neatly summed up in the phrase '[playing the] user card' spontaneously employed by several respondents; it refers to the use of user group opinion to buttress one or other manager's or professionals or their institution's preferred course of action as against that of a colleague's or other institution's...in circumstances where officials do not agree with users it makes sense to challenge their legitimacy by means of various criticisms. Thus they might be dismissed as extremists...unrepresentative...badly organised...or patronised as being sick people who cannot give continuous attention to their duties" (p66)

Brownlea as early as 1987, suggested that

> "participation may be seen not so much as influencing the decision, but rather more achieving a platform for the acceptance of a decision already made elsewhere in the system" (p605)

Hanley et al (2001) review medical research studies, and report how information gleaned from user involvement research can be similarly misused. They cite studies ranging from sub-fertility through to Alzheimer's Disease and state that the views of consumers and the views published, differed markedly. The differences related to key issues such as the usefulness of particular research questions and the implementation of studies' findings in practice.

Hanley et al found that even when users were involved in research programmes. little was known about the degree of power held by the users who were participating. Negative comments by investigators who *had* included users in research programmes suggest that consumer involvement had no impact on the project. They report on comments that the process was time consuming for little benefit, that involvement of users reduced response rates because consumers vetoed the idea of reminder letters, that the remit of the user involvement was not clear enough, and that users' knowledge and understanding of trials varied greatly.

'Patient satisfaction' and 'service evaluation' methods aim specifically to involve users in evaluation of services. They have been extensively employed to monitor how successfully providers are including users' views, especially in the areas of planning and evaluating services. However, despite this laudable remit, patient satisfaction surveys have been much criticised (for a review see Drewett 1997). They have been criticised for poor design, reliance on polite responses, variable user expectations and questionable reliability (Cheetham 1992 and Williams 1994) and for failing to explain the processes that lead to satisfaction or dissatisfaction. Drewett (1997) concludes that

> "It is evident that a lack of innovative ways of involving users other than as sources of data seems to characterize much of satisfaction research." (p197)

The reasons behind including users may elucidate why levels and success of involvement vary. These reasons have been debated within research into clinical medical practice. For some the underlying principles for user involvement may be based on aspirations of increasing patient satisfaction and empowering people (Shepherd 2002, Little et al 2001a and Richards 1998). Others suggest that the risk of litigation reduces if there is an increase in patient satisfaction brought about through increased involvement (Richards, 1998). The benefits of patient-centred practice, to both doctor and patient (and to the NHS generally, through increased compliance and efficiency) have been stressed (Stewart, 2001). For other health care providers, user involvement may be merely to buttress their own agendas (Harrison & Mort, 1998).

Those involved in disability politics may have a different agenda again for seeking to include users in research and clinical arenas. They may see healthcare (be it research or clinical) as being a target for social change for practical, ethical and/or political reasons. Their agenda is based on issues of human rights, as part of the process of dismantling disabling environments. The changes they envisage have far wider ramifications than patient satisfaction or reduced litigation rates, challenging the research agenda itself. Finkelstein (1999) for example suggests that research is not emancipatory if it follows the agenda set by others, most notably the Government or professionals.

Thus different parties may have different agendas for seeking to involve users in health research and practice. The significance of the involvement differs enormously depending on these agendas. So there is reflection about the power relations within research practice in the UK, with an emphasis on involving the user, but the evidence for widespread changes in practice is still lacking.

6.1.2.3.2 The need for detailed consideration of the process

Whatever the reason behind the desire to involve users, little mention has been made of what individual practitioners and researchers (be they medical researchers, social scientists or health service managers) may need to do to implement this new way of working. Jakubowska & Crossley (1999) suggest that doctors who wish to use users views legitimately, need to

> "unlearn some skills and attitudes: speaking in jargon, using scientific and medical language, assuming that expert knowledge can answer every problem, and automatic presumptions that the doctor should be in control...instead (they should) behave as an equal member of the group, and recognise the validity of other's knowledge and contribution" (p2) (words in parenthesis added).

Macaulay et al (1999) discussed community and lay involvement in research beyond healthcare. They comment on how the examination of the process can foster genuine involvement of participants. They focus on the attributes that researchers and group members bring to successful partnerships and outcomes. They include respectful relationships and engendering trust, awareness of political issues; self-awareness of biases and perspectives; tolerance for complexity, unpredictability, and conflict; seasoned group process skills and commitment to equality of relationships and conflict resolution. Coulter (1997) when discussing healthcare suggests that

> "educational strategies to help clinicians adapt their consultation styles to incorporate patients' preferences need to be developed and evaluated" (p117)

Rhodes (2001), cautions against cursory inclusion of users within research. She suggests that if investigators stick rigidly to protocols, and restrict users input then the input given by users 'becomes simply another tool in the researcher's methodological repertoire'. She suggests that involving users in setting up the initial protocol to avoid ending up 'in a strait jacket of a research agenda with which they may have a limited or no sympathy'.

6.1.2.4 Complexities of involving users who are at risk of exclusion

There is recognition that from whichever conceptual standpoint research begins, involving users with disabilities in research practice is less than straightforward and still in its infancy.

With regard to the emanicapatory research model, Riddell et al (1998) suggests

> "attempting to fulfil all three criteria (of emancipatory research) in action research with physically disabled people is imaginable...attempting to fulfil these criteria with...people with learning difficulties is more complex. The expertise of the researcher...is not tranmissable to some people with cognitive impairments; the involvement of people may similarly be limited; current models...suggest that the pulls either to the trivial or to the professionally stage managed are hard to resist." (p81-82)

Warmsley (2001) agrees, proposing that whilst there has been a lot of debate about the social model and inclusive research in theoretical terms, there has been little debate about the practicalities and 'struggles' of involving people with cognitive difficulties (and people with communication impairments) in research activities.

Grant (2001) discusses user involvement, empowerment and research with people who have learning difficulties and concludes that

> "those who have attempted to put into practice strategies for user involvement in research point to the absence of agreed ground rules, the inappropriateness of easy prescriptions and the tolerance of ambiguity and uncertainty." (p92)

Similarly, Drewett (1997) conclusions are based on general population satisfaction surveys mirror this conclusion. Meyers & Andersen (2000) reviewed survey methodology (one common method used in patient satisfaction) and suggest that the failure to include people with disability is even more marked. They concluded that surveying (both instruments and sampling methods used) was significantly biased against including people with a disability. Edwards & Staniszewska, (2000) agree and confirm that heavy reliance on quantitative global satisfaction measures is seen as contributing significantly to this cursory involvement of users (Discussions beyond this relating to research into how services are evaluated are outside the remit of this thesis but can be found in Edwards & Staniszewska, 2000).

Some of the practical difficulties of involving users at risk of exclusion have already been discussed in chapter 1. All those issues are to be borne in mind for this discussion.

Additional issues are raised when considering the practicalities of involving users in research, which will be discussed below.

6.1.2.4.1 The need for confidence (in self or process)

Cassidy (2000) makes suggestions to overcome some of the practical difficulties of involving those at risk of exclusion in the research process. His suggestions relate to engendering a feeling of confidence on the part of the participants in the research process. He suggests that attention be paid to details such as engendering an atmosphere of trust and relaxation when conducting collaborative meetings. He points to minutiae such as venue surroundings and the warmth of the greeting that people receive, timing meetings to be convenient to the users, with flexibility of agenda within agreed aims and objectives. He suggests methods to relax people within the group and encourage sincerity by valuing the person's opinions and experiences

Kerruish (1995) cites feminist researchers struggling with the complexities of involving people. She draws on the writing of Acker et al (1983) who highlighted the practical difficulty of involving non-researchers in the research process. The researchers attempted to include the non-researcher in all stages of the process but felt their own skills were uniquely required for aspects such as the transcription, analysis and interpretation of the interview material themselves. The categorizing of information was a particular problem, where the researchers felt they influenced the selection of the material. Their solution to this issue was to feedback their findings and interpretation to validate both the findings and the involvement of the participants.

In the field of aphasiology, a recent research project came to a similar conclusion of differentiated roles within the research process (Van der Gaag, et al (pending)). Having begun their research using an expert panel consisting of both people with aphasia and other experts such as statisticians and academics, the expert people with aphasia suggested a new configuration to the process. The advisory groups were split so that on each occasion consultation would be a two-stage process. The non-aphasic experts would meet initially to discuss 'technical data.' This would be followed by the combined consultative meeting, at which everyone was present.

This project stressed the importance of involving users at all stages of the project. It highlighted that people with aphasia were confident in the role both parties had to play in the process.

6.1.2.4.2 The need for time and resources

Kitchen (2000) discusses a further practical hurdle for inclusive research. He interviewed disabled people about their views on disability research. He reported that though the group saw a need for action-based research strategies, where disabled people are involved as consultants and partners not just researchers, however,

> "when offered the opportunity to conduct research on whatever aspect of disability and society they wished almost without fail the interviewees (including strong advocates of inclusion) declined...they wanted inclusive research to be conducted but were unprepared to undertake such research" (p40-1)

Though issues of self-confidence were raised, the main reason given was lack of time.

Time allocation is a major consideration if user involvement in health care research is to be realized. Many authors confirm that this practicality cannot be understated.

> "There is no quick and dirty option, or at least not a meaningful one. Time is essential in order to work with people, to amend the process, and to assess the agenda for discussion in lights of others' issues" (Jakubowska & Crossley 1999, p 2)

The question of resources is also one that needs consideration. If users are to contribute, they will need to have sufficient skills (for which they may need training), they will need remuneration for the time taken to contribute to such exercises as assessing protocols, and regular meeting attendance as a result of active participation in projects.

6.1.2.4.3 The need for enabled instruments and sampling methods

Meyers & Andresen (2000) investigated how standard methods used to gauge users' views are less likely to reach disabled people than to reach non-disabled people. They suggest that standard modes of administration of various survey instruments for example, run the risk of being tokenistic, by not allowing sufficient time or by being offensive or alien in their content. They point out that this is not limited to the completion of questionnaires or surveys (as discussed in chapter 1) but includes aspects such as sampling methods. One routinely-used sampling method is to ring a randomly selected telephone number, so called random digit dialling. If the call is not answered within a set number of rings or is answered by an answering machine, that person is not included in the consultation exercise. Meyer & Andresen note that people with disabilities may routinely take longer to get to the telephone and may screen calls using the answer-phone for a variety of reasons. Though the sampling therefore appears to include people who have impairment, without addressing such detail, the reality is a lack of genuine participation. They suggest including people with disabilities in the design of instruments before they are used, and addressing sampling methods to ensure that 'we stop deceiving ourselves that results from our population-based research are entirely representative'.

6.1.2.4.4 The need to avoid abusive involvement of users

Kerruish (1995) describes the process she went through when investigating what residents thought determined a good quality mental health service. She describes how she identified that her original research protocol was likely to be oppressive for the research participants, and that there was a risk of her misrepresenting their views. Having identified these potential limitations, she changed her methodology to ensure that she and people with mental health impairments worked together as allies, ensuring that the information gained was representative and the research process upheld basic human values such as equality, reciprocity, empathy. Kerruish also documents evidence to show that more accurate information was provided when researchers spent time getting to know people and when they had regular contact with participants during the research.

Warmsley (2001) also suggests that for people with learning difficulties to engage as equal partners, it may be that the role of advocate is necessary, and that that role is often taken on by the researcher. Trust therefore needs to be established and researchers mentioned above were keen to demonstrate their genuine interest in, and respect for the people with whom they are researching. These authors, therefore, proposed that use of participatory or emancipatory methods can overcome misuse.

However, this is not necessarily the case. Northway (2000) demonstrates this with regard to one particular aspect of participatory research. She suggests that researchers investigating such disabilities as mental illness or learning difficulties often advocate nurturing close relationships between both parties in the research enterprise (Kerruish 1995 and Cassidy 2000). They consciously seek to build up relationships with research participants that diverge from the traditional role of ‘objective observer’, and are instead actively engaged in a close working relationship (Northway, 2000). However, as Northway then points out, very careful thought should precede fostering these relationships. When it comes to the end of the research, difficulties may arise

> “ending research with people who have limited social networks may mean either that they are subjected to a very negative experience or that the researcher is required to maintain contact with their co-researchers long after the research project has ended” (p34)

Carrick et al (2001) raise another issue related to the potential abusive role of the researcher who works within the participatory paradigm. The participant may feel an obligation to take part in the research, even divulging information when they would rather not, because of a feeling of obligation to the researcher with whom they have established a non-traditional relationship.

> “They could be left feeling used or left feeling that others are interested in their opinions. The impact is dependent on how the research is conducted. If participation can be experienced as what I term a ‘fair social transaction’ then the approach is acceptable. What is fair must be judged based on a subjective consensus between researcher, participant and disinterested other, and there being no obvious harm done” (p222)

The researcher who is striving to conduct research in a way that does not misuse users then has a difficult balance to strike. Objectivity should be abandoned (Bury 1996). If users are to be participants within the research process, a relationship has to be established for research to legitimately take place. The balance must be struck between establishing a relationship that enables open discussion amongst those with equal power, and fostering a *dependent* relationship, or becoming so close that ending the relationship when the research finishes is problematic.

Honesty within the collaboration about aims, roles and aspirations, is likely to negate some of the potential pitfalls. But the potential for misuse is recognised. Additionally, a researcher can strive to practice participatory research but it is difficult to know how to stop misuse of such information, no matter how ethically and legitimately obtained, once it goes into the public domain.

6.2 Conceptual and methodological issues of social relations within aphasiology and within the research project

There is evidence to suggest that some SLTs have been open to introspection and change. Previous discussion demonstrates that members of the SLT profession have shown their willingness to challenge old traditional paradigms, embracing the social model of disability, and altering their clinical practice as a result. SLTs such as Pound, Parr and Byng have been instrumental in extending this inclusive approach into the field of research within speech and language therapy. Pound (1996) for example challenges, among others things, the methods used to conduct research into communication disability. She enthuses that

> "the qualitative in-depth interviews with aphasia 'experts' (people with five or more years experience of living with aphasia) offer an exciting alternative to professionally constructed and motivated medical research agendas by valuing and validating 'lay' accounts of what living with aphasia is all about" (p13).

There are examples of pioneering collaborative research put into practice, where SLTs have worked inclusively with people who have aphasia. Ireland & Wotton (1996) reported on research that sought to evaluate a counselling service for people with aphasia. There were two researchers, who were also the people who provided the service. One was an SLT, the other was a teacher prior to acquiring aphasia. Both were trained counsellors. When examining the collaborative research process they comment on both positive and negative aspects. They acknowledge the differing positive contributions made by both parties, but highlight the difficulties in involving someone with language impairment fully in a collaboration that culminated in a peer reviewed journal article. They recognize that

> "meeting the linguistic demands of academic culture proved to be somewhat of a barrier to the final stages of collaboration. However, the experience of this project suggests that, with support, people with dysphasia can undertake research into their own condition and can contribute to writing up and dissemination. One of the main challenges for collaborative research is to think creatively and flexibly about ways dysphasic people can involve themselves in all aspects of the research process. " (p590)

Parr, Byng and Gilpin with Ireland (1997) provide another example of how SLTs and people with aphasia have worked within the participatory paradigm. Parr and Byng both trained and worked as SLTs. Gilpin and Ireland are both trained as teachers. Both had strokes that left them living with aphasia. Together these researchers designed the project, interviewed 50 people with aphasia about their experience of living with aphasia. This information was classified, indexed and analysed to identify responses, themes and issues pertinent to the topic. The resulting information was then framed within a book entitled 'Talking about aphasia'. Throughout the research process the investigators were supported by two advisory panels; one consisting of academic, clinical and professional specialists, and the other made up of people who have aphasia. Thus other SLTs had been successful in working on inclusive research projects with people who had aphasia.

6.2.1 The social relations of the research project

I began and ended my exploration of how to investigate the impact of acquired aphasia, as a non-disabled, healthcare provider, with a career history predominantly in acute clinical or research settings. As such there were a number of challenging issues I had to address as I undertook this research project. I will discuss the personal outcomes that I have arrived at as a result of this process in the last section of this thesis. However, there were conceptual and methodological issues that arose from my status that needed to be addressed. They related to the legitimacy of my involvement in disability research, the legitimacy of the project as an endeavour and the end product of the project, the CDP.

As a non-disabled, health care provider I could only be justifiably involved if there was a demonstration that there was equality within the power relationships between myself and the people with aphasia that I came into contact with as a result of the project. I needed to address the way I have involved people with aphasia throughout the project and to ensure that the methods of the project were not abusive.

As has been mentioned previously, there is an appreciation of the inequality of power, status and gain within traditional social relations of research. Within this project the potential for these inequalities to be perpetuated was recognised.

6.2.1.1 My research role as a non-disabled healthcare provider

Having trained and practiced as a SLT my role as a researcher involved in a project relating to disability could be questioned. However, as has been discussed, the contribution of health providers to the field of disability research is seen as being legitimate if a number of factors are demonstrated as set out in section 6.1.1:

- an acknowledgement of the previous and potential inequalities within the research relationship
- a need for partnership to be established

- a need to relinquish power and to become a resource for the use of disabled people
- a rejection of independence and an open alliance between her/himself and disabled people, against traditional individualistic conceptions of disability and service delivery.

I was being forced to examine my own prejudices and experiences of people with disability. My reason for becoming a SLT had been people with aphasia. I had always wanted to work with people who had aphasia. I had spent all my working life offering a service to people who had aphasia.

I had first begun to significantly question my own views on my role as provider, when I moved from working in the acute healthcare sector, into community health services. I had always felt uncomfortable in the acute sector, feeling that SLTs' aims, methods and ethos for service delivery were inherently different from many other healthcare providers in that setting. However, I did not question the view that essentially disability was located within the individual and that it was our job to reduce the impairment to enable the person with aphasia to engage in their desired lifestyle again. Moving into community-based health services changed my views. The details of this in the context of challenging my personal and provider role in the provision of health care (including future clinical and research practice) are discussed more fully in the final section.

The tool I was developing also came under scrutiny. At this point, having moved into community healthcare service provision, I would use elements of the DQ to begin the negotiation process, but became increasingly aware of its individualistic bias. I became committed to the idea of locating the DQ within the social model of disability, as one step towards enabling people with aphasia to identify the barriers and facilitators in everyday life that existed for them. Once I was able to commence the research project, I hoped to enable SLTs to establish a dialogue with the person at this level to ensure irrelevant, inappropriate interventions did not take place. My clinical practice was being informing my research agenda.

As discussed in chapter 3 the literature about inclusive research and social models of disability can make uncomfortable reading for non-disabled health professionals. Scullion (1995) for example citing Thompson (1993) suggests

> "that researchers 'name the enemy we are fighting' and the enemy, according to many disabled authors is the whole of society, but with particularly

> vehement criticism being reserved for the institution of medicine. Perhaps because of their subservience, other professions such as physiotherapy and nursing appear to be cast rather less in 'the enemy' role, but there are criticisms from within these groups." (p319).

If I was to have a legitimate role I wanted to show my allegiance to the social model of research practice. My starting point for that was the inclusion of the advisory panel, and the re-examination of the constructs behind, and construction of, the CDP as it stood at that point (draft 1). Until that point the tool was a professionally-informed instrument. People with aphasia had not had control of any aspect of the development process. Having the advisory panel ensured that that changed. The impact of that collaboration will be discussed later in this chapter.

6.2.1.2 My role as a non-disabled researcher

A second significant issue to be addressed was that of being non-disabled. As has been discussed earlier in this chapter, there have been those who question the inclusion of non-disabled people in disability research. As with addressing my perceptions of my provider role, so I addressed the issue of my status as non-disabled, my role in oppressing disabled people and the benefits that would accrue to me by doing the research project.

Before the creation of the advisory panel, the balance of power in my relationship with people with aphasia in the research project had been skewed. As is mentioned, involvement until that point had been at the level of information providers. I was in control of all aspects of the project. The benefits of publishing the CDP on an academic, professional and financial level would be solely mine. The tool as it stood should enable SLTs to establish a meaningful therapeutic dialogue with someone who was living with aphasia. However, the remit of the tool was still limited.

Obviously, these considerations were running in parallel to considerations about my being a health professional. So the conclusions reached for both were the same. I agreed with Barnes (1992) that it is not necessary to have an impairment to conduct good research. He concludes that the experience of impairment is not a unitary one, and that having impairment does not necessarily give an affinity with disabled people or an inclination to do disability research. I was mindful of the caveats relating to non-disabled people conducting disability research however, that any involvement must be cautious and considered, constantly bearing in mind the potential for oppression and abuse of power.

I also had to address my attitudes to disability, from a personal perspective but also as they informed the aims and use of the CDP itself. I will discuss the personal aspects in the last section of the thesis. However, the attitudes I held would influence the very nature of the CDP. I had to revisit the CDP to ensure that its use would not further oppress those with whom it was used. So there were a number of issues relating to my non-disabled status.

Kitchin (2000) interviewed a number of disabled people about their attitudes to disability research. He found that the disabled status of the researcher was not an issue as long as the researcher was approaching the research from a 'disabled-friendly position'. The sections that follow exemplify how I sought to equalise the power relationships within the research project, more generally.

6.2.1.3 The research project

Carrick, Mitchell and Lloyd (2001) suggest that

> "the extent to which the research process is empowering or oppressive will depend on the research questions being asked, the power dynamics of the setting in which the research is conducted, and the particular people involved" (p223)

This project evolved out of the realisation of the inadequacies of then current methods of assessment practiced by SLTs with people who had aphasia. My principle motivation at the beginning of the project, had not related to becoming a researcher, but to effect change in how services were delivered to people who had aphasia. My starting point was how I could make speech and language therapy input more appropriate. I was aware that there was an over-reliance on impairment-based practices. I saw a need to redress the imbalance of assessment methods. It was necessary to ensure that assessment procedures (and therefore intervention) related to communication for life. I saw a need for a dialogue to take place to allow this to happen and saw the DQ as facilitating this dialogue.

However, I had not at that stage appreciated the individualistic focus of the DQ, the lack of consideration of the role that external factors had to play in disabling someone with aphasia, nor the limited way in which people with aphasia had been involved in developing the tool. Equally, the process of development itself had taken place *within the existing predominant research paradigm.* The CDP's ultimate aim was to expand the relevance of assessment procedures, but again the existing paradigm of service delivery would not be challenged. The balance of power between SLT and the person with aphasia would still be unequal and unaltered if I had continued the development of the DQ without involving the advisory group and without confronting some of my own prejudices. Though being led by what Kerruish (1995) called basic human values, throughout the first three stages I had not considered the power relations within the project or specifically what role I or people with aphasia had played. I saw the goal (a social model assessment tool) as being enabling for people with aphasia and thus reflected little on the process of the research.

There now follows a reflection on the social relations of this research project. To support this reflection, Table 6.1 documents the stages of development and the level of involvement of people with aphasia at the various stages.

6.2.1.3.1 Stage 1

At the beginning of the project (phase 1), the concept of the tool (the DQ), constructs and implementation of the process was professionally conceived. I observed the reaction of people with aphasia to completing the DQ, noted opportune comments made relating to participants views on the instrument, and altered it when obvious difficulties or inadequacies were observed or expressed. However, no options were sought from the users about the tool itself. Invovlement was piecemeal and incidental.

When field testing the DQ in the later phases of stage 1, people with aphasia were involved, almost exclusively, as information providers. I did take advice from people who had aphasia but in a cursory manner. In retrospect it felt a little like the manager-professional contributors described by Harrison & Mort (1998), who ‘played the user card’. I took advice but ignored it if it didn’t fit in with my conceptualisation of the tool. In retrospect a number of important issues were raised that were not acted upon until much later in the process, when they were raised again and I was receptive to the significance of the comments. These included comments about the process being hard to follow, and mood state being influential.

Stage 1 had included people with aphasia purely as information givers.

6.2.1.3.2 Stage 2

By stage 2, people with aphasia were consciously included in the project. The views of the aphasia experts (those who had lived with aphasia for at least a year) were canvassed in DQ user interviews. People with aphasia, who had completed the DQ, were asked their opinions of the tool and the procedure. They were being given an opportunity to have their views heard, to become part of the development process. This stage felt more inclusive. The person doing the interviews was independent of me and of the tool. The depth of the questioning, and exploration of ideas expressed by the people with aphasia offered an opportunity for those present to feel some degree of control of an aspect of the development process.

However though this stage was deliberately inclusive it still did not force me to reflect on my role as researcher, nor on the degree of control people with aphasia were able to exert on the process.

The way in which the inclusion was implemented exemplifies the limitations of the inclusion. The DQ focus group was just one meeting. When the DQ was administered with the people with aphasia who would form the DQ user focus group, it was the first time that we had met. Hetu et al (1988) caution against interviewing on first meeting as intimate aspects such as how the phenomena affects personal relationships are likely to be underreported on the initial meeting.

Completing the tool on the first meeting was never the intended method of administration for the tool, and was seen to have negative consequences, for the research process and the participants. One participant reported feeling uncomfortable about discussing such issues on the first time of meeting.

> *"the first time its first time I and we did ask for things like that and I should have said straight away take it easy please instead I just said this one and that one".*

This respondent clearly demonstrated that he felt uncomfortable rating issues he had been asked to make on his first meeting with the researcher. There were factors that undoubtedly exacerbated this feeling of powerlessness for this respondent. He had significant comprehension impairment, was an hour late for the appointment and arrived flustered. Though he was the only one who mentioned the difficulty of completing the tool on the first meeting it was clearly problematic for him. At this point the research was being carried out unfunded, and in half a day discretionary study leave per week, with participants being recruited from a wide geographical area. Restrictions of time and resources had therefore overridden consideration of appropriate research methods and sensitivities to the participants involved.

The involvement of people with aphasia at this stage was reminiscent of how Rowan (1981) describes traditional research, with participants permitted a very restricted range of behaviour to be counted. The person's actions do not belong to the individual but to the researcher and the research plan. There was evidence that in some instances the implementation of the process was less than affirming. Additionally the modification of the tool was still wholly under my control.

6.2.1.3.3 Stage 3 and 4

Stages 3 and 4 were the most inclusive. However, within these stages there was evolution. I began with group and individual in-depth interviews. The advantages of qualitative research methods have been discussed. In-depth interviews were conducted for two reasons. The first was to gain perspectives and experiences about the range of experiences that are associated with living with aphasia. This information informed changes that were made within the tool, and served as a means of ensuring the validity of the final version of the tool. The second reason for completing in-depth interviews was to inform and educate me, as a health professional, and as a non-disabled individual. This was only partial. It could not be claimed that there was any alteration in the power relationship as a result of the interviews. It is possible that people felt a sense of gain and reciprocity through having their views listened to, acknowledged and used to effect change, but the research process was still distant to them. They had no control over it.

I was still in the traditional expert model approach, despite canvassing experiences more positively and engaging with people who had aphasia, in a state of active questioning about my views and prejudices. Though my own personal views and prejudices may have been being altered (this will be discussed further), the social relations of the research had not.

It was only after the interviews that the research process shifted beyond traditional research relations. The liaison with the advisory group was the most significant step forward. The inclusion of the advisory panel felt like a dramatic departure from what had gone before. The alteration of the power relationship felt significant. People with aphasia were there to advise me, not merely be used to supply information.

The panel played a key part in the development of the CDP. They advised me on how sections should be categorized, what should be included in the sections, and the acceptability of the categorization and the rating systems. They constantly challenged me to rehearse the purpose of the tool, and kept me focused on the user's perspective. As the process progressed the panel members were increasingly able to step back from their own experiences and contribute to the wider picture. They were able to consider the wider context of the constraints of tool administration. Without the panel, decisions would have been made in a vacuum. As a panel we discussed, came up with a reasoned stance on one position, and then decided, collectively, how to implement the consequences in an aphasia-friendly way.

During this process, I began to see that decisions could and should be made by the advisory panel. They suggested how the tool should be modified and I enabled those changes to take place. By doing so, I felt that power was taken out of my hands and placed collectively with the group. I was a member of that group and as such had rights to contribute to the discussions and decision-making, but the decision-making was shared.

There were a number of occasions of disagreement. These instances always moved the alliance forward. One related to the validity of including the external influences section. The direction of the debate focused on whether it was acceptable to include this section *at all*. One panel member was quick to voice his uncertainty about the section. He questioned the need to discuss issues that he felt were self evident. His message was “we all know it’s easier if people give you extra time, worse if you interrupted so waste time to talking about it?” The social model of disability suggested that external influences needed to be addressed. I had introduced this section based on this sound theoretical reasoning specifically to make it more acceptable to people with aphasia. This section was the cornerstone to relocating the tool from a medical to a social model perspective. The direction of the discussion was therefore both surprising and somewhat unnerving for me.

The discussion that ensued forced me to consider whether something that was philosophically important would also be of therapeutic significance. I was able to reflect and articulate that the rationale for this section was to raise awareness for the person with aphasia of the strategies around communication impairment that were successful or not for them, some they may be aware of, others they may not have considered and therefore could try out. Identifying both barriers and facilitators could help in terms of therapy planning, working to maximise the facilitators and reduce the barriers. It could also contribute to the formation of the ‘self-with-aphasia’ identity as previously mentioned.

This discussion about self-awareness of people who have aphasia brought another issue more sharply into focus. All the advisory panel members had lived with aphasia for many years, and had all been exposed to therapies that aimed at raising awareness of their own skills and limitations, and the barriers and facilitators around them. They would therefore differ from people who had been living with aphasia for a relatively short time. For this group there are issues that the advisory group had not considered but were highlighted through discussion.

The first was that people who were newly aphasic would probably not yet have established a part of their identity that incorporated aphasia. Raising awareness of these external influences was seen as particularly pertinent for people who had recently acquired aphasia whose 'self-with-aphasia' identity may well not be established or acknowledged. The panel of experts all knew their acquired 'self-with-aphasia' very well. People who had recently acquired aphasia might not be in that position and this section could help them with that process of redefinition. This included consideration of prediction and control. If a person had recently acquired aphasia, s/he may not have identified which factors (be they people or situations) had an influence on how s/he communicated. At this point in someone's life with aphasia, the person may be conceptualising the difficulties s/he was experiencing as being located wholly within her/himself. S/he may not have considered the contribution external factors were making to this experience. S/he may feel that the world as a person with aphasia was frighteningly unpredictable, things might seem to happen at random, beyond that person's control. If s/he could establish that talking in noisy situations was always difficult, or that communication with one person in particular was usually successful, for example, then the process of identifying these influences could bring some degree of prediction into a seemingly chaotic world. For the team of the SLT and the person with aphasia, there is a starting point to explore why certain things or people are helpful or hindrances, and begin to identify how to manipulate them to maximise participation.

The final issue highlighted by the discussion within the panel (a discussion which lasted over two sessions) was that of the role of acknowledging the person's experience as legitimate. Part of the purpose of the CDP was simply to give the person with aphasia a means of expressing the reality of her/his situation. To be able to state that certain situations or people were problematic was seen as valid. Experience of administering the DQ had shown me that this was particularly the case for those who had little or no means of expressing themselves verbally. Though people at that stage were not asked about external influences, people with severe expressive difficulties were often the ones who were notably relieved at having had the opportunity to 'voice' their experience of living with aphasia, as if the process had in some way been cathartic.

So through this particular discussion I was able to define and confirm the purpose of the tool and why the perspective of one panel member might initially differ from mine. From a personal perspective, when the discussion began I felt somewhat defensive in my need to justify why this section should be included. By the end of the discussion I felt exhilarated by the depth and frankness of the interchange, by the practical benefits in terms of the suggested outcomes, and by the knowledge that we had all gained a degree of insight into the purpose of the CDP, of both the process and purpose of collaborative working that had not been there before the discussion took place.

Equally, for the members of the panel who had aphasia, there was a feeling that each member growing sense that their experience of aphasia was not the only experience of having aphasia. Different people would be differentially aware of what factors could help or hinder in different situations. Northway (2000) suggests that

> "Within participatory research the participants and the researchers both work together and learn together" (p29)

This was an example of where we were all working and learning together. It was an example of where my original view prevailed, having had a full and frank discussion. There were occasions where it did not.

There was debate about what factors would hinders writing. The panel suggested that having a hemiplegia should be included as being a barrier to writing. I thought not, as nothing could be done by a SLT to effect change in this area and the main purpose of this section was to identify barriers that were amenable to change by the SLT. However, the discussion which ensued convinced me that a further purpose of establishing the new identity should include the presence of a hemiplegic arm. Raising awareness and issues of identity were also key. Emphasizing the fact that there was a distinction between difficulties arising from motor control and difficulties arising from letter or word selection, was crucial in terms of establishing a 'self-with-aphasia' identity. Additionally simply being able to express and validate the fact that writing was hampered by the physical impairment was seen as key. The item was therefore added.

The collaborative process of the advisory group felt fundamentally different to what had gone before. The process involved the advisory panel members controlling many aspects of the modifications, decision-making and development of the CDP. As Kitchin (2000) experienced

> "interviewees favoured a partnership approach where instead of merely advising the researchers, disabled partners have a degree of control over the research process which is not tokenistic" (p38)

The final stage (stage 4) returned the tool to the people who would be using it, to check its clinical usability, with the final decisions being taken to the advisory panel. By the questions asked of the pilot testers and the need for solicited comments made by those with whom they administered the CDP, this process remained participatory. People with aphasia were actively included in the feedback of clinical utility and, most significantly despite health professionals being canvassed for their opinions, the advisory panel were the final arbiters.

6.2.1.4 Reflections on working with the advisory panel

The CDP changed considerably as a result of the direct collaboration with the advisory panel. Table 5.13 documents the modifications directly attributable to the involvement of the advisory panel.

6.2.1.4.2 The challenges

The embracing of people with aphasia as collaborators in research work is not without its practical and ethical dilemmas. The practical consequences of including people with aphasia actively in this type of research are significant. The logistics of arranging meetings were less than straightforward when dealing with people whose written and verbal communication was compromised. Letters had to be written in an accessible way (different for each group member depending on their differing communication needs – see appendix 6.1 and 6.2), reminders had to be sent before every meeting, diary entries had to be double checked, the timing of meetings and breaks had to be borne in mind.

When group members could not attend, information was prepared in advance and sent to a panel member. Issues that needed their consideration were highlighted so that their comments could be included within the group in their absence (see appendix 6.2 and 6.3). After the meeting had finished written summaries of the content of the meetings were sent to the absent member. Such documentation is extremely time and energy consuming.

During the meetings it was necessary to ensure that those with the most impaired language were included and their contributions valued. Group interaction is fast and complex. Aphasia can reduce someone's ability to comprehend spoken language and to formulate replies quickly enough to enter the conversation. More subtle markers of intent to speak such as facial expression, gesture or pausing can get lost in this quick-fire environment. Additionally being unable to find a word or phrase consistently can restrict a person's ability to verbalise suggestions particularly if they require nuance of phrase. Intricacy and/or significance of the person's contribution can be masked by aphasia. Enthusiasm for the discussion could complicate this process.

As can be seen from table 4.3, more than the other group members, John's access to both understanding and articulating language was difficult. The linguistic complexity of discussion had to be kept in control. Efforts were made to revisit topics or conclusions made previously. John was actively encouraged to contribute, by specifically offering him the opportunity to share his views rather than relying on him to interject. When issues relating to choosing accessible wording arose, I felt John was best placed to offer insight into whether the phrasing was accessible or not. I was also, aware that focussing this degree of attention on him specifically because he had the most significant impairment, could be stigmatising and detrimental to the emancipatory philosophy I was attempting to engender. I therefore approached him at the end of a session when all other group members had left and asked if he would help me finalise the wording. I had separate meetings with him alone to discuss options for wording. I hoped that by doing this, John would feel valued for his contribution but not embarrassed by the focus on his impairment. I would sometimes send him the options in advance (as can be seen in appendix 6.3). I put forward John's choices as possible options. His conclusions were always ratification by the other group members.

As has been discussed there were a number of occasions when the needs of psychometric rigour and the needs of accessibility of the CDP conflicted. Discussion concerning issues such as how to rate various sections, the hierarchy of item presentation, language used (e.g. whether, or how, to include the word 'aphasia' or not) took place. The debates have been discussed in chapter 5. Discussing psychometric matters with people unfamiliar with the complexities of test construction is complicated. Discussing them in accessible language with people who have language impairment was even more challenging. I felt, however, that to be truly inclusive it was best not to 'filter' information purely in relation to what was easy for me to convey.

I wanted the panel's contribution when weighing up the merits of the competing influences of psychometric robustness versus 'enabling' the CDP. The challenge for me was to make the background information accessible, to facilitate debate. I did this by taking time before the meetings to prepare support information. I then brought this written or pictorial information, together with clearly thought out questions that needed to be addressed. I would present the information, describe why there were competing interests and then use the facilitative techniques mentioned above to ensure accessible discussion. Appendices 6.4 - 6.8 were used when discussing the different possibilities for rating scales, for example.

As mentioned, there were examples of disagreement. I endeavoured to use my skills to present information, facilitate discussion and listen to the views that were proposed. During and when concluding the discussions I was constantly mindful of my part in the discussion in terms of use of power and direction. Ultimately, however, I was the one who made decisions, following debates. In addition, I was the one who chose the agenda for each meeting. I was the one who chose what information to present to the group. Ensuring that my influence was not overpowering or negating that of the other group members was testing. This process required self-examination, examination of the research process, and examination of the research paradigm within which we were operating.

6.2.1.4.2 The benefits

When I first convened the advisory group I thought its function was to advice me how pictures could be incorporated into the tool. As I read more widely, as the group progressed, and their experience and views were expressed I saw that the group would fulfil a much greater role. The advisory panel challenged every aspect of the CDP. As has been mentioned , they made me consider, challenge and reconsider whether each section should be included, how the rating would work, the need for rating, how accessible and acceptable items and their depictions were. They challenged but also provided insights, guidance, solutions to problems, and perspectives I would have been unaware of had I not consulted with them in such a close way. The panel have also been instrumental in guiding me through the process of collaborative research.

The panel kept me focused on the fundamental purpose of any tool used within aphasiology. Through their challenges and discussions I was forced to clarify my thinking about the *raison d'être* of the tool. At a fundamental level, I had to re-evaluate the reason for assessment, what assessment is, should and could be.

The panel have guided me through the philosophical and practical gamut of involving users meaningfully in the research process. One of the main issues they have raised for me is that of accountability. Moore et al (1998) suggest that

> "this issue, of who values the research…is critical…research is always prejudicial and notions of independence and objectivity fictitious. Researchers are always accountable somewhere along the line (p15).

I was relatively untroubled by accountability to funders. Though I was funded for a year, by a medical health charity, the majority of my work took place without funding, enabling me to be flexible in both setting and implementing the research agenda. I was accountable to my academic supervisor, Sally Byng. Happily she was one of those at the forefront of championing the rights of people with aphasia, and working tirelessly to challenge the traditional structures and practices within which healthcare providers practice. I had nothing but wholehearted support and encouragement from her in my endeavours to change my own perceptions and practice. I also feel I was accountable to people with aphasia. The advisory group constantly grounded the work in the lived experience of having aphasia. They fedback their views on whether I was getting it right, then and *in the future,* for the constituency of people with aphasia.

There is no doubt that involving people with aphasia in participating and influencing research was demanding. It challenged my personal and professional prejudices, attitudes, and practices. It was time-consuming, and required detailed, thoughtful preparation and implementation. The process was complex and organic. These very complexities however, fed the discussions that enabled the process, and the thinking of all of us to grow and develop.

6.2.1.4.3 Advisory panel interviews

I have considered the role I played in this research project. I have argued that the changes in research practice that I adopted facilitated an open, collaborative partnership between the advisory panel and I, working towards a participatory method of research. However, as Carrick et al (2001) suggest, whether the research has taken place within a 'fair social transaction' must not be the judgement of the researcher.

It was therefore insufficient for me to attest to the validity of the research process. To obtain the views of those who had been my research partners over the most extended period of time, in depth interviews were conducted with members of the advisory panel.

Reporting these interviews could have been taken place within the methods and results of stage 3 and 4, covered in chapters 4 and 5. However, their sole purpose was to verify how successful my attempts at inclusive research had been. All descriptions pertaining to them have therefore been confined instead to this chapter. The interviews do not form part of the process of development of the CDP, but are only of interest in how they inform the discussion relating to the social aspects of the research process.

The person conducting the interviewers was known to myself and the members of the advisory group, and was experienced in conducting qualitative interviews with people who had aphasia. She interviewed each member of the advisory team individually. Her focus of questioning all related to social relations of the advisory group; she asked questions about the group members perception of their own roles and the role played by me; their perception of the purpose of the meetings; their degree of understanding of the research process; their view of the CDP itself and the use it could be put to; the group members perceptions of the power relationships within the group, and their perception of their own contribution to the process. The interviews were audio-taped and transcribed.

6.2.2 User participation within *this* project.

I shall be referring in detail to the information gleaned from the advisory panel member interviews within this section. However, this information will be interspersed within considerations of the three essentials on which Oliver (1992) suggested an emancipatory research paradigm must be based, namely reciprocity, gain and empowerment.

6.2.2.1 Power

From a personal perspective I believe I have always had *some* appreciation of the power relations inherent in healthcare research. I have always taken issues of accessibility and truly informed consent seriously.

Working with people who have communication impairment increases awareness of issues such as accessibility. However, it cannot be presumed that issues such as accessibility and properly informed consent are routinely considered by SLTs.

Appendix 6.9 shows an example of the information and consent form used in a study investigating outcome assessment in adult aphasia (title and identifying names have been deleted). The study was conducted by a SLT under the direction of a department of audiology and speech pathology. It highlights the need to take such details as lay out and linguistic simplicity seriously, if consent is to be truly informed for people with impairments of auditory or written comprehension. There is too much linguistic information, presented in an unclear format within this form. There are no pictures to aid comprehension. It is questionable whether signing this form, demonstrates truly informed consent for people with aphasia.

At the early stages of this project, when I was recruiting for user focus groups of people with aphasia I took care to ensure that participants were not coerced into participation, that their involvement was truly informed from the beginning and throughout their involvement. Revisiting appendices 2.7 and 2.8 showing the 'aphasia-friendly' information and consent forms used at the start of this project demonstrates that these issues have always been carefully considered.

Though such issues have always been considered important, it was not the case that power was distributed evenly between the researcher and the researched throughout this project. As has been discussed it was only in the final stages of this project, with the involvement of the advisory group, that these issues have been actively addressed.

During the running of the advisory group, effort was made to ensure that the group was collectively responsible for decisions that were taken about the tool development, and that group members felt they and their contributions were being valued. This was achieved by timing the meetings to be convenient to the group members, ensuring the atmosphere of the meetings was relaxed, friendly yet methodical, and that people were really listened to and their opinions valued. If a panel member could not attend their views on that subject were canvassed in other ways. The quotations below give testament to the fact that these things were largely achieved.

Panel member Harry

"I think we made a huge difference I think... Well I'm not sure it could have been done without us really. It couldn't have been done without us."

Panel member Sue

"she listened attentively and carefully. Was careful to... include your erm...

views."

Panel member Sue

"there were occasions when I couldn't make a meeting and she was very careful to send me the stuff so that I could do it at home, and then back to her so she could include that for the project. It kept me involved as well."

Panel member Harry

"it was officially my day off and when I was here I felt quite refreshed...so the timing generally was okay because I didn't have to... it wasn't one of the many agenda for the day. Time to get there... a few cups of coffee, biscuits. Two hours. Lovely environment. Nice people. Very democratic process."

So people felt valued and included in the process. There was also a need to ensure that the environment was such that panel members could feel in control of the process. This would contrast with previous relations within this research where the researcher had control of how the information that had been gained was used. The quotations below suggest that the advisory panel members did feel in control of the process, though as the last extract suggests there was an acknowledgement by one panel member that the project belonged to me ultimately despite her feelings of involvement and gain. When asked who was in control of the process, panel member Harry replied

"Oh we were definitely, yeah we were"

and then

"Every step was in a way guided by people with personal experience of aphasia."

When panel member Sue was asked if she sensed it was the researcher's project she replied

"No, no. Personally I felt really valued... valued as a team member"

She did, however, conclude that

"she was very inclusive, and erm... careful to make sure that everybody was open to take part, everybody was able to say what they felt. Overall we all knew it was Kate's project."

This acknowledgement is not seen as necessarily negative. As Kerruish (1995) suggests

> “Where the researchers take more control in the research, it is important to be clear why this is, and to be completely open with people so they do not feel used.” (p139)

One final aspect of the project that relates to power is how the information gained is disseminated. To ensure that there was no misuse of the contribution of the advisory panel, I did a number of things. I consulted each panel member individually about whether they wished to be referred to by their own name or by pseudonyms to preserve anonymity when writing up the contribution of the panel in this thesis. I then fed back the information that I will write in this thesis to the advisory group members. Again a process of editing and abridgement had to take place, before the information could be presented. The quotations that are presented and relate to the advisory group have been agreed by each member of it.

6.2.2.2 Reciprocity

The second theme when considering social relations within disability research is that of reciprocity. A feeling of being involved in a collaborative exercise further strengthens the likelihood of empowerment. Collaboration can be fostered by ensuring that all members feel they are contributing to the process positively, without a sense of being coerced into participation, decisions or judgments. The quotations below again attest to this being the case.

Panel member Harry

“Erm... it was...was consultative, and collaborative”

and then

“I felt that we were into it...thinking, and really getting into particular things and big discussions.”

He goes on

“I didn’t think Kate tried to coax us or push us into any ideas or...or be influenced by her particular slant on things. I thought it was very democratic. I thought Kate put a lot of... she’d obviously put a lot of hard work in. She kept it all together. She erm...I don’t think she pushed us in any way. My feelings, she has a vague concept and an idea of how it will look but every step she would check it for feedback.”

He concludes

“I think the team were no shrinking violets. We would...I guess there were certain things that people felt a bit strongly about, you know I see what you

mean but erm... whereas somebody would say I think it's important. Obviously that's for whatever reason...you feel a bit stronger than I do, but I can see your point and because you feel that strongly we should take it on board and reshape it, re-draw it, that's what I think."

Panel member Sue agreed

"she was very amenable to all our suggestions"

Sue concludes

"Well working as a group, as a team was great. We met..., I felt it was a real team effort and not just Kate asking us to do tasks for her. I thought she was so much a part of the team as well, there was no distinction between us and them...it allowed us the freedom of saying what we truly felt."

John concurs. In answer to the question about whether his opinion matters he replies

"I suppose yes. I suppose I did agree. I did argue. Argues a bit and I can remember when she was quite ... a lot of times she was more...oh yes kind of thing. She suddenly ...she thought it was perfectly okay to say no it's a so and so"

(Interviewer – "so you could see her rethinking her opinions?")

"Yeah...it was great"

The feeling of reciprocity through mutual respect and involvement is therefore demonstrated.

6.2.2.3 Gain

The final theme to consider when examining research relations is that of gain. As has been discussed, if participatory working is to be achieved, then both parties involved need to feel that they have gained something from the process. The one-sided nature of the researcher walking away the better, whilst leaving the people with a disability in the same state as before is not acceptable. This was a small scale research project so the gains made are not likely to be enormous. However, the quotations below demonstrate a sense of the research being a positive experience, which increased feeling of self worth.

Panel member Harry suggests that

"It was rewarding as we saw it come together...rewarding... the process of it was...it was good to come up with some idea and they were well received, and I thought I'm pleased with that. I remember Kate..."I'll write that down...that made me feel good."

And then again

"A good experience yeah...I would do it again and I hope to do something like it again"

Panel member Sue concurs

"it gave me a lot of satisfaction to be a part of producing something like this which I know will be very useful to a lot of people, it was a good feeling"

as does panel member John

"I actually enjoyed it. I found it was interesting"

and later

"I thought it was marvellous...and for me something to come out thinking wow! I understand that"

Furthermore, group members Harry and Sue are counsellors and both felt that the finished product will enhance their work with people who have aphasia.

Sue

"I've gained a tool I can use with my clients"

This will be discussed in more detail later in the chapter.

6.2.2.4 Emancipatory, participatory or more of the same?

When beginning the project, nine years ago, consideration of social relations within research production was not widespread in the health research community. Oliver and Zarb had only just published their groundbreaking articles relating to relations of research production in the field of disability studies. By the end of this period, emancipatory research was very much on the agenda, and views about power relations within research practice had changed fundamentally. Today, anyone involved in disability research has to question her/his role within this wider political arena.

Without doubt, were I to begin the project now, its design would be fundamentally different; with the involvement of people with aphasia at its inception, discussing and designing the protocol and then collaborating throughout the process. It is possible of course that were people with aphasia involved at the protocol stage, they might choose not to back the project in the first place!

The final stages of this project were clearly the most inclusive but could it be said to be participatory, emancipatory or actually just more of the same? For research to be seen to be truly inclusive the research participants must feel a sense of power over the proceedings, they must experience the process as reciprocal, and feel that they have gained something from the experience. In the wider context, for the research agenda to be inclusive, the people who constitute the focus of enquiry should dictate the choice of research that is conducted, the way it is conducted and the people who will conduct it.

The quotations and discussion above show that once people with aphasia were involved in long term, meaningful dialogue with the researcher, power transferred in part away from the researcher and towards members of the advisory team who had aphasia. All the members of the advisory panel who had aphasia felt they had gained from the experience, citing reward from involvement in both the process and involvement in what they all perceive will be a new and useful tool to aid people with aphasia. They all expressed feelings of the group being collective, inclusive and candid. So in all these regards, the final stage can be said to have been a participatory partnership.

There are strong parallels with the work of Kerruish (1995) (previously described) in terms of the social relations within the research process. She describes how she began from a strongly quantitative background, and the project then became

> "more a story of the gradual revelation of how and why the pre-planned methodologies had to change so that they were more appropriate" (p122)

Carrick et al (2001) highlight, the personal characteristics of those involved on both sides. There is a need for humility (on the part of the researcher), and openness and commitment from both parties. The research has to be relevant to the participants, engendering strength of purpose for all involved. Kitchin (2000) endorses this aspect of inclusive research suggesting that

> "research undertaken needs to be carefully selected, presented in a way that is unambiguous, have clear connections between theory and the lives of disabled people, and needs to be acted upon." (p29)

One of the strengths of this project was the immediacy of the connection between the discussions and the impact the successful outcome would have on the way people with aphasia would experience healthcare delivery. All the people with aphasia who were on the advisory panel had received speech and language therapy, and were in regular contact with many other people who were doing so currently. As can be seen from the quotations, they all immediately saw that the CDP was novel in its approach.

Beyond the personal characteristics of those involved (shared knowledge and expectations, openness to change, honesty, commitment) are the practicalities of the involvement. Mention has been made of timing the meetings, and the welcoming nature of the physical environment. Other details such as the lack of tape recording were seen as important. Kerruish (1995) suggest that

> "a tape recorder served to emphasize the power and control of the researcher at the expense of the notion of equal partnership" (p124)

I am not convinced that the lack of tape recorder, in and of itself, has a major significance in terms of affecting the power balance within the relationship. I think it is quite possible to have an inclusive equitable interaction that is being audio-taped. However, rather than influencing the type of interaction that might be taking place, I feel it may be *indicative* of the type of interaction. If there is no tape recorder then this may be symptomatic of the level of reciprocity and mutual respect within the encounter. If the interaction is truly discursive, with decisions emerging by consensus, in a manner that is mutually respectful, the need for tape-recording might be lessened or negated.

The benefits of having a long-standing relationship have also been discussed. Kerruish (1995) has cited authors who demonstrate that people move beyond public responses (Goffman 1978 and Laslett & Rapoport 1975), give better information as their relationship develops (Cornwall, 1984), and give opinions that are more true to their real feelings than if they had been involved in one-off encounters. The two major areas of consultation undertaken in this project, that needed consideration with regard to duration of contact, are that of the individual in-depth interviews and the convening of the advisory panel.

The individual interviews (in contrast to the DQ user focus group interviews) were conducted on the fifth meeting that had taken place between me and the people with aphasia. Each person had been involved in providing information at three monthly intervals over the course of the first year of having aphasia. At each meeting the person with aphasia had completed a series of assessments, the last of which had always been the administration of the DQ. Thus, the participants who underwent the in-depth interviewing, were all known to me, following regular meetings at which we had investigated jointly the impact of the aphasia on their lives.

In contrast, the initial meeting of the advisory panel was the first time I had met those involved. So, at the beginning of the meetings, it may well have been that more publicly acceptable opinions were being expressed to me. However, as time went on this ceased to be the case and, as the quotations above support, there was no evidence that any panel member felt constrained by any barriers of social acceptability.

These two types of interaction similarly contrast in terms of the qualitative method used. The in-depth interviews were conducted individually, whilst the advisory members met as a group. Cassidy (2000) is a strong advocate for the group process in empowering those with communication difficulties to express their views. Kerruish (1995) similarly

> "decided to abandon the idea of individual interviews in favour of group discussions. This approach was more participative and less oppressive than individual interviews" (p125)

I do not believe one method is intrinsically more or less oppressive than another. For those with communication difficulties it can be argued either way. Group discussions can be less accessible to those with an impairment of comprehension, as discussed above. Gaining access to turn-taking can be similarly compromised if someone has an expressive loss. However, in an individual interview the pressure to state views in isolation from anyone else can be intimidating. Within a group someone can engage in a word finding search in an un-pressurised way, whilst someone else 'holds the floor'. By the time the person has found the word, they can contribute in a way that is relatively effortless, in contrast to the potentially embarrassing silence that could have ensued during the word search had the interaction been one-to one.

In this project, the individual in-depth interviews covered topics that may have been too personal for group discussion such as the impact of aphasia on the person's relationships, work opportunities, emotions. Each respondent had known me for over a year and had explored such issues with me several times through the DQ. Though I have no way of refuting an allegation of oppressive methodology through individual interviewing, I believe the manner of the interaction in terms of style of interaction was similar to the methods used in the advisory group; listening was focused, attention was total, respect was wholehearted.

The way in which the relationship did feel qualitatively different was the degree to which participants had control over the situation. In both situations the interaction during the meeting was respectful and upholding basic human values, but the difference came with what was done with the information. For the individual interviews the information given was then taken away and used without reference to the individual who had given it; they lost control of it. For the advisory group, they told me how I should progress and use the information that we had arrived at through the partnership during the meeting. They then saw a physical demonstration of this collaboration as their suggestions were incorporated into the CDP.

I therefore suggest, that in the latter stages of this project, through the use of the advisory panel, there was a genuine partnership that could be described as participatory. I acknowledge that this was well overdue and small scale. However, I felt that it ensured the validation of the latter part of the process, the CDP itself and led to personal changes that will have far-reaching implications for me in terms of inclusive practice in the future.

6.2.3 Legitimacy of the CDP itself

The discussion so far has focused on the social relationships within the research process itself. However, the research project has a specific aim; to develop a tool that would be instrumental in facilitating healthy living with aphasia. Finkelstein (1991) suggests that

> "the medical model and its rehabilitation service approach should always be determined in the context of the social (barriers) model and not vice versa…in effect this means that the extent, duration and nature of medical interventions should be guided by an understanding and analysis of the barriers to be overcome, rather than on the functional limitations of the individual" (pp35-6)

and Worrall & Cruice (2000) point to the fact that

> "Aphasia-friendly self–report measures are needed to evaluate new interventions that are based on the social model of disability" (p1153)

The CDP includes elements that could be cited traditionally within the medical model of disability; it has a series of rating scales; it asks questions relating to how impairment limits a person's life; it requires the joint administration of the healthcare provider and the person with aphasia. What benefit is there in researching in an inclusive way if the end product of the research collaboration merely continues the existing power structures of the traditional medical paradigm? The legitimacy of the tool itself therefore must also be questioned.

The issue is the social validity of the CDP itself. I have emphasized the advantages of the CDP in chapter 5. Many of these advantages relate to the tool's social validity; the primacy of the perspective of the person with aphasia; the design being focused on maximising the accessibility and acceptability of the CDP to people with aphasia; validating the experience of living with aphasia; challenging the power relationship within the therapeutic context by ensuring that the person with aphasia is recognised as the expert in the assessment.

If the CDP is accepted as a socially valid instrument for exploring the impact of aphasia on someone's life, what then are the implications for implementation of any action suggested by the process of exploration? Carrick et al (2001) describe a research project aimed at eliciting users' views of taking anti-psychotic drugs. They demonstrate that

> "(the) participants' views...made me aware of the need to try and effect some change, rather than pointlessly detailing misery" (p218).

This is the case with the CDP. Though it acknowledges the experience of acquiring and living with aphasia, it is much more about how to effect change to enable greater participation in attaining life goals. The question then is how that is to be achieved.

There is debate within clinical practice associated with people who live with aphasia. A gap is perceived to exist between the clinical practice of those who focus on impairment-based assessment and therapy, in contrast to those whose focus is based on ideas developed from the social model of disability. The gap is seen as widening and causing fractionation within the world of speech and language therapy, across the world. This perceived divergence has been discussed by Petheram & Parr (1998) in the U.K., Duchan (2001) in the U.S. and Worrall (1992) in Australia.

Petheram & Parr (1998) in a clinical forum describe aphasiology as a 'fashion victim'. They suggest it is at the mercy of both internal and external pressures. External pressures such as accountability within the medical 'marketplace', are seen as leading to division. Internal pressures relate to academic and political theories such as cognitive neuro-psychology on the one hand and the disability politics and social model theories on the other. Parr & Petheram suggest that these two influences lead to a lack of theoretical coherence and that this runs the risk of leading to fragmentation that may plunge clinical practice into a state of crisis.

Duchan (2001) characterizes the two differing approaches currently threatening the stability of clinical practice.

> "Two quite different ways of approaching clinical practice. One is on an impairment view, whereas the other is based on a social view of communication disorders. Impairment practices cast the clinician in authoritarian roles; presume that the communication disability is in the client; focus on the objective, separable, controllable parts of communication...social

> practices require the clinician to be a support person for their clients and theirs carers affiliates; the SLT serves as a member of a support team that works with clients to increase their communicative opportunities and life participation options" (p41)

So if the CDP is a socially valid tool, based on the social model of disability does this mean that impairment-based therapy will cease to have a place within work done between clinician and person with aphasia? Does the CDP automatically lead to therapies that are based on the social model to the exclusion of impairment-based practices. As discussed in chapter 5 I would argue no. Jordan and Kaiser (1996) for example, when talking about incorporating the social model of disability into the practice of speech and language therapy, suggest that

> "there is no doubt that greater precision in therapists' understanding of individuals' language deficits and ability to treat these are in the interests of aphasic people as a group." (p157)

Part of how to effect change *may well* be by the use of impairment-based therapies. Just as I do not believe that one or other of group or individual interviews are always, by definition, the most appropriate methods of investigating personal experiences, so impairment-based practice is not always and exclusively to be denied or advocated. Certain impairment-based therapies may well have a place as long as the starting point is the definition of the barrier by the person with aphasia, and the use of a therapy or practice is a tool to achieve healthy living with aphasia. Duchan (2001) proposes that

> "part of the current sense of fragmentation and difficulty that clinicians have in deciding on best clinical practices arises not from the variety of choices, but because the impairment approach is operating out of context. It is difficult to determine what to assess, teach, and evaluate about a client's communication problem if one does not know what gets in the way of that client's participation in everyday life contexts...if this social life goals approach is adopted as common practice, then impairment work can be incorporated into it, *not the other way round*" (p41) (emphasis added)

It is also crucial to consider the manner in which goals for therapy are arrived at. This is both in terms of what procedures take place but also the relationships between the parties involved. I suggest that a decision between impairment-based therapies and disability-based therapies does not have to be made a priori. The decisions that *must* be taken, are who will be setting the goals for therapy, how and within what relationship.

I believe, that the CDP, used properly, enables a stance to be taken that validates the perspective and control of the person with aphasia in this regard. The SLT should be acting as a facilitator for this process. The pilot testers uphold that the practice of using the CDP actively encourages therapists to question their role.

"It has lead on to further discussion and moving away from impairment towards living with aphasia"

"More holistic approach – addressing what they want to do as opposed to focussing on impairment biased"

"Made me very keen to do more education/teaching in hospitals, nursing homes, day centre on aphasia and facilitating communication"

"Makes you think about the need to inform the general public more"

So the role of the SLT should be as a resource, setting up the dialogue within this context. Once the CDP has been administered the SLT should then provide a 'menu' of available options from which the person with aphasia can choose. The menu should be orientated to the reduction of barriers identified within the CDP. It should be explicit and accessible. It should highlight the options for intervention be they direct language work, consultation with communication partners (family members, shop keepers, work colleagues), or concentration on identity issues (work on challenging others views, one's own views, demonstrations and celebrations of past and present aspects of character or characteristics).

All the analysis of the legitimacy of the CDP has so far been solely from my perspective. It is, of course, important to balance this opinion with the views of people who live with aphasia. The quotations below suggest that members of the advisory group see the CDP as valid and useful. The advisory group members were asked what they thought of the CDP. Here are some of the responses.

Group member, Harry

"To involve the client in the assessment process basically...it was an assessment procedure that gave the client more powers... that's not the right word? Control... no that's not the right word either. But it gave the client, the aphasic client something like power, it enabled, it was very enabling...instead of being a speech and language therapy piece of material with a lot of words, it kind of shifted it over and allowed the client, the

aphasic client to feel a bit more empowered I think...and able to participate in letting the therapist erm... know what their concerns and worries were I think..."

Panel member Sue described the process of deliberating until the group were completely happy with the end result

"I'm pretty sure we arrived at a series of words and then broke it down until we reached the word that we felt... that we all felt was right. Talked in circles...You see I'm aware of confidence and control, because I think that's really important, you have confidence and more control. You think. So... those were important... I think we had... we started off with ability and you know broke it down... so it was less... it had to fit the picture in the same way that the picture had to fit the words...I could read the words...{indistinct} deliberated and struggled with the words, finding the right words for ages and ages, we came up with a good thing...I think it's very accessible"

When asked if they felt the CDP would have been helpful when they were undergoing speech and language therapy, their responses were as follows

Group member, Harry

"I do think it would have been helpful. Because anything that involves the patient more and equalises the whole relationship is...It's aphasia friendly."

Panel member Sue

"the old style of working was very... the only word I can think of is regimented, you do it this way or... it was the only way to do it...whereas this gives you more flexibility. It looks friendlier"

When asked if they felt it would have been helpful now for people with aphasia they replied

Group member, Harry

"yeah I think people with aphasia are really gonna be empowered and ... helped by this....you know I could really see that being useful with somebody who's severely aphasic"

Group member, Harry

"It's going to be a fantastic resource it really is, it really is"

6.3 Personal outcomes and future changes

I have discussed concepts behind, and methods of involving people who live with aphasia in the development of the CDP. The validity and legitimacy of the CDP itself has been scrutinised. However, there was a level at which further examination of the implications of user involvement still needed to take place. The genuine attempts to follow participatory practice had significant personal and professional implications. I had to challenge a number of issues; my training and background; my personal perceptions about disability and people with disabilities, the purpose of health care delivery; decision-making within the research itself; the effects of these issues on future practice.

6.3.1 Examination of my own training and background

Bricher (2000) suggests reflection on the social model leaves a reflective, non-disabled researcher feeling uncomfortable and apprehensive about undertaking the researcher role. My objective had been to develop a tool to measure the impact of aphasia from the perspective of the person with aphasia. This was done from the viewpoint of being a non-disabled, SLT with a career background in acute medical institutions, latterly at one of the most prestigious hospitals in the country, priding itself on its training of post-graduate doctors. The hospital and I were entrenched in a heirarchical medical model of healthcare delivery. I had been closely involved in the clinical application of cognitive neuro-psychology and what Jordan and Kaiser (1996) had described as the explosion of theoretical insights at the impairment level and in the incorporation of some of these ideas into day to day practice. However, they go on to suggest that

> "there is no doubt that greater precision in understanding of therapists' understanding of individuals' language deficits and ability to treat these are in the interests of aphasic people as a group, but as Parr, Pound and Marshall (1995) suggest 'scientific, highly theoretical therapy programmes run the risk of exciting the therapist whilst failing to engage the aphasic person in a more equal relationship (p9)'" (p157-8)

As has been discussed, I began the process of introspection when I came out of the acute sector and started providing a service to people in their own homes. Two aspects were immediately apparent in this environment; firstly, services needed to be led by those who were to receive them and secondly that impairment-based therapies often had little or no place in this situation. I worked in the community alongside people with aphasia, constantly thinking of ways to make the skills I thought I had available to those who could benefit. I attempted to put the people I saw in charge of how my services should be provided. Together we would untangle the role played by aphasia in impeding their participation in their life, and attempt to construct bridges between them and what they wanted to do.

The process of confronting the limitations of some impairment-based therapies in the face of living with aphasia, as I had done on entering community healthcare, was humbling, and fundamentally challenging.

6.3.2 Challenging my own negative perception of disability

I have described how I had begun to address the way the person with aphasia and I would attempt to negotiate strategies for increasing life participation. I began to appreciate the veracity of the statements made by Jordan & Kaiser and Parr et al and to take steps to equalise the power relationship within my clinical practice. As I have discussed I had to rethink my attitude to the role played by SLTs, giving the decision-making over to those with aphasia, often reducing or eliminating impairment-based therapy altogether. More fundamentally, however, I was scrutinizing my views on the nature of aphasia and my attitude to it and disability more generally.

My many encounters with people living with aphasia had confirmed the negative views I held about what living with aphasia was actually like. There is a wide-ranging, well-established and extensive literature relating to the negative impact of living with aphasia. Seminal articles report the negative effects of acquiring and living with aphasia; Brumfitt (1993b) describes losing your sense of self as a result of acquiring aphasia; Hermann & Wallesch (1989) report the significant negative psychosocial changes associated with chronic aphasia; Starkstein & Robinson (1988) discuss depression associated with aphasia.

More recent discussions of disability and self image however, have often stressed the significance of positive experiences and self images (Swain & French, 2000). I had acknowledged the inequality of the relationship often inherent in the therapeutic relationship, and set about altering that in my everyday practice as described above. Though agreeing with the affirmative model in conceptual terms, I had difficulty in reconciling this view with my experience of living with aphasia (albeit vicarious). I had difficulty seeing how attitudes towards a new 'self-with-aphasia' identity could be affirmative. I had difficulty seeing how my role as a healthcare provider could be anything other than trying to 'cure or care' for someone who found themselves newly aphasic.

The breakthrough for me came when I considered the nature of identity and acquired disability, and the relationship of disability and illness. I had little difficulty appreciating the affirmative message of disability for someone who had always been disabled. Though recognising the social pressures and conditioning that would exist to undermine positive self images, I could see how being positive about ones identity as a disabled person was wholly legitimate and attainable had one always been disabled. Swain & French (2000) for example propose that

> "As with non-disabled people, the quality of life of disabled people depends on whether they can achieve a lifestyle of their choice. This, in turn, depends on their personal resources, the resources within society and their own unique situation. The central assumption of the tragedy model is that disabled people want to be other than as they are, even though this would mean a rejection of identity and self. (p576)

The difficulty for me was exactly this notion of rejection of identity and self. I felt that someone who had *acquired* a disability would not want to reject her/his identity and self. They wanted to be the person they *had* been. They might however, reject the new, acquired identity and self, especially in the face of ableist views that abound and which they themselves may well have held. The idea that someone whose identity had been based on one life circumstance and persona, that was now radically altered, could embrace this new identity in positive ways was difficult to accept. What I had failed to appreciate was both the multifaceted and the transitional nature of identity and self.

As has been discussed, given the multifaceted nature of identity, one's self image can be aligned as much to gender, age, cultural or racial group as to able-bodied status. Though occupational and able-bodied status may be threatened when someone acquires aphasia, many of the other characteristics that define self and identity can remain the same. The person who acquires aphasia has to establish a new identity that accommodates altered communication and its sequalae. The key aspect for me was that the *new* identity was not necessarily a redefinition of every aspect of identity.

Additionally, interviews conducted with people who had been living with aphasia for a year (stage 3) confirm the possibility of a positive self-image and attitude whilst living with aphasia. A year is not a long time to adjust to a new identity, and yet the extracts below highlight that though there are many negative feelings and pessimistic self-perceptions for people who have acquired aphasia, there are those for whom positive self-image and attitudes are possible. The following excerpts are given by people who were able to identify positive things, which have been *consequential* on them having aphasia.

Int. "would you say that you are a different person now to how you were before the stroke?"

B[1] *"yeah I'm better person, definitely a better person I'm more mindful of things in general"*

Int. "In what way?"

B *"well I am even more considerate with other people I like to enjoy life a little bit more and I can for years I hadn't laughed...er...er... and meant it but now I can laugh and I can enjoy it...and I don't speak with a forked tongue any more, because I mean what I say."*

The second respondent concurs and goes as far as rejecting her previous identity.

A *"It's quite interesting actually. But there's lots of things... so because I clam up and I keep quiet erm... I get more opinions about things, now I listen, might be no I won't do that yes I will do that, oh that's awful. Those are my opinions so I actually think it's quite a good thing."*

Int. Right so you see that as something that's quite positive.

A *"In... with all my new.... it's almost like A's dies and now I'm having to... not create but having to... the new A's evolving... and how far have I got... you mean on that line?"*

Int. "Yes."

A *"Do I want to be able to walk into a room and be able to talk to everyone again? No. So I'm very nearly there."*

Int. "Right. So you don't want the old A back?"

A *"No."*

So self-with-aphasia can be a positive identity. I see health care providers as having a role in facilitating the transition between one identity and another. The attitudes of the healthcare provider to the new identity are crucial. Jordan & Kaiser (1996) propose that

> "if the therapists hold a negative attitude to disability (or aphasia) it impedes the potential of the aphasic person to take more control over their response to the consequences of the stroke on their life." (p146) (text in parenthesis added)

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[1] *B and A refers to names of respondent, Int. refers to interviewer*

Developing and maintaining an affirmative attitude towards 'self-with-aphasia' identity is critical, as is the emphasis on barriers and facilitators external to the person with aphasia. *Concentration* on impairment-based assessment and therapies can run contrary to these ideals. Identifying the social aspect of oppressive attitudes to a newly disabled person may lessen this internalisation of negative attitudes described above by Kleinman (1988), Corker & French (1999) and Hogan (1999). SLTs could be instrumental in facilitating the transition from old to new aspects of identity. They must ensure that they are not complicit in preventing the transition.

From a personal perspective therefore there was an evolution of thought away from the *necessity of* negativity associated with acquiring aphasia towards a clearer view that there *is* negativity automatically associated with enforced changes in self image, that impairment cannot be minimised or ignored. However, the newly disabled 'self-with-aphasia' identity can be integrated into a reworked positive identity and that this reworked identity is only an aspect of a multifaceted identity.

On an ideological level also there was a feeling of needing to ally myself to the disability movement. Clear (1999) suggests that

> "this idea of personal identification as an important condition of this kind of social research may provide some component of research framework, which helps to overcome the potential for perpetuating alienating power relationships" (p446)

6.3.3 Challenging use of language

I had begun to identify with the disability discourse and felt a need to take on personal and public ownership, to embrace the ethos and ethics of the social model of service and research delivery. Schlaff (1993) reminds us that therapists are continuously redefining disability to themselves and to others by their actions and in their oral and written communication about disability. She suggests that demonstration of commitment to a particular philosophy can be highlighted through the use of language. My adoption of the first person within this thesis is a demonstration of how language can be used to alter the tenor of the message being delivered. I have deliberately chosen to reject the traditional use of the passive when discussing issues that required personal reflection on my part.

Bricher (2000) points out that language is never value-free and has in the past been used to reinforce oppression. Similarly in a more positive light, by judiciously using different terms, language can be a powerful instrument to force others to challenge their own ideologies. So on the positive side, language can demonstrate allegiance to a particular philosophy, and encourage others to reflect on their own position. However, in contrast it can also be used to alienate. Language can serve several functions in this regard. Having made the developments in our own thinking, we can then signal our allegiance through the careful use of language.

Oliver (1996) discusses the use of language and its relationship with social relations. He cites Foucault (1972) who suggests that the way we talk about the world and experience it are inextricably linked. He cites Hugman (1991) who believes that language is a central aspect of discourse through which power is reproduced and communicated, and lastly, Ignatieff (1989) who suggests that the language of citizenship raises political questions that demonstrate that welfare is not about caring but rights, that language is political. As such the language that accompanies political rights movements can be combative. Rights are ‘demanded’, those who are perceived as being reactionary are described as ‘the enemy’ (health care providers being described as ‘parasites’ (Davis, 1993)), existing processes are seen as ‘oppressive’ and ‘discriminatory’. Though not necessarily denying the truth of the analysis, the language associated with any civil rights movement can be alienating to those cast in the role of oppressors.

This negative language is not obligatory. Though people making the statements may well be angry about the situation and indeed be demanding change of an unfair and oppressive world order, divisive language is not essential. Some authors within the disability movement made their points about the same situation no less forcefully but without the use of such confrontational language. Terms such as ‘bringing about change’, highlighting ‘needs’, emphasizing ‘autonomy’, ‘powerlessness’, ‘prevention of progress’, and ‘expecting equal opportunities’ have been utilised.

The final issue relates to respect. If people are demanding respect for one group of people they should give it equally to other groups. If language is disrespectful, it does not help the case, but again can lead to alienation. It is undeniable that change was needed, and that people with disabilities were and are discriminated against especially within health provision. It is also true that the language used to question that situation can challenge those seen as perpetuating that state in a way that antagonises and polarises, or it can do so in a way that seeks to challenge and enlist those same people as allies to be included in the process of change. Both these stances have legitimacy, both are powerful, but neither is intrinsically just. Both have their place.

Bricher (2000) cautions against the flippant use of language without ideological change. She asks

> "Is it presumptuous, as a health professional and as a mere novice in researching disability, to identify with the disability discourse? Is there a need to prove one's allegiance before adopting social model terminology? It is all too easy to use the words, but it is actions that really count. Are there different language rules for insiders and outsiders?" (p785)

I would argue that it is indeed possible to adopt the language of the social model in a tokenistic fashion, without altering the thinking behind the prejudices one holds. For some, language can be seen as a trivial practicality. However, I believe, that if one has changed perspective relating to disability, this demands a change in the use of terminology.

Language then should be carefully measured within all spheres that we feel we could be in anyway influential. Obviously, we must address our use of language with colleagues (in written or spoken communication). However, attention should also be paid when talking in everyday life. Discussions that arise relating to one's job can serve to raise awareness of disability rights within society more generally. The language used must therefore not only be precise but also accessible. Gradwell (1999) discusses this theme of accessible language but uses it in relation to how non-disabled people communicate with people who have a disability.

> "Non disabled allies must recognise their own role in disabling us, and find the means to address that role. And then let us know in language we can understand" (p36)

Obviously when the people with whom you are working have a communication disability this is fundamental.

The language I have used over time for example has changed as my thinking has evolved. It should be acknowledged that the choice of terminology is far from straight forward. The first and most obvious term to decide on was the name for the people at the centre of the research. The options included 'person with aphasia', 'aphasic person', 'client', 'patient', or 'person living with aphasia'.

'Patient' was discarded for its obvious connotations with the medical model of disability. 'Client' was also rejected. Though in common usage within speech and language therapy today, I feel it is misleading. 'Client' suggests that that person has control of the situation, is powerful and directs the operation of the service provision. For the very many reasons previously discussed, this is not necessarily the case when people with a disability receive healthcare within the U.K. The phrases 'person with aphasia' and 'person living with aphasia' though cumbersome, were therefore utilised when reference needed to be made to the person using services who also had aphasia. The choice of 'person with aphasia' in preference to 'aphasic person' was to emphasis the primacy of the person in contrast to their disabled status. As can be seen, the non-descript noun 'person' is used when the language status of the service user does not need to be specified. This, of all the terms, signals the neutral, yet unique characteristics of whoever is being discussed.

I have also chosen to employ the term 'non-disabled' in preference to 'able-bodied'. This is in response to the writing of Hughes & Paterson (1997) relating to the stigma of 'otherness' that people with disability face constantly. 'Non-disabled' may give people without a disability a taste of feelings of separation and alienation, and make them challenge their views.

Though this discussion may seem to be dealing with minutiae, I believe that the way concepts are expressed is of key importance. Though the detail may seem trivial, the significance of the thinking behind the choice of language is not. It should also be noted, however, that as Oliver (1996) suggests in terms of the 'political correctness' of the language used

> "what is acceptable can change over time, even between writing something and the text appearing in published form" (p5)

Though considerable thought may go into choosing terms that feel most comfortable, all language, particularly language associated with radical change, is subject to the vagaries of shifting acceptability within a political and social arena.

I aimed to ensure commitment to the cause and practice of equality of rights for people with disability, I was also aware that in practical terms, I hoped to ensure that my reading and thinking effected changes in my research and clinical practice rather than becoming an exciting academic exercise in much the same way as the field of cognitive neuro-psychology had done (Jordan & Kaiser 1996). I agreed with Llewellyn & Hogan (2000) who state that

> "much wasted debate can be avoided were we to compare models in terms of their utility as they inform research and clinical practice in a particular setting,

> rather than focus on their relative claim to 'truth' status". (Models of disability) are useful in terms of supporting work that aims to facilitate the lived experiences of people with disabilities so that both the clinical prognosis and the quality of life can be enhanced". (p165)

Walmsley (2001) adds a helpful new dimension to the debate by suggesting that the term 'inclusive research' be used to subsume both participatory and emancipatory research. She suggest that

> "it has the advantage of being less cumbersome and more readily explained to people unfamiliar with the jargon and nuances of academic debate, including people with learning difficulties" (p187-8)

So models of disability and use of language are important and should be considered and debated, but only to the point where they inform positive and practical benefit to the constituency of people whom they seek to represent.

6.3.4 Commitment to change beyond the research project

The insights I have gained through developing the CDP, especially through employing inclusive methods latterly, are of maximum advantage if they serve to confer positive, practical benefits to the people with aphasia in a permanent and sustainable fashion. Zarb (in Barnes and Mercer, 1997) proposes that

> "Emancipation is not an event or series of events with a fixed beginning and end. Rather it is an on-going dialectical process of growth and development" (p53)

The process of personal change developed as the project developed, and as people living with aphasia became more central to the changes being made in the CDP. The tool itself moved away from the medical model into the social model of disability, and so did I.

The CDP therefore has developed within the social model framework, and efforts will be made to ensure it will be used within this context. As has been discussed within the course of the research my attitudes towards therapy and health care provision have been challenged and significantly altered as a result. The final question I had to address was how I could ensure that my future practice was legitimate in terms of these new ways of thinking. My research experience with the advisory group and the reading within the field of disability had left me rethinking my priorities with regard to service provision for people living with aphasia. Moore et al (1998) caution that

> "all will not simply be well just because disabled and non-disabled people conduct research together; integrity and credibility have to be carefully established in relation to both academic rigour and political commitments (p95)

One major personal and professional change was to leave the National Health Service. Tyne (1994) suggests that

> "Advocacy endeavours cannot afford too close alliance with service system; compromised interests weaken the capacity to speak out with commitment" (p250)

I chose to join an organisation that espoused the principles of the social model of disability and service delivery in an overt fashion. The organisation is a charity called 'Connect'. Its vision is a world where communication disability is not a barrier to opportunity and fulfilment. Connect's mission statement it

> "to work in partnership to create practical, creative and lasting ways of living with communication disability. We achieve this through an integrated programme of therapy, education and research. We aspire to a number of values which underpin our work: respect...communication...responsive... participation...equality...creative...healthy...excellence" (p1 Connect 2001)

As demonstration of these commitments, for example, four of the trust board members have aphasia, all interviewing panels include at least one person who has aphasia and two members of Connect's paid staff are people who live with aphasia. One paid employee is a counsellor, and one a person employed for three days a week to 'fit the people with aphasia into the Connect strategy, operations and decision-making structure'. All employees (paid and volunteers attend communication access and disability awareness training). Most of the literature is produced in aphasia-friendly language and format (including recruitment information and some of the annual report for example). These features contribute to this fledgling organisation being ground-breaking amongst service providers for people with aphasia.

Any profits that accrue from the sale of the CDP will benefit the charity, not me personally (though obviously I gain financially by being employed by Connect). The aim of the work undertaken will be two-fold. Initially the CDP will be finalised and published. The second area of work is to identify how Connect's ethos and method of service delivery can be disseminated to a wider constituency than those who actually attend the London centre. I will oversee the identification, development, production and dissemination of publications and courses that promote Connect's unique participatory approach to service provision for those with communication disability, focusing initially on influencing a wide range of stroke service providers.

This represents the culmination of the process of development of both the CDP, and period of considerable personal and professional change. The CDP departures from the traditional ethos of service delivery to people living with aphasia. Pilot testing suggest that for some SLTs, the CDP facilitates them to join with people who have aphasia to focus intervention on areas that are most pertinent to that person. It has encouraged some SLTs to reflected on the wider role health care providers can play in effecting change for people who live with disability. The use of inclusive methods and research into the field of disability had profound effects on my philosophy about research, disability and service provision for those with living with aphasia. It led to a critical examination of both the purpose of healthcare measurement, and the various methodologies that could contribute to exploring aspects of health care. It concluded in rejection of the medical model of disability, adoption of the social model, analysis and acceptance of the legitimacy of an instrument such as the CDP, and finally a new direction for future practice.