QUALITY OF LIFE
IN
AUTISTIC SPECTRUM DISORDER

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ABSTRACT

The limitations of using survival rates and symptom levels as the only outcome variables in clinical practice and research have become evident, particularly with people who have a lifelong and incurable disorder, such as Autistic Spectrum Disorder (ASD). For them, a more important consideration may be whether an intervention has the result of making life more of less 'worth living'. As such, quality of life (QOL) is increasingly seen as a key consideration in evaluating services, the ethical debate regarding health care resource allocation, when testing the effectiveness of new treatments and the development of clinical guidelines for these groups of people. However, factors contributing to QOL for people with ASD are not yet understood, and have to date received little attention by researchers. As such, there is currently no ASD-specific QOL assessment scale described in the literature. This thesis describes the development and validation of such a scale.

The research presented here included 15 adults with a diagnosis of Asperger's Syndrome, High-Functioning Autism and High-Functioning ASD without a learning disability associated with Grampian Autistic Society, a family member or key worker for participants, 15 control participants attending a local community centre, and professionals within the field of ASD. The scale development was based on the literature of QOL assessment in other relevant disorders. Face/content validity was investigated through a developed feedback questionnaire given to the participants with ASD, their indentified proxies and the professionals in the field (n=46). There is currently no 'gold standard' for measuring QOL

in ASD. Therefore, in order to investigate the concurrent validity of the QOL-ASD, the well-established generic measures WHOQOL-BREF and EQ-5D were used (n=30). To assess the QOL-ASD's test-retest validity, the scale was given again to the participants 7 days after the initial assessment (n=30).

Due to the small number of participants included, the results presented here should be interpreted with caution, and could be considered as a pilot of a larger scale study. These results indicate that the QOL-ASD has good face/content validity, good concurrent validity, good test-retest validity and good internal consistency. A significant positive relationship between the QOL-ASD and age was detected.

The preliminary results of the research into the QOL-ASD indicate that this scale is valid and reliable as a tool to measure QOL in ASD, and as such some evidence has been found to support its use in clinical practice and research with this group.

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QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

CHAPTER 1: INTRODUCTION

1.0 OVERVIEW

What is quality of life (QOL)? Is it an objective entity, or inherently subjective? Can it be measured? And can a tool be developed to assess QOL for people with a differing cognitive functioning than the people developing it? These are some of the questions central to this thesis, and an attempt will be made to address them in this introduction to the theory and research underpinning the explorations undertaken and presented here.

1.0.0 Aims

- To conceptualise quality of life.
- To discuss measurement of quality of life
- To define, describe and discuss Autistic Spectrum Disorder.
- To conceptualise quality of life in Autistic Spectrum Disorder.
- To discuss measurement of quality of life in Autistic Spectrum Disorder.

1.1 CONCEPTUALISING QUALITY OF LIFE

Objective dimensions of health are important when measuring the clinical course of a disorder, and evaluating the effectiveness of interventions for it. However, there is increasing recognition that it may be as meaningful, if not more so, to establish how a

person feels, rather than professionals making a judgment on their behalf on the basis of clinical measurements. The limitations of using survival rates and symptom levels as the only outcome variables are becoming clearly evident, particularly when treating people with life-long and incurable disorders. Perhaps the most important indication is whether an intervention has the result of making life more or less '*worth living*'. Quality of life (QOL) is therefore increasingly being seen as a key consideration in: evaluating services, the ethical debate regarding health care resource allocation, testing the effectiveness of new treatments, and the development of clinical guidelines.

1.1.0 Definitions and conceptualisations of quality of life

There is currently no consensus over a definition of QOL. The literature covers a range of components: functional ability (including role functioning), the degree and quality of social and community interaction, psychological well being, somatic sensation and life satisfaction. Frank-Stromborg found in a review of the literature in 1988 a variety of terms equated with QOL: life satisfaction, self esteem, well being, health, happiness, adjustment, value of life, meaning of life, and functional status. This author further found QOL being described in terms of objective measures, such as income, housing, physical functioning, work, socio-economic status, and support networks, and in terms of subjective measures, such as attitudes, perceptions, aspirations, and frustrations.

Several attempts to define QOL have been made. Shin et al. (1978) suggested that QOL consists of having the resources necessary to satisfy the individual's needs, wants, and desires, as well as participation in activities ensuring personal development, self

actualisation and satisfactory comparison between oneself and others. Mendola and Pelligrini (1979) defined QOL as an individual's achievement of a situation satisfactory to them within the limits of their perceived physical capacity. Lawton (1997) described QOL as the evaluation of the behavioural and environmental situation of the person, and has proposed a model of QOL consisting of four components: objective environment, behavioural competence, psychosocial well being and perceived QOL. Despite the lack of a clear definition of QOL, it is fundamentally recognised as a concept representing individual responses to the physical, mental, and social effects of daily living, which influence the extent to which personal satisfaction with life circumstances can be achieved. It involves more than adequate physical well being, it includes perceptions of well being, a basic sense of satisfaction and a general sense of self worth (Bowling, 2001). Based on the above, QOL will in this thesis be understood as meaning *'a concept representing the individual's response to the physical, psychological and social effects of living, influencing the extent to which personal satisfaction with life circumstances can be achieved, involving a perception of well being and a sense of self worth'.*

As such, one challenge when evaluating QOL for people with an illness or disorder, is rising above the limitations of the widely used negative definition of health as *the absence of disease*. The World Health Organisation's (WHO, 1952) definition of health is of total social, psychological and physical well being, but still evaluations of health status in the western world seem to typically focus on disease, illness, and other negative concepts. Furthermore, an important issue when conceptualising QOL is to recognise the impact of cultural and social factors. If QOL is in any way a subjective perception, it

will necessarily be influenced by the individual's frame of reference, as is recognised in the WHOQOL Group (1994), who included in their definition of QOL the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals. This inclusion is particularly important when considering QOL for people who belong to a marginalised or stigmatised group in society. If groups such as these internalise the negative attitudes and beliefs that surround them, they may have particularly modest reference points when evaluating their QOL.

1.1.1 Disability versus impairment

As outlined above, QOL includes perceptions of well being, a basic sense of satisfaction and a general sense of self worth (Bowling, 2001). With the stigmatisation of people with disorders in our society, these QOL elements might be seen by some as unrealistic when considering QOL in these groups. Of relevance here is the difference between the biomedical model of disability and the social model of impairment (Makin, 1995). Whilst the biomedical model sees disability as caused by a disorder, the social model perceives the disorder as causing impairment, which becomes a disability when society fails to support the individual's special needs. Therefore, if the person with a disorder struggles to function in their social or physical environment, this could be perceived as a failure to address their individual needs. Meeting these individual needs may be achieved through adapting the environment in which the person functions, for example through carefully worked out routines.

Furthermore, these elements that are crucial to QOL suggest the need to open our minds to a new and more inclusive view of disease and disorder. An example of this is Kitwood's (1997) social psychological model of dementia, which is a disorder currently explained by most within a biomedical framework in neurological decline of cognitive functions. Kitwood (1997) however, questions the explanatory value of the medical model for 4 fundamental reasons: (1) Some cases of advanced dementia have shown no neurological damage at post-mortem (Homer et al, 1988), (2) There have been cases of substantial neuropathological decline with no accompanying dementia symptoms (Burns et al, 1991), (3) Paths of decline amongst people with dementia are often highly disparate, a strong and consistent correlation between a clinically established degree of dementia and extent of neuropathology at post mortem is lacking and (4) Neurological processes proceed very slowly, yet dementia frequently proceeds much faster, for example following hospitalisation. Kitwood and Bredin (1992) state that the clinical presentation of dementia is far from being a direct consequence of degenerative process in nervous tissue, but rather that the dementing process should be viewed as a dialectical interplay between neurological impairment setting upper limits to how a person can perform, the personal psychology of an individual and the social psychology surrounding them. They further hypothesise that many of the difficulties experienced by the person with dementia are not a result of the disorder, but the 'malignant social psychology' in which the person exists, where the people involved in care for the person might be well-intentioned, but lacking in insight and necessary skills. Kitwood and Bredin (1992) criticise the implicit 'hypercognitivism' (see Post, 1995) of Western accounts of dementia, where personhood is equated with cognitive abilities.

Russell (1996) takes these ideas even further and challenges us to go beyond the narrow idea of dementia as a contraction of life to a more complex vision of an individual and creative world of people with dementia where they may have a more personal, unique, and individual experience ***because*** of their dementia. This idea has also been presented by Oliver Sacks (1985) in his case descriptions of people with Gilles de la Tourettes Syndrome, where he describes people who value the tics and the rapid reactions they have as a consequence of their disorder, and although on medication during the week to conform to the restricted societal view of normality, are medication-free at the weekends to then utilise these tics in their creative outlets. Similarly, some researchers have found cancer patients to report benefits from their illness, such as an increased ability to appreciate each day and greater feelings of personal strength, self assurance, and compassion, thus being more satisfied with their global QOL than healthy comparison groups (e.g. Taylor et al., 1984).

1.1.2 Quality of life as a dynamic construct

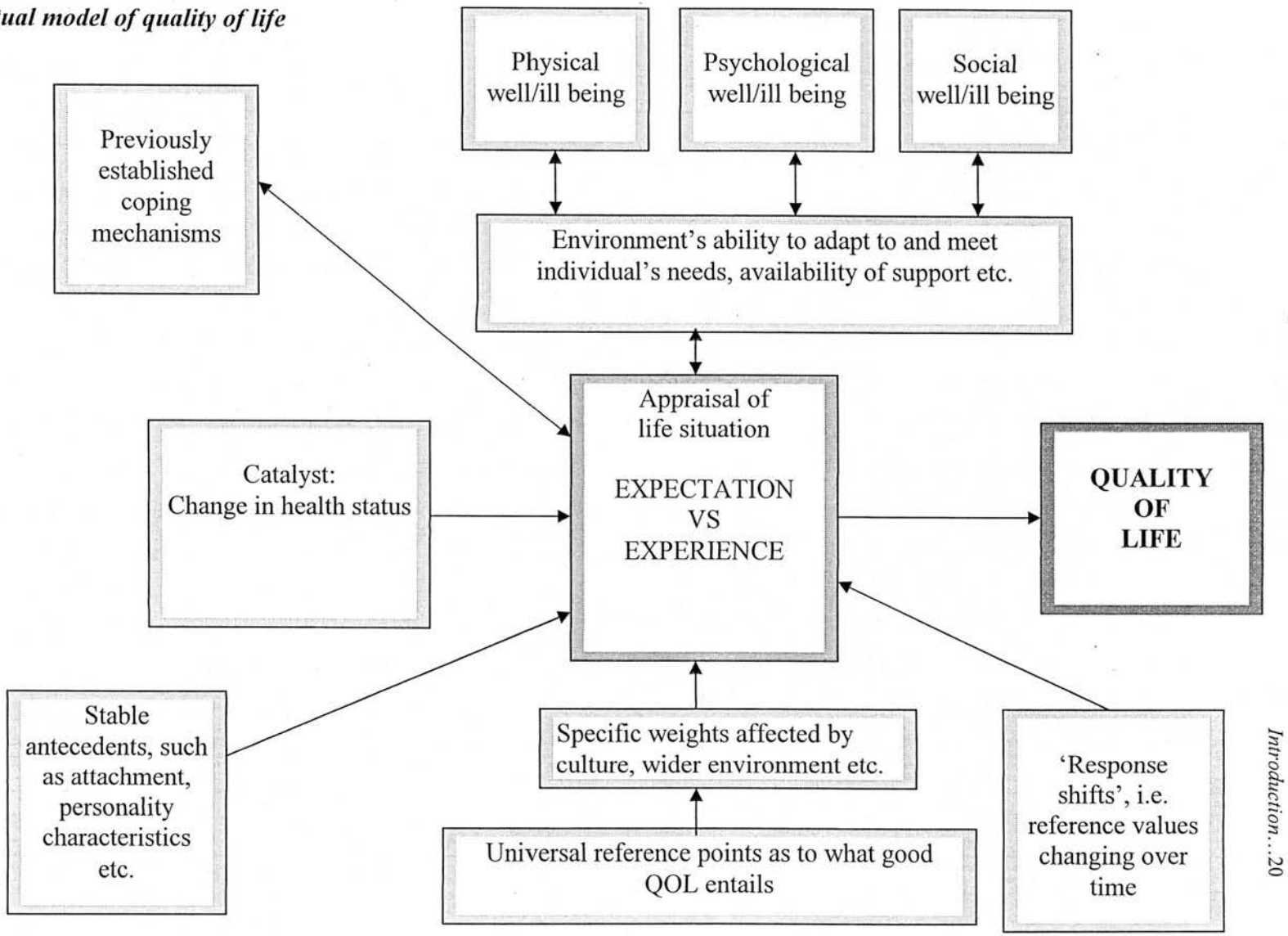
The primary aim of any intervention for a disorder is to enhance QOL by reducing the impact of this disorder. However, people suffering from severe disease do not automatically report having a poor QOL (Evans, 1991). Thus, the correlation between QOL and symptoms seems neither simple nor direct (Carr et al., 2001). Attempting to address this incongruity, Calman (1984) has proposed that we consider QOL as the discrepancy between our expectations and our experience. Furthermore, psychological, sociological and health service research all provide evidence that QOL is a dynamic

construct, and as such the reference value of people's expectations could change over time (Carr et al., 2001). The latter has been labelled a 'response shift'. Suggestions have therefore been put forward that raising expectations of health is an essential part of the 'critical consciousness' of improving community health. According to a model developed by Sprangers and Schwartz (1999), this response shift is only one of the determinants of changes in self-assessment of QOL. The other interacting elements that may influence this are: a catalyst such as a change in health status, mechanisms such as behavioural, cognitive, and affective processes that accommodate changes in health status and antecedents such as stable characteristics or the individual's disposition.

1.1.3 A conceptual model of quality of life

Based on the literature covered above, a conceptual model of QOL could be proposed (Figure 1). The person experiences a 'catalyst' (Sprangers and Schwartz, 1999), such as a change in health status. The person then appraises their situation based on the discrepancy between their expectations and their experience (Calman, 1984). This appraisal process is furthermore influenced by a number of other factors: (a) Previously established coping mechanisms (Sprangers and Schwarts, 1999), which are again affected by the appraisal process, (b) Stable antecedents, which are relatively stable characteristics of the person, e.g. attachment, personality etc. (Sprangers and Schwartz, 1999), (c) Universal reference points as to what good QOL entails, to which specific weights are attached depending on the person's culture and environment (WHOQOL Group, 1995), (d) The person's physical, psychological and social well/ill being (WHO, 1952). These factors, however, affect the person's appraisal of their situation through the

Figure 1. A conceptual model of quality of life



ability of the surrounding environment to be adapted to and meet this person's individual needs and the availability of appropriate support (Makin, 1995). These environmental factors could in turn have an effect on the person's functioning. The 'Response shifts' (people's reference values changing over time) suggested by Carr et al. (2001) seem important to include as a factor, despite the lack of clarity regarding their influences.

1.1.4 In conclusion

There is increasing recognition that a meaningful variable when evaluating the clinical course of a disorder is how a person evaluates their life as being 'worth living', particularly when considering people with life-long or incurable disorders where the usefulness of survival rates and symptom levels may be limited. Quality of life (QOL) is therefore increasingly being seen by clinicians and researchers as a key consideration. Despite there currently being no consensus over a definition of QOL, several attempts to define it have been made, and one such attempt is the definition suggested on page 15 of this thesis. Based on the literature presented, a conceptual model has been proposed, in which QOL is a result of an appraisal process based on the discrepancy between a person's expectations and experience, which is influenced by factors such as the person's physical, psychological and social functioning via the ability of the surrounding environment to be adapted to and meet this person's individual needs.

1.2 MEASURING QUALITY OF LIFE

There has been a rapid increase in the use of QOL evaluations as a technique of clinical research since 1973, when only 5 articles listed 'quality of life' as a reference key word

in literature databases. During the subsequent five-year periods, there were 195, 273, 490, and 1252 such articles (Testa & Simonson, 1996). There are currently over 1000 generic and health-related QOL assessment scales that have been developed using a variety of approaches to measurement (Hedrick et al., 1996), and over 1000 new articles are each year indexed under 'quality of life' (Muldoon et al., 2001).

1.2.0 The value of quality of life assessment

QOL scales have at least eight potential uses in aiding clinical practice: (1) prioritising problems, (2) facilitating communication, (3) screening for potential problems, (4) identifying preferences, (5) monitoring changes or response to treatment, (6) training staff, (7) aiding clinical audits, and (8) facilitating clinical governance (Higginson & Carr, 2001). However, there are several properties required to ensure that a measure can be used routinely in clinical practice, including: (a) the appropriateness of the measure (which is not always the case, as most assessment scales were developed for use in clinical research where time and budgetary constraints are different from those in clinical practice, and the purpose is to assess changes over longer periods of time in individual patients rather than differences between groups of patients in relatively short-term studies), (b) its responsiveness to clinical change, and (c) its interpretability in terms of what it is that constitutes a meaningful change, and to whom (Higginson & Carr, 2001).

1.2.1 Challenges in quality of life assessment

Callahan (1992) has defined QOL as the subjective consciousness of a person in a given situation. He further states that reality is bipolar, and subjective consciousness exists as an individual respond from their particular standpoints, whilst objective reality exists beyond the individual's perspectives, and that because of the dynamic nature of subjectivity, it is extremely difficult to make reliable and valid assessments of another individual's consciousness. When dealing with human beings who can pretend, deceive, co-operate or not, the problems and obstacles of objective assessment are legion. Aksoy (2000) has even concluded that it is not possible to measure the QOL of an individual either accurately or reliably.

Probably the greatest challenge of assessing QOL lies in its uniqueness to individuals, which instruments may not be taking into account when imposing standardised models of QOL and pre-selected domains. They may therefore be measures of health status rather than QOL. Carr et al. (2001) have summarised three main problems when assessing QOL: (1) people have different expectations, that is their evaluations of their QOL are made within the horizons of possibilities that they see for themselves, (2) people might be at different points on their illness pathway when their QOL is measured, and (3) psychological, sociological, and health services research all provide evidence that QOL is a dynamic construct, thus the reference value of their expectations may change over time (Carr et al., 2001).

Through attempting to quantify and compare QOL between different groups using standardised generic assessment scales, a 'disability paradox' has been detected, i.e. people's QOL scores do not necessarily correspond with their functional and health problems. For example, one study found more than half of a group of patients to report having good or excellent QOL despite reporting severe problems in performing daily tasks, being socially isolated and having limited income and benefits (Albrecht & Devlieger, 1999). Similarly, people in hospices have reported lower scores than apparently healthy adults on psychophysiological and functional well being, but not on social and spiritual well being (McMillan & Weitzner, 1999). Furthermore, Bowling (2001) found discrepancies between the free responses people made about the areas of their life that were most affected by their illness and those elicited using 'prompt cards', which casts further doubt that the scores from standardised measures captures the person's QOL. However, using individualised assessment scales also has inherent difficulties. For example, some people may not understand a weighting system (Macduff & Russell, 1998). Furthermore, people assessed might not readily volunteer all factors important to them, particularly those related to mood (Vachon et al., 1995), or this information may change over time (Higginson et al., 1994).

The complexity of QOL as a concept means that difficulties might be identified that are outside the usual remit of medical care (Feinstein, 1992). Higginson and Carr (2001) have suggested that this raises a number of ethical concerns: (1) The act of assessing QOL in a clinical setting might result in an expectation that the clinician will be able to influence it, if not what would the purpose of measuring it? (2) Some pressure groups,

such as The Movement for Independent Living in the US, have objected to the clinical measurement of QOL as it represents the 'overmedicalisation' of life and clinical interference in aspects of peoples' lives that should not be the concern of the clinician, and (3) Chronic disorders affect and are affected by broader aspects of peoples' lives, such as their relationships and social support, and information on these aspects can influence treatment decisions and assessment of health care needs.

1.2.2 Using assessment scales in quality of life research

When measuring QOL, relevant components and domains are typically identified, as simply asking people to rate their QOL on a Likert scale is generally seen as too vague and ambiguous. These domains and components may then be translated into a quantitative value that indicates overall QOL. This is a complex task, drawing from the field of clinimetrics, psychometrics, and clinical decision theory (Testa & Simonson, 1996). Because most components of QOL cannot be observed directly, they are commonly evaluated according to the classic principles of item-measurement theory (Lord, 1980). The three study designs most commonly used in QOL evaluations are: (1) cross-sectional or non-randomised longitudinal studies, describing predictors of QOL, (2) randomised studies of clinical interventions, and (3) the study of cost effectiveness and cost-benefit. The rationale for a QOL evaluation in clinical research should be described in an analytic model, including a hypothesis of the relationship between predictor variables, response variables, and the time frame within which the effects on QOL will be obtained (Testa & Simonson, 1996). Additionally, the inclusion of a QOL evaluation in a study must be meaningful. The routine inclusion of QOL assessments in

clinical trials without a clear structure or well-defined rationale has been subject to criticism (Lancet, 1995).

An attempt at a basic taxonomy of QOL measurement reveals a variety of approaches. A first distinction can be made between *objective* and *subjective* measures, where objective QOL measures are based on the assumption that what constitutes good QOL are shared by everyone, whilst subjective QOL assessment is based on the conviction that only the person assessed can judge her/his own QOL. Both approaches then need to consider that QOL is a multidimensional construct (apart from a very limited number of objective measures using a single-dimension or –item measure).

Some objective measures will combine all information collected to produce a *single index number*, others summarise individual items relevant to different domains, i.e. using a *profile approach.* For the former, several weighting systems can be used to combine sub-scores apart from determining them to be of equal importance. Researchers can make a judgment based on their own preferences, a panel can make this weighting decision, using an entirely statistical approach is possible, or this can be left up to the person directly or by using hypothetical scenarios. For the latter, a utility-weighting approach may be used where the person states a preference for a certain health state, either by using a time dimension such as the use of Quality Adjusted Life Years (QALYs), or by not using a time dimension but instead using utilities set by a representative sample or by the person assessed. Finally, the subjective value basis of the person assessed can be used to identify their own domains and determined weights.

For subjective measures, some may emphasise mainly cognition or affect. These are based on the concept that QOL can be defined as people's evaluation of how their lives satisfy the standards and expectations they have for themselves. For this, a global measure can be used with single items or multiple items, where several areas of a person's life are rated and averaged or added to obtain a total QOL score. Domain-based measures can further be used, which explicitly lists the domains in life to be evaluated, which then may be weighted or not.

1.2.3 Generic versus disease-specific quality of life measurement

There is much debate in the literature around the issue of using generic or disease-specific QOL measures. Generic scales have been designed to be applicable to all people with a variety of conditions, and can as such be used to make comparisons between various groups on QOL aspects that are commonly affected by all conditions. They are as such important instruments when decisions are made regarding the allocation of scarce healthcare resources. Furthermore, generic measures have commonly been fine-tuned and validated over years in response to rigorous research, and as such there are some very robust generic measures available in the literature. However, the main limitation of generic instruments is that they are not necessarily able to identify the specific QOL aspects important in a disorder, which has been argued is central to the measurement of outcome (Hutchinson and Fowler, 1992). It has therefore been suggested that generic QOL scales need to be complemented with disease-specific measures in order to detect clinical changes important to the disorder investigated

(Guyatt et al., 1986). It has also been argued that the need for generic QOL scales will decrease as better disease-specific instruments are developed (Bowling, 2001).

The evidence in the literature points to the fact that different areas of life are affected by different disorders (Bowling, 1996a, 1996b). Condition- or disease-specific measures contain only items relevant to the symptoms and difficulties of a particular condition, as well as the interventions employed to address them. Therefore, the advantage is that they include the QOL aspects of most relevance to the person with this condition, and the effectiveness of the interventions in helping to improve them. As such, they tend to be sensitive to small changes in the QOL aspects most relevant to the condition in question, as demonstrated in the research (e.g. Epstein et al., 1989; Testa & Simonson, 1996), which may be clinically significant. These also have an increased likelihood of capturing change over time in these aspects (Guyatt et al., 1987; Howard & Rockwood, 1995). The use of disease-specific QOL scales avoids asking irrelevant questions, and as such the assessment of QOL can be kept as brief and efficient as possible. However, disease-specific assessment scales, if available, have often been developed ad hoc for a single study, and not sufficiently validated.

Because of the limitations of both generic and disease-specific measures, it is recommended that any QOL study should include both (Wisniewski et al., 2007). This, however, does increase the burden on respondents and research, as well as the need for a greater number of statistical tests, which increases the likelihood of detecting statistically significantly results by chance (Fitzpatrick et al., 1998).

There is currently no disorder-specific QOL measure available for use with people with ASD, and no critical review described in the literature of the use of generic measures with this group. Reviews of generic measures used with other disorders are found in the literature, such as with bipolar disorder, which has been found to display similar theory of mind deficits as those in ASD (Inoue et al., 2004). This review, by Namjoshi and Buesching (2001), found through comprehensive literature searches that the QOL instruments that have been used with people with bipolar disorder most commonly included the 36 Item Short Form Survey (SF-36: Ware, 1993), the SF-20 (Stewart et al., 1988), the SF-12 (Ware, 1993), the Mental Health Index (Stewart et al., 1992) and the Medical Outcome Study Cognitive Function Scale (Stewart et al., 1992), as well as another seven well-established generic QOL instruments. Their conclusion was that none of these instruments captured all aspects of QOL in bipolar disorder, and that to do so it would be necessary to include a time-consuming battery of scales burdensome to the person assessed. Their recommendation was therefore that there was a need to develop a disease-specific QOL measure for this disorder.

1.2.4 Psychometric properties of quality of life assessment scales

Gill and Feinstein (1994) conducted a critical appraisal of the use of QOL assessment scales included a total of 75 articles, using 159 different scales, of which many were judged by the authors to be unlikely to capture the essence of QOL. The conclusion reached was that the psychometric principles underlying these scales may not be satisfactory for the clinical goal of indicating what clinicians and individuals assessed

perceive as QOL. Most of these scales were therefore judged to have poor face, or content, validity.

1.2.4.0 Validity of quality of life assessment scales

Validity refers to the extent to which an assessment scale measures what it set out to measure (Prince, 1998). There are several aspects of validity worth establishing, which in the literature seems to have different definitions and categories. *Face/content validity* refers to the appropriateness of the scale, which has been argued is the most meaningful of all aspects of validity when dealing with constructs as complex as QOL (Senn, personal communication, 2001). This can be investigated through collecting feedback on a scale from the people with whom the scale is designed to be used, or other people with relevant specialist knowledge.

Construct validity refers to the degree to which a measure is successful in showing multiple associations between the attribute in question and other abstract questions, requiring that the construct assessed has certain relationships with other constructs and a lack of relationships with others (Dijkers, 1999). Evidence to support this can be gathered through semi-structured interviews or focus groups with 'key informants', where the construct is discussed. Additionally, an exploratory factor analysis may help to establish whether the construct is homogenous or multi-dimensional.

Concurrent validity is tested by the extent to which an assessment scale relates to other measures given at the same moment in time (Prince, 1998). This can be done in several

ways. The assessment scale can be compared to an existing *criterion* measure, which should be the current 'gold standard' for assessing the construct. As there is currently no such gold standard for assessment scales of QOL in many disorders, this entails a real difficulty when attempting to establish the criterion validity of these scales. Alternatively, *convergent and divergent validity* can be tested in relation to each other. This means comparing the assessment scale to a measure of a similar construct and also to a different one, hypothesising that it would correlate more strongly with the former than the latter. Lastly, *known group validity* can be used, in which the scores obtained from the scale are divided into groups defined by a pre-defined criterion expected to relate to the construct assessed. The value of the latter two types of validity will depend on the rationale underlying the chosen constructs/criterion.

Finally, *predictive validity* refers to the extent to which an assessment scale can predict future variables. This type of validity is not commonly reported in the literature, possibly due to data for most studies being collected over short time intervals.

1.2.4.1 Reliability of assessment scales of quality of life

Reliability refers to the consistency of an assessment scale when given repeatedly under similar circumstances (Prince, 1998).

Inter-rater reliability tests the stability of the assessment scale when given and rated by different researchers in the same interview (Prince, 1998), which is important to establish when assessing QOL with people with disorders that are making self-

completion of assessment scales too difficult, and as such benefit from interviewer-assisted completion.

Test-retest reliability tests the stability of an assessment scale over time. The scale is given to the person assessed by the same assessor at two moments in time under the same conditions, and the correlation between the two established. The time interval used is a matter of judgement on the part of the researcher. This needs to be within a timeframe based on the literature or good clinical judgement.

Finally, the *internal consistency* of an assessment scale refers the extent to which its component parts, or individual items, address a common underlying construct (Prince, 1998). However, it has been argued that this psychometric aim might be in disagreement with the goals of attaining construct validity and comprehensiveness (Brazier & Deverill, 1999).

1.2.4.2 Sensitivity to change

As well as being valid and reliable, the assessment scale must be responsive to changes caused by clinical interventions or other changes, be sensitive to true changes in QOL and not include an inadequate range of responses leading to floor or ceiling effects (Testa & Simonson, 1996). A challenge in this regard is the question of what constitutes a clinically meaningful change in ASD.

1.2.5 In conclusion

QOL scales have a multitude of uses in aiding clinical practice, such as screening for potential problems and prioritising them, and facilitating communication. QOL has been described as the subjective consciousness of a person in a given situation, and the point has been made that because of the dynamic nature of subjectivity, it is extremely difficult to make reliable and valid assessments of another individual's consciousness. As such, probably the greatest challenge of assessing QOL lies in its uniqueness to individuals, and people's QOL scores do not necessarily correspond with their functional and health problems. When measuring QOL, relevant components and domains are typically identified, which may then be translated into a quantitative value that indicates overall QOL. An attempt at a basic taxonomy of QOL measurement reveals a variety of approaches, and distinctions can be made between objective and subjective measures and measures producing a single index number versus those using a profile approach. Another distinction is between generic and disease-specific measures, which both have their strengths and limitations. Whilst generic QOL scales have the advantage that they are often very well validated and can make comparisons between disorders in terms of QOL, it seems that the effects of therapeutic interventions to improve QOL in a condition are best measured with sensitivity by disease-specific instruments that focus on the domains most relevant to this condition. However, the disease-specific QOL instruments available are often not well validated. All measurement of QOL should: address the objective and subjective components important to the population assessed and target and measure what it claims to measure

(be valid) and generate values that are consistent under constant conditions (be reliable). Additionally, the measurement must be sensitive to true changes in QOL.

1.3 AUTISTIC SPECTRUM DISORDER

The concept of Autistic Spectrum Disorder (ASD) has in recent years received increasing attention, as the distinction between 'classic' Autism and Asperger's syndrome (AS) is seen as less than definite by some, particularly when considering people with Autism at the more able end of disorder severity, namely High-functioning Autism (HFA; Macintosh & Dissanayake, 2004; Simpson, 2004). Others would argue that these are distinct disorders with significant similarities, a view supported by current diagnostic guidelines (World Health Organisation [WHO], 1992, American Psychiatric Association [APA], 1994). These stipulate that unlike Autism, in AS there must be no delay in language or cognitive development. However, as concluded by Macintosh & Dissanayake (2004) in their review of the literature, there is currently insufficient evidence to support or refute the distinction of these disorders.

1.3.0 Defining Autistic Spectrum Disorder

The concept of 'the autistic spectrum' was introduced by Lorna Wing in 1981, and is presented as a continuum along which related disorders, such as Autism and AS, are placed according to levels of symptom severity. Although there is an ongoing debate in relation to which disorders can be included in this continuum (Rapin, 2002), there is general acceptance that the core ASDs include Autistic disorder (or classic Autism), AS, Rett's syndrome, childhood disintegrative disorder (CDD) and pervasive developmental

disorder not otherwise specified (PDD-NOS). Other disorders have also more recently been suggested as belonging to the autistic spectrum, such as dyspraxia, developmental language disorder and attention hyperactivity disorder (Rapin, 2002). As space here is limited, this thesis will consider HFA and AS, as these are the diagnoses given to participants included in the research presented here, along with a general ASD diagnosis, used by clinicians where there is sufficient doubt as to which of these most adequately coins a person's difficulties.

1.3.0.0 Autism

'Autism' is derived from the Greek *autos,* meaning 'self' and therefore translating as 'selfism'. Leo Kanner first used it in the present context in 1943, drawing attention to a set of characteristics he had observed in some children, including delay in acquiring speech, echolalia, a tendency to reverse pronouns in speech, repetitive behaviour, an aversion against environmental changes, and an 'extreme autistic aloneness'. Autism is now conceptualised as a pervasive developmental disorder characterised by a triad of impairments (Wing & Gould, 1979). These involve (1) difficulties in communication, such as limited or delayed language abilities or problems with using language to express needs, (2) impaired social skills, such as an apparent disinterest in other people and social activities, as well as difficulties in understanding emotions and displaying empathy, and (3) limited imagination, such as lack of ability to engage in pretend play. Stereotyped behaviour such as lining up objects and hand flapping are also common.

Current diagnostic criteria stipulate that in order to receive a diagnosis people should have deficits in each of the three key areas of impairment: social interaction, communication, and repetitive or stereotyped patterns of behaviour (International Classification of Mental and Behavioural Disorders – Tenth Edition [ICD-10], WHO, 1992; Diagnostic and Statistical Manual of Mental Disorder - Fourth Edition [DSM-IV], APA, 1994).

1.3.0.1 Asperger's syndrome

In 1944, Hans Asperger published his account of four children he had observed to have what he named 'autistic psychopathy' (English translation in Frith, 1991). He appeared to have been unaware of Kanner's description of Autism at this time, and it is reported that when the two became aware of each other's work they both thought these were describing different disorders (Frith, 2004). Asperger's work remained relatively undiscovered until Lorna Wing (1981) highlighted the concept of AS in the 1980s, as she had observed similar characteristics in some children.

The diagnostic criteria for Asperger's Syndrome (AS) are similar to those for Autism, with the central difference being the absence of a delay in language or cognitive functioning. People with AS generally function intellectually in the 'normal' range, above the cut-off for learning disabilities. There are similar social deficits and repetitive behaviours in AS as in Autism, often manifesting themselves as a narrow range of interests, although stereotyped activity is often more complex. There should, in addition, be observable deficits in levels of social, occupational, or other important areas

of functioning, and a diagnosis of AS should not be given if criteria for Autism are met (WHO, 1992; APA, 1994).

1.3.1 Epidemiology of Autistic Spectrum Disorder

The literature reveals great discrepancies in the reported prevalence of ASD. Fombonne (2005) has reviewed forty-three prevalence studies published between 1966 and 2004 in an attempt to address these reported variations, ranging in this sample from 0.7/10,000 to 72.6/10,000 for Autism alone. This review found prevalence rates to be significantly negatively correlated with sample size, that is small scale studies tended to report higher prevalence rates. Furthermore, a significant correlation was found between year of publication and prevalence rates, with all studies reporting rates over 7/10,000 being published since 1987. On this basis, the author concluded that the most meaningful procedure would be to base an estimation of current prevalence rates of Autism on the twenty-eight studies published since 1987, which results indicate a prevalence of Autism of between 10/10,000 and 16/10,000, and he suggests adopting the midpoint of this as a working rate for Autism prevalence, namely 13/10,000.

Fombonne's (2005) review of studies into the prevalence of ASD shows that the coverage of population included in the studies varied greatly, the areas studied varied in terms of service development and that screening procedures utilised ranged from simple letters including a few clinical descriptors of ASD-symptoms to well-validated rating scales. This could in part explain the variance in the reported prevalence of ASD, as Kielinen et al. (2000) have found that applying different diagnostic criteria to the same

data can reveal up to a three-fold variation in rates of Autism.

Fombonne (2005) further reports that the proportion of people with Autism who also have a mild to moderate learning disability across the studies considered was 29.3%, whilst 38.5% were found to have a severe learning disability. In terms of gender differences, Fombonne (2005) reports a median ratio of 5.5:1 male to female among the people studied within the normal range of intellectual functioning, and a ratio of 1.95:1 male to female for people with Autism with a learning disability.

Other disorders along the Autistic Spectrum have been less studied in epidemiological studies than Autism, and when studied they use less stringent diagnostic criteria. This may be partly because disorders such as AS only relatively recently became recognised as a separate diagnostic category in both ICD-10 (WHO, 1992) and DSM-IV (APA, 1994). However, on the basis of the studies conducted, Fombonne (2005) has suggested an average prevalence rate for PDD-NOS of 20.8/10000, 2.6/10,000 for AS and 1.9/10,000 of CDD.

Combining all these estimates, Fombonne (2005) suggests a conservative prevalence rate of ASD to be 36.4/10,000. However, he concludes that the screening procedures utilised in most studies may be affecting variation in reported rates as outlined above, and as such this figure is probably an underestimate. He therefore continues by reviewing nine recent epidemiological studies of superior methodological quality, such as proactive case-finding techniques consisting of multiple and repeated screening

phases and using standardised diagnostic measures. These studies combined give an average prevalence estimate for ASD of 60/10,000, i.e. 0.6%, which he suggests to be a more reliable rate.

1.3.2 Theories of Autistic Spectrum Disorder

1.3.2.0 Theory of mind deficits

Theory of mind is used in the literature as meaning the ability to 'mind-read' or 'mentalise' (Baron-Cohen, 2000), and involves the hypothesis that the key impairments in ASD may be attributed to a deficit in being able to understand the thoughts and feelings of others and appreciate that other people have thoughts that are different to those of one's self. This skill is central to interactions with other people, informing the comprehension and prediction of behaviour of others. It is also noted that this skill is essential to having empathy with others. A distinction is made between first-order and second-order theory of mind, where the former is thought to be the ability to hypothesise what somebody is thinking and feeling about a situation and realise that these may be different from one's own, whilst second-order theory of mind is described as the realisation that another person can hypothesise about the thoughts and feelings of a third person. The theory of mind concept is relatively easy to test empirically, and several studies have found people with ASD to have difficulties with theory of mind tasks compared to matched controls (e.g. Perner et al., 1989).

Criticisms of the theory of mind deficit hypothesis include the objection that this is a purely cognitive theory that fails to consider the effect of overt expressions of internal

states, such as tone of voice and facial expressions (Trevarthen et al., 1996). Additionally, people with HFA or AS have been found to perform better on theory of mind tasks than those with lower functioning ASDs (Bowler, 1992).

1.3.2.1 The extreme male brain theory

Asperger (1944) suggested initially that ASD was a type of extreme maleness. A theory has been since been developed by Simon Baron-Cohen (2002), who has put forward two dimensions that may inform our understanding of gender differences in brain functioning: empathising and systemising. The empathising dimension is described as the ability to reflect on other people's thoughts and emotions, which enables the person to predict behaviour and respond to other's emotions, a skill which is thought to be found more commonly in females. Baron-Cohen (2002) argues that males are more prone to systemising, which he has defined as the drive to construct and analyse systems to enable a person to discover the rules underpinning them and thereby inform the behaviour of these systems. Both males and females are proposed to empathise and systemise to different degrees, but varying levels of these abilities results in five main 'brain-types' occurring on a continuum. At one end there is the extreme female brain with exceptionally well-developed empathy and undeveloped systemising skills, then the female brain with a relatively greater degree of empathic than systemising ability, through to the middle of the continuum where a person has a 'balanced brain' and empathy and systemising are equally well-developed. The male brain arises when systemising is better developed than empathising ability, and finally the extreme male

brain is the outcome when systemising is far greater than empathising skills, which is hypothesised to be the brain-type present in people with ASD.

There has been extensive research into the extreme male brain theory of ASD, in which this theory has found support. On tests of theory of mind, which according to Baron-Cohen includes empathising, children with Autism have been found to do worse than boys without Autism, who in turn perform worse than girls without Autism (Baron-Cohen, 2002). Similar results have been presented for tests of ability to interpret facial expressions (Grossman et al., 2000). Furthermore, adults with AS and HFA were found to perform significantly worse on the Empathy Quotient (Baron-Cohen & Wheelwright, 2004). People with ASD have also been found to show obsessions with closed systems such as computers and railways (Baron-Cohen & Wheelwright, 1999). However, Hodges (2004) has argued that this theory of ASD fails to take into account individual experiences of emotion and that it needs further empirical exploration.

1.3.2.2 The theory of weak central coherence

Uta Frith has put forward the theory of weak central coherence with the focus on accounting for the deficits found in ASD, and argues that this can also explain areas of strength amongst people with this disorder (Frith, 1989; Frith & Happe, 1994). Central coherence is thought to enable rapid understanding of a stimulus or situation as a whole, as it is described as a form of information processing ability to gather a quick overall gist or gestalt sense of an object or situation. This ability appears to vary between people (Happe et al., 2001), and it is argued that weak central coherence amongst people

with ASD cause them to become overly focussed on the individual parts of a stimuli or situation at the expense of the overall picture. This theory of ASD could account for problems with interpretation of facial expressions and other non-verbal stimuli, and could also explain unusual skills often observed, such as the ability to assemble jigsaw puzzles based on the shape of the piece instead of what is depicted on it. However, it has been pointed out that this theory does not explain the problems amongst people with ASD have with relating to others on an emotional level (Trevarthen et al., 1996). Similarly, Hodges (2004) has again highlighted that this theory is mainly cognitive and fails to consider emotional functioning.

1.3.2.3 Impairments in interpersonal relatedness

Hobson (1993) has presented a theory of ASD based on a psychodynamic perspective of emotional development, namely emotional relatedness in children, which suggests that difficulties in this area are central to ASD. In this theory, the proposition is that there are normally three stages of development in children: (1) the development of a sense of self in relation to others, (2) the enabling of relatedness to other people through observation of the expression of relatedness such as tone of voice, gestures and eye contact and (3) an understanding developed of the relationship between a child's own subjective experience and others' expression of emotion. Hobson (1993) argues that this process is underpinned by an innate ability to recognise interpersonal contact, which is thought not to be present in people with ASD. Furthermore, this author has stated that displays of atypical interpersonal relatedness are present in children with ASD earlier than cognitive impairments, and as such the former leads to the latter. However,

although Hobson (1993) finds support for this theory in clinical evidence, there appears to be a lack of empirical evidence to sufficiently corroborate this theory.

1.3.3 In conclusion

The concept of Autistic Spectrum Disorder (ASD) is incurring increased debate. There is current general agreement that disorders such as High-functioning Autism and Asperger's syndrome can be placed along a continuum of severity of a triad of impairments, involving difficulties in communication, impaired social skills, and limited imagination. A prevalence rate for ASD of 0.6% has been suggested. Several theories of ASD have been put forward, involving deficits in theory of mind, having an extreme male brain, suffering from weak central coherence, and having impairments in interpersonal relatedness. These theories are supported by a varying degree of empirical evidence, and most have been criticised for being overly cognitive, and as such failing to consider emotional functioning.

1.4 CONCEPTUALISING QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

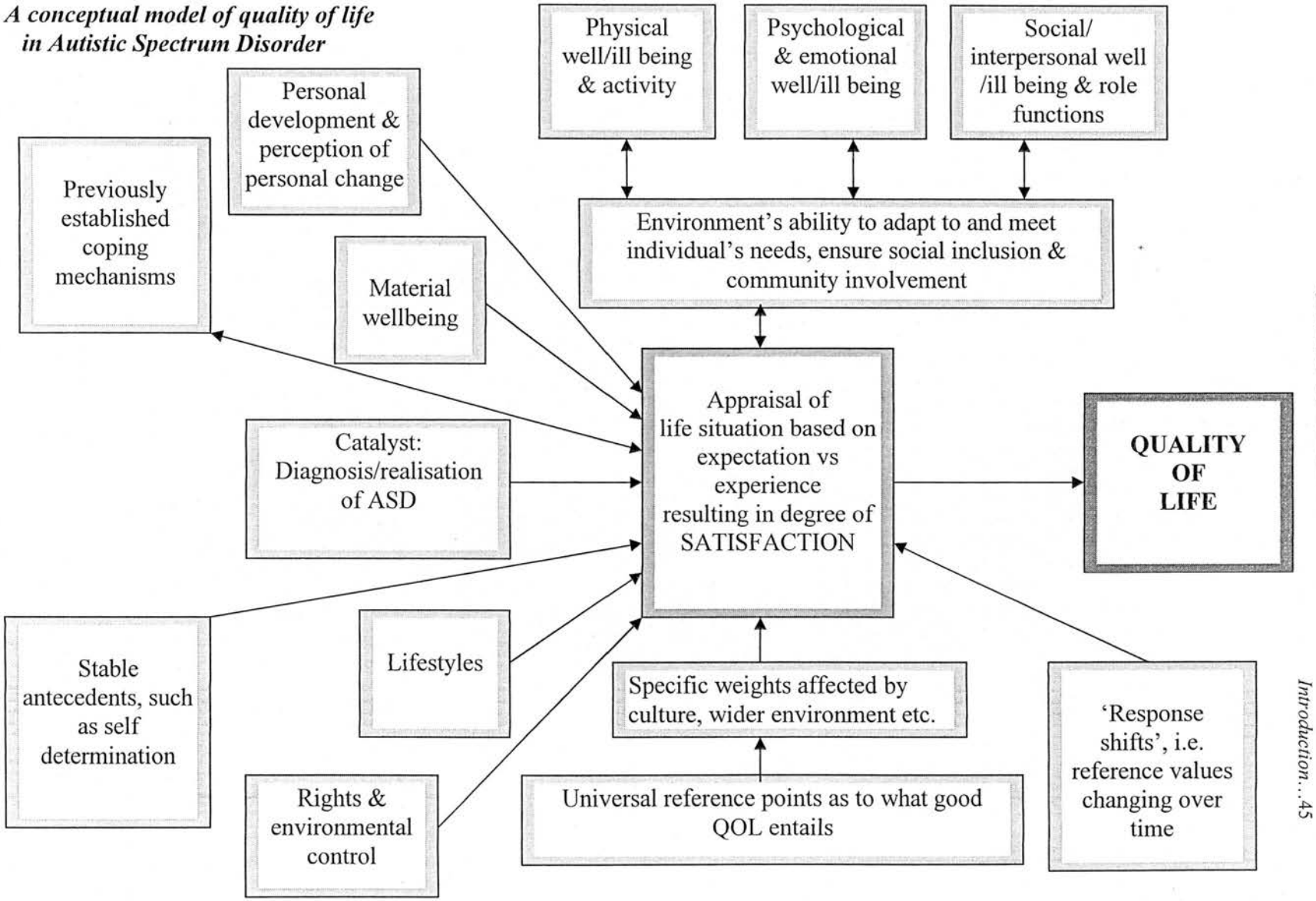
As for other lifelong and incurable disorders, the ability of health care professionals to affect QOL for the person with ASD is more realistic than altering the course of the disorder. As such, QOL is becoming a variable to interest of clinicians and researchers in this field. As in the QOL literature in general, there is a present no consensus over a definition of QOL in ASD, and few attempts have been made to conceptualise it. Drawing on learning disability research, Schalock and Keith (1993) have suggested

QOL in ASD to include well being, satisfaction, social interpersonal relationships, lifestyles, role functions and activity. Schalock (2004) has distinguished eight QOL domains in ASD as: emotional well being, interpersonal well being, material well being, personal development, physical well being, self determination, social inclusion and rights. QOL in ASD has further been defined by categories of environmental control, community involvement, and perception of personal change (Garcia-Villamisar et al., 2002).

1.4.0 A conceptual model of quality of life in Autistic Spectrum Disorder

Based on the attempts to conceptualise QOL in ASD by the three authors outlined above, the conceptual model of QOL presented on page 20 of this thesis can be modified to understand QOL in ASD (Figure 2). The person experiences the catalyst of a diagnosis of, or otherwise realising that they have, ASD. The person's QOL is based on the way the person appraises their situation based on the discrepancy between their expectations and their experience, which results in their degree of satisfaction with their life situation. This appraisal is influenced by previously established coping mechanisms and antecedents, such as self determination. Furthermore, as well as being influenced by universal reference points and culturally influenced weights as to what good QOL is, the appraisal is influenced by the person's physical well/ill being and activity levels, psychological and emotional well/ill being and social/interpersonal well/ill being and role functioning. These factors affect the person with ASD's appraisal of their situation through the ability of the surrounding environment to be adapted to and meet this

Figure 2. A conceptual model of quality of life in Autistic Spectrum Disorder



individual needs, and ensuring their social inclusion and community involvement. Other factors influencing the person with ASD's appraisal and thus satisfaction are personal development and perception of personal change, material well being, lifestyles and rights and environmental control.

1.4.1 In conclusion

Although QOL in ASD is becoming a variable to interest of clinicians and researchers only a few attempts have been made to conceptualise it. Based on the suggested dimensions of QOL in ASD suggested in the literature, a conceptual model of QOL in ASD has been proposed, in which a person's experience of their QOL is based on the way that they derive satisfaction in their situation based on the appraisal of their life.

1.5 MEASURING QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

Despite growing consensus that the concept of QOL should dominate policies and services for people with ASD (Wehman et al., 2002), QOL in ASD has to date received little attention (Magerotte & Willaye, 2000), and the factors contributing to QOL for people with ASD are not yet understood (Jennes-Coussens et al., 2006). The relevant reported literature is sparse, and this is particularly true for people with high-functioning ASD. Furthermore, although research has shown that the effects of therapeutic interventions to improve QOL in any condition are best measured with sensitivity by disease-specific instruments that focus on the domains most relevant to the disease or disorder under investigation (e.g. Epstein et al., 1989; Testa & Simonson, 1996), there is

to date no specific QOL scale for ASD described in the literature. However, a variety of generic QOL scales have been used with people with ASD.

1.5.0 Quality of life of families of people with Autistic Spectrum Disorder

The literature reveals that there has been more research into the QOL of the families of people with ASD than the person with ASD themselves. As this is not the area of most interest to the research described in this thesis, only a few examples are presented here in brief. Using a subjective QOL questionnaire, QOL of siblings of children with ASD has been found to be significantly lower relative to controls (Ferreira & Scheuer, 2005). The QOL of mothers of people with ASD has been found to be impaired on the SF-12 (Ware, 1993) as a consequence of having a child with ASD, but not the QOL of fathers (Allik et al., 2006). Using Structural Equation Modeling (SEM: Lee, 2007), a significant relationship between perceptions of positive contributions of ASD to the family and family QOL has been found, such as family closeness, learned lessons in compassion, change of outlook of life, patience, and personal empowerment (Bayat, 2005).

1.5.1 Quality of life of children with Autistic Spectrum Disorder

With children with Autism, the Autoquestionnaire Quality de Vie Enfant Image (Assumpcao et al., 2000) have been utilised to measure QOL (Assumpcao et al., 2006). This method of assessing QOL has been validated (Assumpcao et al., 2000), but with children without ASD. Elias & Assumpcao (2006) reported findings that children with ASD present similar QOL scores to children without ASD.

1.5.2 Quality of life of adults with Autistic Spectrum Disorder

It has been argued that it is not possible to study QOL in adults with ASD and a learning disability in a direct way, but that measures of behaviour and independence are related to people's QOL. As such, the Adult and Adolescent Psychoeducational Profile (AAPEP: Mesibov et al., 1988) has been employed (Persson, 2000). The AAPEP aims to measure independence, skills and QOL, and includes subscales on vocational skills, independent functioning, leisure skills, vocational behaviour, functional communication, and functional behaviour. It uses methods of direct observation, as well as interviews with caregivers at home and work/school. Using this procedure, the QOL of adults with ASD has been found to improve following the introduction of The Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) programme (Persson, 2000). This procedure has been validated with people with a moderate to severe learning disability, half of whom had an ASD.

Self-report procedures have also been used with people with ASD. The Quality of Life Survey (QLS: Sinnot-Oswal et al., 1991) has been used with people with ASD and a learning disability, interviewing the person assessed directly, or using the person's job coach if the person had no verbal language (Garcia-Villamisar et al., 2002). The QLS includes 18 questions grouped into three categories: environmental control, community involvement and perception of personal change. Using the QLS, people with ASD and a learning disability have been found to meaningfully improve their QOL by participating in a supported employment programme, i.e. a job in the community with no more than two people with ASD in one workplace, but not in a sheltered workshop group, i.e. a

segregated programme with only disabled co-workers (Garcia-Villamisar et al., 2002). However, the authors do not report how many of their participants were able to be interviewed directly, nor do they report any validation research having been done with people with ASD.

1.5.3 Quality of life of adults with High-Functioning Autistic Spectrum Disorder

The widely used World Health Organisation's Quality Of Life measure, the brief version (WHOQOL-BREF: WHOQOL Group, 1998), has been also used with young men with AS (Jennes-Coussens et al., 2006), on the basis that the effect of this disorder is thought to be greatest at this period of people's lives (Tantam, 1991), when the person is expected to complete school, find employment, develop a social network etc. (Collins et al., 2000). This measure includes 24 items forming four domain scores on physical health, psychological health, social relationships, and environment, as well as two questions addressing overall QOL and health. The WHOQOL-BREF found the participants with ASD to report lower QOL overall relative to controls. Furthermore, they were more dissatisfied with their physical QOL relative to controls, which the authors suggest may be connected to deficits in motor skills and sensory hypersensivity, decreasing motivation to participate in physical activity and thereby contribute to less optimal physical health. The young men with ASD described their leisure time being spent watching TV and movies, using the Internet, playing video games, and reading, in contrast to those without ASD, who engaged in a variety of sports. However, this is likely to be connected with the social impairments found in AS, which the participants in this study also reported. Although the number of close friends was found to be similar

for the two groups, this must be considered with some caution, as people with ASD commonly over-rate the quality of their connections with others (Barnhill et al., 2001). A significant difference between the groups was found on QOL scores in the social domain, with the most striking difference between the groups being that the majority of young men with ASD reported never having dated or having been in intimate relationships. Across the two groups results showed that viewing one's social network as supportive was significantly correlated with greater overall QOL. These authors further described how participants with ASD reported communication difficulties, and that they had felt less stressed and happier overall once they finished or quit obligatory education. The WHOQOL-BREF has been very well validated (e.g. Melbourne WHOQOL Field Study Centre, 2002), however not with people with ASD.

In their research, Renty & Roeyers (2006) have outlined the investigation of the impact of disability and support characteristics on QOL for adults with high-functioning ASD, using the Quality of Life Questionnaire (QOL.Q: Schalock & Keith, 1993). This is a 40-item, widely used self-report scale administered in an interview, which consists of four sub-scales of satisfaction, competency/ productivity, empowerment/independence, and social belonging/community integration. Their demographics revealed QOL to vary in relation to daytime activities, with those people studying or having employment having significantly higher QOL than those without. Their results further showed that perceived informal support was significantly related to QOL, however received informal support was not. This suggests that a person's perception that people surrounding them are available to provide support if needed, is more important to one's QOL than the

actual receipt of this support. Similarly, received formal support was not found to be associated with QOL differences, whilst the discrepancy between needed and received formal support was strongly so. In terms of disability characteristics, no evidence that IQ or ASD-specific features contributed to QOL was detected. The limitations of this study include relying exclusively on the Autistic-spectrum Quotient (AQ: Baron-Cohen et al., 2001) as a diagnostic tool and using a cross-sectional design, and as such only being able to make assumptions about causation. Furthermore, it was initially designed for, and has been validated with, people with learning disabilities (Schalock & Keith, 1993), however the authors quote a personal communication with the scale authors from 2003 stating it has also been found to be suitable for people with ASD.

Craig (1999) describes in his dissertation a multiple regression analysis in which only one variable of the ones investigated significantly predicted scores on four QOL measures, namely 'hours spent with friends'. [1]

Thus, in the sparse literature describing research into QOL for people with high-functioning ASD several measures have been used, most of them generic and some

1 Unfortunately, the abstract available describing this research does not give any detail as to what measures were employed, and communication to the author with a request for more detail has had no response; therefore any evaluation of the quality of this research and as such the meaningfulness of the results is impossible.

developed for use with people with a learning disability. Only one report studies the validity of these scales with this population. Caution must therefore be used when considering the results of these studies, particularly if these scales are used to make comparisons between the effectiveness of interventions for ASD and other disorders, as the scales may not include aspects important to this disorder and as such ASD may compare unfavourably. Despite these limitations, QOL of life in ASD is beginning to be recognised and researched, and as such the results of these studies can be used to inform further investigations into this area.

1.5.4 In conclusion

QOL in ASD has to date received little attention and the factors contributing to QOL for people with ASD are not yet understood as the relevant reported literature is sparse. There is to date no specific QOL scale for ASD described in the literature, but generic QOL scales have been used with people with ASD, such as to measure the QOL of their families, and positive contributions of ASD to the family QOL have been found, including family closeness and learned lessons in compassion. With adults with ASD and a learning disability it has been argued that it is not possible to measure QOL in a direct way, and as such measures of behaviour and independence have been used, finding improvements in QOL for people with ASD following structured teaching programmes. Self-report procedures have been used by some with people with High-Functioning ASD, such as the Quality of Life Survey, the World Health Organisation's Quality Of Life measure, the brief version and the Quality of Life Questionnaire. These studies have found that QOL for people with ASD and a learning disability can

meaningfully improve by participating in a supported employment programme, that people with ASD report lower QOL overall relative to controls, and that QOL in ASD is dependent on daytime activities and perceived informal support. However, none of scales used in these studies have been well-validated for ASD.

1.6 AIMS

This thesis will include a review of QOL assessment in disorders with features relevant to ASD in an attempt to identify aspect of possible relevance to ASD. These will then form the basis for the development of a new, ASD-specific QOL assessment scale, named Quality of Life in Autistic Spectrum Disorder (QOL-ASD). A research study will subsequently be conducted, investigating varying aspects of validity and reliability of this new scale. The findings reported will be commented upon in the context of the suggested developed conceptual model of QOL in ASD, however thorough evaluation of this model is beyond the scope of this thesis, as the factors contributing to QOL in ASD can only be meaningfully evaluated in subsequent research should the QOL-ASD be found to be a valid and reliable instrument.

Aim 1: To develop a new ASD-specific QOL assessment scale, the QOL-ASD.

Aim 2: To conduct a research study of the validity and reliability of the QOL-ASD.

1.7 OVERVIEW OF THESIS

Chapter 2 will outline the process forming the development of the QOL-ASD. Chapter 3 will present the research study of the validity and reliability of the QOL-ASD. It will describe investigations into the psychometric properties of this scale, including its: face/content validity, concurrent validity, internal consistency and test-retest reliability. The final chapter of this thesis (Discussion) will attempt to evaluate both the process of the development of the QOL-ASD and outline its strengths and limitations. It will furthermore critically examine the validation study conducted of the QOL-ASD. Finally, this chapter will aim to put this research into the context of the current literature, and to form some conclusions as to how the findings presented in this thesis have added to our knowledge of QOL in ASD.

CHAPTER 2: Development of the Quality Of Life – Autistic Spectrum Disorder Scale

2.0 OVERVIEW

The Quality Of Life – Autistic Spectrum Disorder (QOL-ASD) scale was developed through three stages: (1) Identification of possible items through literature searches of relevant disorders, (2) Ranking of identified items according to the degree of inclusion in QOL scales across relevant disorders, and (3) Ranking of items and identifying cut-off for inclusion in the QOL-ASD by the scale development team and literature on QOL in ASD. This process is detailed below.

2.1 IDENTIFICATION OF POSSIBLE ITEMS THROUGH LITERATURE SEARCHES OF RELEVANT DISORDERS

2.1.0 Procedure

The research team consisted of the lead researcher and thesis author (LF), a Clinical Psychologist with extensive clinical and research experience with ASD (GM), a Professor of Clinical Psychology who is one of the leading clinicians and researchers in the field of ASD in Scotland (TM) and an Autism Consultant who works with providing diagnostic recommendations for ASD in the NHS (JF).

Firstly, LF went through all disorders outlined in current diagnostic guidelines, ICD-10 (WHO, 1992) and DSM-IV (APA, 1994), in order to identify disorders with clinical

features relevant to ASD. Secondly, LF performed literature searches, using the search terms *theory of mind deficit, impaired empathy, impaired executive function* and *stereotyped behavior and rituals.* The disorders identified through these processes where discussed in the research team, and five relevant disorders were concluded upon as the most relevant to ASD: (1) Schizophrenia, (2) Bipolar Disorder, (3) Personality Disorder, (4) Obsessive Compulsive Disorder, and (5) Attention Deficit Hyperactivity Disorder. Literature searches were then performed by LF to identify QOL measures developed for these disorders. Search terms used were: *Quality of life assessment, -measure, -scale,* and *-questionnaire.* All literature searches were performed using Ovid, including the following databases: Ovid MEDLINE (R), Books @ Ovid, Journals @ Ovid Full Text, NHS Scotland Journals @ Ovid, All EBM Reviews, AARP Ageline, AMED, British Nursing Index and Archive, CINAHL, EMBASE, ERIC, PsycINFO, Social Work Abstracts and NASW Clinical Register.

2.1.1 Schizophrenia

Theory of mind deficits are considered to be at the very core of the impairment in ASD, tests of theory of mind skills are central to assessment of ASD (Baron-Cohen & Wheelwright, 2004), and theory of mind deficits have been detected in people with ASD in several studies (e.g. Perner et al., 1989). Similar impairments have been found in schizophrenia (Murphy, 2006). Searches revealed seven Schizophrenia-specific QOL scales. Aspects of QOL included in these scales are outlined in Table 1 below.

Table 1. Items included in Schizophrenia-specific quality of life scales

ITEM	PETiT	S-QoL	S.QUA.LA	Lqo3LP	SQLS	QLS-100	QLS
Psychological/mental well being	x	x	x		x	x	x
Mood	x				x		
Energy levels/activity	x				x		
Biological functioning/physical health	x	x	x	x	x	x	
Self esteem	x	x			x		
Coping abilities/resilience	x	x			x		
Subjective aspects of cognition	x						
Communication	x						
Stigma/strangeness	x						
Family relationships	x	x	x	x	x		x
Social relationships/friends	x	x	x	x	x	x	x
Aptitude towards productivity	x						
Education, employment & work			x	x		x	
Response & attitude towards medication	x						
Autonomy/self care		x	x			x	
Environment/living situation/housing			x	x		x	

Table 1 continued overleaf

Table 1 continued.

ITEM	PETiT	S-QoL	S.QUA.LA	Lqo3LP	SQLS	QLS-100	QLS
Safety/security/legal status			x	x			
Sentimental life		x					
Justice			x				
Freedom			x				
Truth			x				
Beauty & art			x				
Politics			x				
Money/finances			x	x		x	
Love			x				
Sleeping			x		x		
Sexual life			x				
Leisure activities			x	x		x	x
Food			x				
Religion				x		x	
Access to community services						x	

As can be seen in Table 1, thirty-one items were detected. The Personal Evaluation of Transitions in Treatment (PETiT) was developed by Vorunganti and Awad (2002) and consists of twelve QOL domains, including psychological well being, mood, and energy level and activities. These items were derived from a review of the literature, consultation with professionals in the field, individual interviews with people with schizophrenia and their caregivers and focus groups with people with schizophrenia. The QOL items identified were then researched in a study including 335 people with schizophrenia, which found the PETiT to have high internal consistency (Cronbach's alpha = 0.92) and split-half reliability (Spearman-Brown coefficient of 0.85). Repeating the scale after seven days revealed good test-retest reliability (0.97, $p < 0.001$), and repeat administration at quarterly intervals supported the view that the scale was sensitive to clinically meaningful change (Vogunganti and Awad, 2002). Additionally, the feedback from the participants in this study suggested the PETiT to be user-friendly, clear and brief to complete, taking only five minutes.

The content of the Quality of Life Questionnaire in Schizophrenia (S-QoL; Auquier et al., 2003) was derived directly from people with schizophrenia, using videotaped and semi-structured interviews based on Calman's (1984) approach to the participant's point of view, defining QOL as the discrepancy between expectation and life experience. The S-QoL encompasses eight domains, such as psychological and physical well being and self esteem. The validation study of this scale included 207 people with schizophrenia, and revealed the scale to have good face/content validity, high internal consistency

(Cronbach's alpha: 0.63-0.90) and good test-retest reliability (0.64-0.79; Auquier et al., 2003). The author further reported that the S-QoL showed greater sensitivity to clinically meaningful change than the generic measures used in their study. This they explained by the fact that the scale includes QOL aspects not covered in the generic scales, and as such that the S-QoL was more useful to measure QOL in schizophrenia.

The Subjective Quality of Life Analysis (S.QUA.LA) was developed by Zanotti and Pringuey (1992). [2] This scale includes twenty-two QOL domains, such as mental well being, perceived health and family relations. A validation study was conducted with 92 people with schizophrenia and 357 medical students, which found the S.QUA.LA. to have good test-retest reliability, high internal consistency (0.81-0.88) and being sensitive to change (Nadalet et al., 2005).

The Lancashire Quality of Life Profile (LQo3LP; Oliver et al., 1996) was developed from Lehman's Quality of Life Interview (QLI; Lehman, 1983). The QLI includes eight QOL areas, selected from the literature on previous studies of QOL in psychiatric patients and QOL surveys in the general population. The Lqo3LP covers nine QOL domains, including living situation, health and family relations. It has been found to have good construct, content and criterion validity, as well as high internal consistency,

2 The basis for the QOL items included in the S.QUA.LA is unclear and precise psychometric details can not be given, as it has not been possible to obtain the newsletter where they are described.

in studies conducted with people with mental health problems receiving social services (n=422) and support from mental health teams (n=374) among others (Oliver et al., 1996). The LQo3LP has further been investigated with 404 people with schizophrenia across five countries (Gaite et al., 2000), a study which demonstrated good internal consistency (0.87) and good test-retest reliability (0.82) over a time interval of 1 to 2 weeks.

The Schizophrenia Quality of Life Scale (SQLS; Wilkinson et al., 2000) encompassed ten QOL aspects, such as psychological health, mood and energy levels. The items included in this scale were generated from in-depth semi-structured interviews with 20 people with schizophrenia and was piloted with another 20 such participants, which suggested the scale had good face/content validity. The psychometric properties of the SQLS were then investigated further in study including 161 people with schizophrenia (Wilkinson et al., 2000). The results showed that the scale had good internal reliability (alpha 0.70-0.90) and construct validity when correlating with relevant items of the SF-36 (Ware et al. 1993; rho = 0.72 and 0.65).

The Quality of Life Inventory (QLS 100; Skantze and Malm, 1993) includes QOL domains such as housing, household and self care. Unfortunately, the article describing this scale does not give any details as to how it was developed, but refers to the manual held at University of Gothenburg. The authors state that the QLS 100 has been found to

have good internal consistency and test retest reliability over a seven-day period, but do not provide more detail (Skantze and Malm, 1993)

The Quality of Life Scale (QLS; Heinrichs et al., 1984) consists of four categories, which include intrapsychic foundations and interpersonal relations. The authors have outlined how these categories have been derived from *"consideration of important manifestations of the deficit syndrome in schizophrenia"* (Heinrichs et al., 1984, p. 390). These factors were then studied empirically with 111 people with schizophrenia and a principal component analysis performed, which found that they accounted for 73% of the variance of the QLS (Heinrichs et al., 1984), and as such the conceptual validity of the scale was concluded to be good. This study further found the inter-rater reliability of the QLS to be good (0.84-0.97).

2.1.2 Bipolar Disorder

As in Schizophrenia, theory of mind deficits have been found to be present in Bipolar Disorder (BD; Inoue et al., 2004). Searches revealed one QOL scale developed specifically for use in BD, the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q-18; Ritsner et al., 2005). This scale was developed from the Quality of Life Enjoyment and Satisfaction Questionnaire (Endicott et al., 1993), the basis for which is unknown, as the authors in the article describing the development of this scale do not report the rationale for their selection of QOL aspects to include. The Q-LES-Q-18 includes four domains, such as physical health and subjective feeling, of which the

future plans domain was the only found not to be covered by the existing list of items. The validation study included 339 people with bipolar disorder, schizophrenia or schizoaffective disorder and healthy adults; the scale had good predictive validity (r = 0.76-0.98), internal consistency (Cronbach's alpha = 0.74-0.97) and construct validity in terms of accurately discriminating between psychiatric patients and healthy adults, and when correlated with scores on the Lancashire Quality of Life Profile (Lehman, 1983; r = 0.29-0.66, p < 001; Ritsner et al., 2005).

2.1.3 Personality Disorder

People with ASD have in the literature been found to perform significantly worse on tests of empathy than controls (e.g. Grossman et al., 2000), and test batteries used for diagnosing ASD commonly include tests such as the Empathy Quotient (Baron-Cohen & Wheelwright, 2004). Empathy deficits are thought to be central to a variety of Personality Disorders (PDs; ICD-10; WHO, 1992; DSM-IV; APA, 1994). However, searches revealed no PD-specific QOL scales.

2.1.4 Obsessive Compulsive Disorder

Repetitive or stereotyped patterns of behaviour are one of diagnostic criteria in ASD, as is true for Obsessive Compulsive Disorder (OCD: ICD-10; WHO, 1992; DSM-IV, APA, 1994). Searches revealed that there are currently no OCD-specific QOL scales described in the literature.

2.1.5 Attention Deficit Hyperactivity Disorder

Attention Deficit Hyperactivity Disorder (ADHD) involves many features similar to ASD, such as impairment in executive function (Happe et al., 2006), it is commonly a secondary diagnosis to ASD, and has even recently been suggested as belonging to the autistic spectrum (Rapin, 2002). Searches identified one ADHD-specific QOL scale: The Adult Attention Deficit/Hyperactivity Disorder Quality of Life Scale (AAQoL; Brod et al., 2006). This scale includes four QOL domains, including life productivity and psychological health, of these life outlook was thought equivalent enough to add to the item on future plans. These domains were extracted from qualitative data from people with ADHD, 'experts' in the ADHD field and the ADHD literature. A validation study consisting of 637 people meeting criteria for ADHD and 346 people comprising an non-ADHD control group found the scale to have high internal consistency (0.75-0.93) and good discriminant validity ($t = -5.7$, $p < 001$; Brod et al., 2006). The results of this study further showed this scale to have good construct validity when correlating with general health (SF -36; Ware et al, 1993; $r = -0.41$), depression (Patient Health Questionnaire; Kroenke et al., 2003; $r = -0.57$), interpersonal conflict and negative social ties (Moos Dyadic Assessment; Swindle et al., 1989; $r = -0.29$ and $r = -0.31$), and emotional disruption (Finch Criticality Scale; Finch, 1989; $r = -0.68$).

2.2 RANKING OF ITEMS ACCORDING TO INCLUSION IN QUALITY OF LIFE SCALES

2.2.0 Procedure

All thirty-two items identified (thirty-one outlined in Table 1, with the addition of one items identified in searches of BP and ADHD) were ranked by LF according to number of inclusions in the QOL scales detected in searches across the five disorders deemed relevant to ASD. The resulting order is as shown in Table 2 below.

As can be seen here, the items included in the most QOL scales detected were relationships with family and friends, followed by psychological and physical health. Other items identified were on productivity, living situation and finances. Some scales also included more abstract concepts, such as justice and truth. All items were given a rank order score (1 for most included to 32 least included) according to their place on the list.

2.3 RANKING OF ITEMS ACCORDING TO RELEVANCE TO AUTISTIC SPECTRUM DISORDER

2.3.0 Procedure

The list of the identified 32 QOL items was disseminated by LF to the members of the research team, and all four researchers put these in rank order according to the perceived relevance to QOL in ASD based on their clinical and research experience. Upon the

Table 2. Items ranked as to inclusion in quality of life scales

Number	ITEM
1	Family relationships
2	Relationship with friends
3	Psychological/mental health/well being
4	Biological functioning/physical health
5	Leisure activities
6	Education and work/productivity
7	Living situation/environment
8	Money/finances
9	Energy levels & activity
10	Coping abilities/resilience
11	Independence/autonomy
12	Safety/security
13	Mood
14	Self esteem
15	Cognition
16	Stigma/strangeness
17	Sleeping
19	Religion
20	Access to medical/community services
21	Communication
22	Medication
23	Sexual life
24	Food/eating
25	Future plans/life outlook
26	Sentimental life
27	Love
28	Justice
29	Freedom
30	Truth
31	Politics
32	Beauty & art

receipt of these ranked lists, each item on each list was given a score by LF between one (most relevant) and thirty-two (least relevant) according to their ranking. These scores were then totalled by LF, together with the score received as a results of inclusion in QOL scales as outlined above, so all items got atotal score based on the five rank scores (one from inclusion in QOL scales and four from the researchers' ranked lists). The items were then re-ordered from least total score to largest total score. A cut-off point of meaningfulness was agreed after item number 24 when there was a sharp drop in score, after which there were no items ranked in the top ten by at least one researcher and no items were included in more than one QOL scale. This list was then cross-checked to make sure that no aspects of QOL described in the ASD literature (as outlined in the introduction of this thesis) were excluded. The resulting 24 item list is outlined in Table 3 below.

As can be seen in this table, the items receiving the top scores of relevance were independence, money and education/work, followed by items such as living situation and relationships with friends.

2.4 THE QUALITY OF LIFE – AUTISTIC SPECTRUM DISORDER SCALE

2.4.0 Descriptive data

As outlined in the introduction, employment has been found to affect QOL in ASD in a positive way (Garcia-Villamisar et al., 2002; Renty & Roeyers (2006). Employment status was therefore thought important to determine, and a question about this was

Table 3. Items ranked as most relevant to quality of life in Autistic Spectrum Disorder

Number	ITEM
1	Independence/autonomy
2	Money/finances
3	Education & work/productivity
4	Living situation/environment
5	Relationship with friends
6	Psychological/mental health/well being
7	Biological functioning/physical health
8	Family relationships
9	Access to services
10	Sleeping
11	Eating
12	Mood
13	Truth
14	Safety/security
15	Stigma/strangeness
16	Love
17	Leisure activities
18	Energy levels
19	Communication
20	Justice
21	Cognition
22	Sexual life
23	Medication
24	Self esteem

included on the front page of the QOL-ASD scale. Significant differences between people with ASD and controls have been found on scores on social domains, with people with ASD reporting never having dated or having been in intimate relationships (Jennes-Coussens et al., 2006). Furthermore, viewing one's social network as supportive has been found to be significantly correlated with greater overall QOL (Jennes-Coussens et

al., 2006; Renty & Roeyers (2006), and as such it was decided also to include a question about marital status or significant other. Similarly, friendships have been investigated (Jennes-Coussens et al., 2006), and although found not to be affecting QOL for people with ASD in this study, this could be explained by the findings that people with ASD commonly over-rate the quality of their connections with others (Barnhill et al., 2001). Furthermore, 'hours spent with friends' has been found to be the only variable significantly predicting scores on four QOL measures in a multiple regression analysis (Craig, 1999). In order to investigate this issue, an item on friendships was therefore included in the descriptive data to be collected. People with ASD have reported feeling less stressed and happier overall once they finished or quit obligatory education (Jennes-Coussens et al., 2006). However, QOL in ASD has also been found to vary in relation to daytime activities, with people studying reporting significantly higher QOL than those not (Renty & Roeyers, 2006). An item on education and qualifications therefore seemed important to include in the present study. After discussion in the research team, other descriptive data thought to be of value were age, gender, living situation and diagnosis. The front page of the QOL-ASD (Appendix A) additionally included a section for any other information deemed relevant by the respondents, anonymous ID (usually initials) and one identified proxy, such as partner, a parent or key worker.

2.4.1 Items

It was thought essential to make the scale as user-friendly as possible, and as such that brevity was central. Some items were therefore united as deemed appropriate after

discussion in the research team. These included the items on psychological health and mood, physical health and energy levels, love and sexual life and access to services and medication. Additionally, the language used in the scale needed to be concrete and clear for people with ASD to understand, so this was altered by LF for some items on the advice from JF, making all items as short and concrete as possible. The final 24 are outlined in Table 4 below. One item on QOL overall was also included. Finally, the order of the items was changed to make the scale more logical and "flow better".

2.4.2 Response options

After discussion in the research team, it was concluded that the most important aspect of the response options was that they were as few, clear and user-friendly as possible. It was decided to model the QOL-ASD on the Quality of Life in Alzheimer's Disease scale (QOL-AD; Logsdon et al., 1999), a measure that has been used successfully with people with significant cognitive impairment, and which has been demonstrated to have good validity and reliability with people with a low Mini Mental State Examination (Folstein et al., 1975; Thorgrimsen et al., 2003). Logsdon et al. (1999) found when piloting their scale that their initial response options needed to be simplified to a four-choice multiple response format consistent over all questions, in order to be easy enough for respondents to follow. These options were: Poor, Fair, Good and Excellent. These response options were adopted for use in the QOL-ASD, as having fewer response options in order to minimize the possibility of confusion seemed more important than aiming to collect more finely detailed data. This meant that there was no neutral mid-point for

Table 4. Items included in the Quality of Life in Autistic Spectrum Disorder (QOL-ASD) scale

Number	ITEM
1	Level of independence
2	Level of safety & security
3	Work or educational situation
4	Financial situation
5	Living situation
6	Participation in leisure activities
7	Access to services & medication
8	Family relationships
9	Relationships with friends
10	Romantic & sexual life
11	Physical health & energy levels
12	Psychological well being & mood
13	Self esteem
14	Ability to think & remember clearly
15	Ability to communicate effectively
16	Sleep
17	Eating
18	Degree of truthfulness around you
19	Degree of justice around you
20	Degree of inclusion in society
21	Quality of life overall

respondents to choose, which the researchers thought could be used by people with ASD if they were unsure about the question. It was deemed important to highlight this lack of clarity if occurring. Omission of a neutral mid-point has also been recommended in the questionnaire design literature (e.g. Converse and Presser, 1986; Moser and Kalton, 1972). Reversing of responses and open-ended questions were also avoided, as this was

thought likely to be too complex for many people with ASD to follow. The QOL-ASD scale is presented in Appendix A.

2.4.3 Proxy reports

Although the QOL-ASD was designed to be a self-report scale of subjective QOL, the research team thought that collecting some proxy data would add a valuable dimension to the overall picture of a person's QOL. It was therefore decided to use the procedure of the well-validated QOL-AD (Logsdon et al., 1999; Thorgrimsen et al., 2003), which also gives the scale to a proxy identified by the person assessed as being the closest to them to complete on their behalf. The overall QOL score is then calculated by combining these two completed scales, weighing the person assessed's responses 2:1.

2.5 IN CONCLUSION

The Quality Of Life – Autistic Spectrum Disorder (QOL-ASD) scale was developed through identification of possible items through literature searches of five relevant disorders, and the subsequent ranking of these identified items according to the degree of inclusion in QOL scales, as well as by the research team as to their relevance to ASD. In total, 32 QOL items were detected. After a cut-off point of meaningfulness to ASD and the uniting of some items to improve user-friendliness, a total of twenty-one QOL items were included in the QOL-ASD. A four-option multiple-response format was decided upon, with the responses Poor, Fair, Good and Excellent. The QOL-ASD also included descriptive data based on the QOL in ASD literature, and a proxy report scale.

CHAPTER 3: Validity and Reliability of the Quality of Life – Autistic Spectrum Disorder (QOL-ASD) Scale

3.0 OVERVIEW

The research study conducted into the validity and reliability of the Quality of Life in Autistic Spectrum Disorder (QOL-ASD) scale included investigations into its face/content validity, concurrent validity, test-retest reliability and internal consistency. The method used is outlined in this chapter, as well as the results from these investigations.

3.1 METHOD

All procedures outlined here were submitted in protocol form to the D.Clin.Pcychol. Course Committee at the University of Edinburgh, and approval was received. Approval of all procedures was also sought and received from the Local Research Ethics Committee in Grampian (Appendix B).

3.1.0 Design

3.1.0.0 Recruitment of participants, sample 1

The inclusion criteria for the participants in sample 1 was being at least eighteen years old, having a diagnosis of Asperger's Syndrome (AS), High-Functioning Autism (HFA) or Autistic Spectrum Disorder (ASD), and not having a learning disability. A list of possible participants was compiled by JF based on the inclusion criteria from the records of people receiving a service from Grampian Autistic Society. These were then

approached by post, with a covering letter from JF (Appendix B), with whom they all had a prior relationship, as well as the information sheet from LF (Appendix B). Based on JF's prior knowledge of the person, some were given the letter and information by their outreach worker, in order to relieve any possible anxiety by offering them explanation and support. The information given encouraged possible participants to contact LF or GM if they wanted to participate in the research project. A total of thirty people with ASD were invited to attend.

3.1.0.1 Recruitment of participants, sample 2

All participants with ASD were asked to identify the person closest to them at the initial interview stage, commonly a parent, spouse, sibling, friend, or in some cases a support worker. These were then approached by post, with a covering letter from JF (Appendix B), whom they all knew, and an information sheet from LF (Appendix B).

3.1.0.2 Recruitment of participants, sample 3

For sample 3, details of 30 health care professionals working with people with ASD were collected from various ASD working groups attended by JF and NHS employees working diagnostically with people with ASD. These were sent a letter by LF (Appendix B) outlining the study, with a request to take part. This group was included as it has been found to be valuable to collect feedback on QOL scales from 'experts' in the relevant field in order to ensure the scale's content/face validity (Logsdon et al., 2000).

3.1.0.3 Recruitment of participants, sample 4

A comparison sample was recruited from Arbuthnott Community Centre. 15 adults attending the centre were approached by LF at the centre, with an information letter about the research and a request to take part.

3.1.0.4 Assessment procedure, sample 1

All participants with ASD were reminded again on the day of the assessment of the purpose and procedures of the project, and asked if they still consented to taking part. If they did, written informed consent was obtained. An interview was then conducted with two researchers, JF (whom they all knew) and LF, individually in a quiet room, completing the Quality of Life-Autistic Spectrum Disorder (QOL-ASD) scale. The scale itself took approximately 10 minutes to complete, and with greetings, questions and arranging of the next interview, this meeting took about 30 minutes in total. All participants were interviewed again seven days later by LF, administering the QOL-ASD scale, the World Health Organisation's Quality of Life Scale – Brief Version (WHOQOL-BREF; WHO, 1994) and the EuroQoL-5D (EQ-5D; EuroQoL Group, 1990). This time interval was chosen on the basis that QOL is thought to be a dynamic construct (Carr et al., 2001), and as such it was thought that the time between the two interviews should be relatively short. The time interval chosen was further informed by the validation studies of the QOL scales forming the basis for the development of the QOL-ASD described in Chapter 2 of this thesis, of which the majority of studies had chosen this time scale. Participants were also at the second interview asked to complete a developed feedback questionnaire for the QOL-ASD. This meeting lasted

approximately 45 minutes, 30 of which were used to complete the scales. All participants were reminded again on the day of the second assessment of the purpose and procedures of the project, and asked if they still consented to taking part.

3.1.0.5 Assessment procedure, sample 2

The QOL-ASD was sent to the proxies identified by the person with ASD subsequent to their assessment, with a request to complete it on behalf of the person with ASD. Written informed consent was obtained. The QOL-ASD feedback questionnaire was also included.

3.1.0.6 Assessment procedure, sample 3

The QOL-ASD and the feedback questionnaire were sent to 30 health care professionals working with people with ASD as described above, asking them to complete the feedback questionnaire. Written informed consent was obtained.

3.1.0.7 Assessment procedure, sample 4

The participants in the comparison sample were interviewed by LF, individually in a quiet room, completing the QOL-ASD scale on the first occasion. Written informed consent was obtained from all participants. The scale took approximately 10 minutes to complete. The participants were interviewed again seven days later by LF, administering the QOL-ASD scale, the WHOQOL-BREF (WHO, 1994) and the EQ-5D (EuroQoL Group, 1990). All participants were reminded again on the day of the second

assessment of the purpose and procedures of the project, and asked if they still consented to taking part.

3.1.1 Measures

A) ***Quality of Life – Autistic Spectrum Disorder (QOL-AD):*** As described in Chapter 2 of this thesis.

B) World Health *Organisation's Quality of Life Scale – Brief Version (WHOQOL-BREF):* The WHOQOL-100 (WHO, 1994) was developed to design an instrument applicable across disease types, and has undergone rigorous validation investigations in over fifteen countries world-wide (Orley and Kuyken, 1994). The 100 items contain 24 facets grouped into six domains of physical, psychological, independence, social, environment and spiritual. In order not to overload the participants, this study used the WHOQOL-BREF (WHOQOL Group, 1998). This shorter version was developed from the WHOQOL-100, and contains twenty-four items producing scores on four QOL domains: physical, psychological, social relationships and environment, as well as including two general QOL items. The WHOQOL-BREF has been tested for psychometric properties as a free-standing measure (WHOQOL Group, 1998). This study used datasets from 13 centres who field tested the WHOQOL-100 and five new centres, with approximately 300 participants in each. The results from this study showed the WHOQOL-BREF to have good internal consistency (alpha 0.66-0.84), excellent validity in terms of discriminating between ill and well respondents and good test-retest reliability (0.66 for Physical health, 0.72 for Psychological, 0.76 for

Social relationships and 0.87 for Environment; WHOQOL Group, 1998). The WHOQOL-BREF has been widely used in QOL research (e.g. Besiroglu et al., 2007; Wegener et al., 2005).

C) ***EuroQoL-5D (EQ-5D):*** This well-established generic instrument was developed by the EuroQoL Group (1990), an international and multi-disciplinary research group whose members are involved in assessments of QOL amongst people with different disorders. This scale produces a single index measure based on self-reported scores on five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The respondent also rates their own health today on a visual analogue scale (VAS) from 100 (best imaginable health state) to 0 (worst imaginable health state). The data can be presented descriptively as a health profile and a single index utility score can be calculated. The EQ-5D is designed for self-completion, but in the current study it was interviewer-assisted, i.e. a copy given to person assessed but wording also read out to the person. It is uncomplicated and can be completed in a short time-span. The EQ-5D has been validated in several countries, and has been found to have good concurrent validity when correlated with the SF-12 (Ware, 1993), discriminant validity in terms of identifying participants with chronic diseases, serious illness, hospitalizations and outpatient visits and test-retest reliability (kappa 0.49-1.00) in a general population sample (n = 1644; Chang et al., 2007).

D) ***QOL-ASD Feedback form.*** This questionnaire was developed to gather people's opinion on the items of the QOL-ASD. It listed all 21 QOL-ASD items, with the option

of scoring these as 'not relevant', 'somewhat relevant', 'relevant' or 'very relevant' to QOL in ASD. The questionnaire also asked respondents to answer the following three questions: (1) Do you think this scale covers all the important domains for a person with ASD? If no, please expand. (2) Do you think any of the items not relevant for the QOL for a person with ASD? If yes, please expand. (3) Do you have any additional comments about the scale?

3.2 RESULTS

3.2.0 Descriptive characteristics of participants

A total of 15 people with ASD were included, and the control group consisted of 15 participants. Descriptive data collected for both groups are outlined in Table 5, as well as mean scores on the measures given. Independent sample t-tests were conducted on the continuous data, whilst Fisher's exact probability tests were carried out to examine differences on the categorical data. Significant differences were found between the groups in terms of age, living situation, marital status and employment, as well as scores on the QOL-ASD, EQ-5D, EQ- 5D Visual Analogue Scale, WHO-QOL BREF Overall, WHOQOL BREF Physical health, WHO-QOL BREF Psychological and total WHO-QOL BREF score. The differences between the groups on WHO-QOL BREF Environment and Social were non-significant, possibly suggesting that these domains on the WHO-QOL BREF do not capture the overall QOL differences detected in ASD relative to controls, and lends some support to the hypothesis that a condition-specific measure is required to measure QOL in ASD.

Table 5. Descriptive characteristics of participants

	ASD GROUP (n=15) mean (sd) [range]	CONTROLS (n=15) mean (sd) [range]	SIGNIFICANCE
Age	36.7 (13.2) [22-63]	45.6 (9.0) [33-58]	t: 2.0 $p < 0.05$
Gender	11 male 4 female	10 male 5 female	$p = 0.99$
Living situation	10 alone 2 with spouse 3 with parents	2 alone 13 with spouse	$p < 0.001$
Marital status	13 single 2 married	2 single 13 married	$p < 0.001$
Friendships	2 one best friend 8 several good friends 5 no friends	3 one best friend 12 several friends	$p = 0.05$
Education/qualifications	5 secondary 4 undergraduate 1 postgraduate 5 other	4 secondary 7 undergraduate 3 postgraduate 1 other	$p = 0.25$
Employment	7 part-time 8 unemployed	5 full-time 7 part-time 3 unemployed	$p < 0.01$
Diagnosis	3 Autism 12 AS		
QOL-ASD	53.7 (7.4) [46-66]	67.9 (11.3) [58-91]	t: 4.0 $p < 0.0001$
EQ-5D	12.7 (1.4) [10-15]	15.0 (0.0) [15-15]	t: 5.7 $p < 0.0001$
EQ-5D VAS	62.0 (20.2) [35-90]	82.5 (9.8) [70-95]	t: 3.4 $p < 0.01$
WHOQOL Overall and health	7.0 (1.7) [4-9]	8.3 (0.8) [7-9]	t: 2.5 $p < 0.05$
WHOQOL Physical health	23.4 (5.3) [13-33]	31.4 (2.6) [28-35]	t: 5.0 $p < 0.0001$
WHOQOL Psychological	19.1 (3.8) [11-25]	23.6 (1.9) [22-26]	t: 3.8 $p < 0.01$
WHOQOL Social	11.4 (6.6) [6-30]	11.6 (1.3) [9-13]	t: 0.1 $p = 0.89$
WHOQOL Environment	28.9 (5.1) [22-37]	32.4 (3.1) [29-37]	t: 1.9 $p = 0.07$
WHOQOL-BREF	87.3 (12.8) [73-110]	107.1 (5.4) [110-116]	t: 4.7 $p < 0.0001$

In order to further explore this sample's scores on the generic measures used, the domain scores on the WHOQOL-BREF were transformed into percentile scores, and thereafter compared with the population norms published by Hawthorne et al. (2006). Single sample t-tests were used, with the population norms as the hypothetical population mean. The results are shown in Table 6.

Table 6. Scores on WHOQOL-BREF compared with published population norms

Norms (n=866) Mean (sd) 95% CI	**ASD group (n=11) Mean (sd) 95% CI**	**Control group (n=15) Mean (sd) 95% CI**
PHYSICAL		
73.5 (18.1) 72.3-74.7	58.8 (18.7) 46.2-71.4 t: 2.6 $p < 0.05$	77.5 (21.9) 66.3-88.7 t: 0.8 $p = 0.23$
PSYCHOLOGICAL		
70.6 (14.9) 69.7-71.5	55.0 (14.9) 44.4-65.6 t: 3.3 $p < 0.01$	73.2 (7.0) 68.6-77.8 t: 1.2 $p = 0.12$
SOCIAL		
71.5 (18.2) 70.3-72.7	54.2 (17.7) 41.6-66.8 t: 3.1 $p < 0.01$	72.0 (10.6) 65.9-78.2 t: 0.5 $p = 0.43$
ENVIRONMENT		
75.1 (13.0) 74.2-76.0	66.3 (17.7) 52.7-79.9 t: 0.9 $p = 0.20$	76.3 (9.5) 70.8-81.8 t: 1.9 $p = 0.08$

As can be seen in Table 6, the ASD group consisted of 11 participants, as the WHOQOL-BREF was not successfully completed with 4 people with ASD. The ASD group scored significantly lower relative to the population norms on the Physical,

Psychological and Social domains, but not on the Environment domain. There were no significant differences between the population norms and the control group.

The same procedure was employed to investigate the scores of the sample included in this study and UK population norms for the EQ-5D, published by Kind et al. (1993). Raw scores were converted into a weighted health state index (WHSI), and the scores on the VAS used as they were. Single sample t-tests were used, with the population norms as the hypothetical population mean. The results are shown in Table 7.

Table 7. Weighted health state index (WHSI) and VAS scores on EQ-5D compared with published population norms

Norms (n=3378) No. Mean (sd)	**ASD group (n=15) Mean (sd) 95% CI**	**Control group (n=15) Mean (sd) 95% CI**
	WHSI	
0.8 (0.23)	0.7 (0.2) 0.6-0.9 t: 0.1 p = 0.95	1.0 N/A
	VAS	
83.5 (16.96)	61.3 (23.50) 61.37-79.12 t: 3.1 p < 0.05	77.0 (23.6) 71.0-83.0 t: 0.6 p = 0.59

As shown here, the only significant difference found between this sample and the population norms, was for the ASD group on the VAS, where they scored significantly lower. A striking ceiling effect was further detected for controls on the WHSI.

In terms of the descriptive data collected, only Age was thought meaningful to analyse, as numbers of participants in each category for the categorical data were so low. Pearson's product-moment correlation coefficient was conducted on total QOL-ASD score and age for the ASD group. The result is shown in Table 8. As seen here, a significant positive relationship was found between age and QOL-ASD score for participants with ASD.

Table 8. Correlation between total QOL-ASD score and age (n=15)

	QOL-ASD
Age	$r = 0.65$ $p < 0.01$ CI: 0.38-0.82

3.2.1 Patient-proxy comparisons

As seen in Table 5, a difference was found between mean scores for QOL-ASD (53.7) and proxy QOL-ASD (46.0) for people with ASD. As the planned procedure was to combine these scores to produce an overall QOL score for people with ASD and to investigate this further, a paired samples t-test was conducted on all QOL-ASD items and total QOL-ASD score, for all participants with ASD for whom it had been possible to also collect proxy data (n=10). Scores on the QOL-ASD were given as 1 for Poor, 2 for Fair, 3 for Good and 4 for Excellent. The results are shown in Table 9. As seen

Table 9. Comparison of patient and proxy scores on the QOL-ASD (n=10)

ITEM	Person's Score Mean (sd)	Proxy score Mean (sd)	DIFFERENCE
Level of independence	2.89 (0.60)	2.67 (0.50)	t: 0.43 p = 0.68
Level of safety & security	2.80 (0.42)	2.97 (0.82)	t: N/A p = 1.00
Work or educational situation	2.93 (0.96)	1.90 (0.57)	t: 1.67 p = 0.14
Financial situation	2.20 (0.42)	2.76 (0.83)	t: 0.36 p = 0.73
Living situation	3.03 (0.87)	2.80 (0.63)	t: 1.5 p = 0.17
Participation in leisure activities	2.97 (0.82)	2.40 (0.97)	t: 2.45 p < 0.05
Access to services & medication	3.21 (0.68)	2.70 (0.68)	t: 2.21 p = 0.05
Family relationships	2.59 (0.73)	2.30 (1.06)	t: N/A p = 1.00
Relationships with friends	2.83 (0.71)	1.30 (0.67)	t: 4.99 p < 0.001
Romantic & sexual life	2.24 (0.95)	1.20 (0.42)	t: 1.50 p = 0.17
Physical health & energy levels	2.59 (0.98)	2.44 (0.53)	t: 0.80 p = 0.44
Psychological well being & mood	2.52 (0.63)	2.40 (0.52)	t: 0.32 p = 0.76
Self esteem	2.66 (0.81)	2.50 (0.53)	t: N/A p = 1.00
Ability to think & remember clearly	2.86 (0.88)	2.40 (0.52)	t: 1.15 p = 0.38
Ability to communicate effectively	2.79 (0.62)	2.40 (0.52)	t: 1.5 p = 0.17
Sleep	2.79 (0.49)	2.80 (0.63)	t: 0.36 p = 0.73
Eating	3.00 (0.80)	2.70 (0.95)	t: N/A p = 1.00
Degree of truthfulness around you	2.97 (0.73)	3.10 (0.32)	t: N/A p = 1.00
Degree of justice around you	2.90 (0.62)	3.12 (0.35)	t: 3.67 p < 0.01
Degree of inclusion in society	2.97 (0.82)	2.00 (0.67)	t: 4.58 p < 0.01
QOL overall	3.00 (0.60)	2.20 (0.42)	t: 3.38 p < 0.01
TOTAL QOL-ASD SCORE	53.7 (7.4)	67.9 (11.3)	t: 2.67 p < 0.05

here, significant differences between scores given by the people with ASD and their proxies score were found on five QOL-ASD items, as well as total QOL-ASD score. However, scores on the majority of items were not statistically different, and the procedure was conducted as outlined in the Method, with QOL-ASD scores from the people with ASD and their proxies being combined, weighting the person with ASD's score 2:1. Subsequent analyses were conducted using this combined score.

3.2.2 Face/Content validity

A total of 46 feedback forms on the QOL-ASD were received. Of these, 13 were from people with ASD, 9 were from relatives of or support workers for people with ASD and 24 were from health care professionals working with people with ASD. The results of these feedback forms are shown in Table 10.

Table 10. Feedback on QOL-ASD items (n=46)

ITEM	Mean (sd)
Level of independence	3.4 (0.8)
Level of safety & security	3.6 (0.8)
Work or educational situation	3.4 (0.7)
Financial situation	3.3 (0.8)
Living situation	3.7 (0.5)
Participation in leisure activities	3.5 (0.6)
Access to services & medication	3.6 (0.7)
Family relationships	3.6 (0.6)
Relationships with friends	3.2 (0.7)
Romantic & sexual life	2.9 (1.0)
Physical health & energy levels	3.4 (0.7)
Psychological well being & mood	3.7 (0.5)
Self esteem	3.3 (0.9)
Ability to think & remember clearly	3.5 (0.7)
Ability to communicate effectively	3.4 (0.7
Sleep	3.4 (0.8)
Eating	3.2 (0.7)
Degree of truthfulness around you	3.2 (0.6)
Degree of justice around you	3.3 (0.6)
Degree of inclusion in society	3.1 (0.8)
QOL overall	3.9 (0.4)

As can be seen in this table, all but one item (Romantic and sexual life) received a mean score of above 3 (relevant to QOL in ASD). On this basis, it was concluded that the QOL-ASD was found to have good face or content validity.

3.2.3 Concurrent validity

There is no 'gold standard' as such for measuring QOL in ASD. Therefore, in order to investigate the concurrent validity of the QOL-ASD, the total scores on the QOL-ASD were correlated with the domain scores as well as the totaled score on the WHOQOL-BREF, total EQ-5D score and EQ-5D visual analogue scale (VAS) score. In addition, the overall QOL-ASD score was correlated with the scores on the QOL-ASD item 'QOL overall'. Pearson's product-moment correlation coefficient was used for all correlations. The results are shown in Table 11. As can be seen, strong positive correlations ($p < 0.0001$) were found between total QOL-ASD score and all other variables, with the exception of WHOQOL-BREF Social relationships, where a weak, non-significant correlation was detected. It was on this basis concluded that the QOL-ASD had been found to overall have good concurrent validity. The strong correlations suggest that there may not be the need for a condition-specific measure in ASD, however the non-significant correlation found in the WHOQOL–BREF Social domain may indicate that this domain does not capture QOL in ASD as well as the other domains of this scale.

Table 11. Correlations between total QOL-ASD score and other QOL indices for both groups (n=26)

QOL INDICES	Correlation with Total QOL-ASD Score
WHOQOL Overall & health	0.69 ($p < 0.0001$) CI: 0.44-0.84
WHOQOL Physical health	0.81 ($p < 0.0001$) CI: 0.65-0.91
WHOQOL Psychological	0.68 ($p < 0.0001$) CI: 0.42-0.84
WHOQOL Social relationships	-0.07 ($p = 0.74$) CI: -0.42- 0.30
WHOQOL Environment	0.77 ($p < 0.0001$) CI: 0.57-0.88
WHOQOL BREF Total	0.85 ($p < 0.0001$) CI: 0.71-0.93
EQ-5D	0.67 ($p < 0.0001$) CI: 0.41-0.83
EQ-5D VAS	0.71 ($p < 0.0001$) CI: 0.47-0.85
QOL overall	0.73 ($p < 0.0001$) CI: 0.50-0.86

3.2.4 Test-retest reliability

In order to analyse the data on test-retest reliability, Pearson's Correlation Coefficient was conducted on the baseline and follow-up data for all items. The results are shown in Table 12.

Table 12. Test-retest reliability of the QOL-ASD (n=30)

ITEM	T1 Mean (sd)	T2 Mean (sd)	r, p (95% CI)
Level of independence	3.1 (0.9)	3.8 (0.8)	0.93, p < 0.0001 (0.90-0.97)
Level of safety & security	3.0 (0.8)	3.1 (0.8)	0.91, p < 0.0001 (0.89-0.94)
Work or educational situation	2.9 (1.0)	2.9 (1.0)	0.90, p < 0.0001 (0.88-0.93)
Financial situation	2.8 (0.8)	2.9 (0.8)	0.95, p < 0.0001 (0.92-0.97)
Living situation	3.0 (0.9)	3.0 (0.9)	0.96, p < 0.0001 (0.93-0.98)
Participation in leisure activities	3.0 (0.8)	3.0 (0.8)	0.91, p < 0.0001 (0.90-0.92)
Access to services & medication	3.2 (0.7)	3.1 (0.7)	0.94, p < 0.0001 (0.92-0.96)
Family relationships	2.6 (0.7)	2.5 (0.9)	0.97, p < 0.0001 (0.95-0.99)
Relationships with friends	2.8 (0.7)	2.6 (0.9)	0.93, p < 0.0001 (0.90-0.96)
Romantic & sexual life	2.2 (1.0)	2.3 (0.9)	0.91, p < 0.0001 (0.88-0.94)
Physical health & energy levels	2.6 (1.0)	2.9 (1.0)	0.91, p < 0.0001 (0.89-0.94)
Psychological well being & mood	2.5 (0.6)	2.3 (0.8)	0.97, p < 0.0001 (0.95-0.99)
Self esteem	2.7 (0.8)	2.6 (0.8)	0.92, p < 0.0001 (0.90-0.94)
Ability to think & remember clearly	2.9 (0.9)	2.6 (0.7)	0.94, p < 0.0001 (0.92-0.97)
Ability to communicate effectively	2.8 (0.6)	2.6 (0.7)	0.90, p < 0.0001 (0.87-0.98)
Sleep	2.8 (0.5)	2.6 (0.7)	0.98, p < 0.0001 (0.97-0.99)
Eating	3.0 (0.8)	3.0 (8.5)	0.97, p < 0.0001 (0.92-0.98)
Degree of truthfulness around you	3.0 (0.7)	2.9 (0.8)	0.98, p < 0.0001 (0.97-0.99)
Degree of justice around you	2.9 (0.6)	2.9 (0.6)	0.90, p < 0.0001 (0.87-0.95)
Degree of inclusion in society	3.0 (0.8)	2.9 (0.7)	0.91, p < 0.0001 (0.90-0.94)
QOL overall	3.0 (0.6)	2.7 (0.8)	0.96, p < 0.0001 (0.92-0.98)

As shown here, high values were obtained on all items of the QOL-ASD as well as the total score. It was on this basis concluded that the QOL-ASD was found to have good test-retest reliability.

3.2.5 Internal consistency

Cronbach's Alpha Coefficient was used to investigate the internal consistency of the QOL-ASD. The results are shown in Table 13.

Table 13. Internal consistency of the QOL-ASD (n=30)

ITEM	Corrected item-total correlation	Alpha if deleted
Level of independence	0.69	0.67
Level of safety & security	0.48	0.67
Work or educational situation	0.74	0.66
Financial situation	0.40	0.67
Living situation	0.40	0.67
Participation in leisure activities	0.50	0.67
Access to services & medication	0.07	0.68
Family relationships	0.56	0.67
Relationships with friends	0.63	0.67
Romantic & sexual life	0.27	0.68
Physical health & energy levels	0.84	0.65
Psychological well being & mood	0.68	0.67
Self esteem	0/66	0.66
Ability to think & remember clearly	0.53	0.67
Ability to communicate effectively	0.67	0.67
Sleep	0.60	0.67
Eating	0.52	0.67
Degree of truthfulness around you	0.20	0.67
Degree of justice around you	0.63	0.67
Degree of inclusion in society	0.63	0.67
QOL overall	0.74	0.67
Total QOL-ASD score		**Apha 0.68**

As can be seen here, Cronbach's Alpha was found to be 0.7, which is an acceptable value. Some items showed a low Corrected Item-Total Correlation, such as Access to services (0.07), Romantic and sexual life (0.27) and Degree of truthfulness around you (0.21), however when deleted alpha did not increase. It was therefore concluded that the QOL-ASD had good internal consistency.

3.2.6 Norms

The raw scores for the ASD group were converted into standard z scores in order to create norms for the QOL-ASD. The results are outlined in Table 14, which shows raw scores (RS), Z scores and percentiles for normal distribution. However, the numbers of participants forming the basis for these norms are so low that these are for illustrative purposes only.

3.3 CONCLUSION

The QOL-ASD was tested for a variety of validity and reliability indices, using a sample consisting of 15 people with ASD and their identified proxies, 15 control participants and 'experts' in the ASD field. The scale was found to have good face/content validity, concurrent validity, test-retest reliability and internal consistency. The only significant relationship was found between the QOL-ASD and the descriptive data collected for people with ASD in terms of age, where a positive relationship was found.

Table 14. Standard scores for the QOL-ASD (n=15)

Raw score	**Raw score**	**Raw score**	**Raw score**	**Raw score**	**Raw score**	**Raw score**	**Raw score**	**Raw score**	**Raw score**	**Raw score**	**Raw score**	**Raw score**
46	47	48	50	51	52	54	56	58	60	62	65	66
Z	**Z**	**Z**	**Z**	**Z**	**Z**	**Z**	**Z**	**Z**	**Z**	**Z**	**Z**	**Z**
-1.39	-1.23	-1.07	-0.74	-0.58	-0.42	-0.1	0.23	0.55	0.87	1.2	1.68	1.86
Percen-tile	**Percen-tile**	**Percen-tile**	**Percen-tile**	**Percen-tile**	**Percen-tile**	**Percen-tile**	**Percen-tile**	**Percen-tile**	**Percen-tile**	**Percen-tile**	**Percen-tile**	**Percen-tile**
8	11	14	23	28	34	46	59	71	81	89	96	97

CHAPTER 4: DISCUSSION

4.0 OVERVIEW

This thesis has presented results from a study consisting of two stages. Firstly, the development of an Autistic Spectrum Disorder-specific quality of life (QOL) scale, the Quality of Life – Autistic Spectrum Disorder (QOL-ASD), was outlined. Secondly, the validity and reliability of the QOL-ASD was investigated empirically. This was done in an attempt to add to the meagre body of research into QOL in ASD. This chapter will aim to critically evaluate the results presented in this thesis, and consider the issues arising in the context of the current literature.

4.1 THE DEVELOPMENT OF THE QUALITY OF LIFE – AUTISTIC SPECTRUM DISORDER (QOL-ASD) SCALE

The development of the QOL-ASD was based on QOL scales reported in the literature relating to five disorders with features relevant to ASD. Schizophrenia and Bipolar Disorder were included, as these disorders both have been found to display theory of mind deficits (Inoue et al., 2004; Murphy, 2006), one of the main impairments detected in ASD (Baron-Cohen & Wheelwright, 2004). Impaired empathic abilities are commonly found in people with Personality Disorders (ICD-10; WHO, 1992; DSM-IV; APA, 1994), as they are in ASD (Baron-Cohen, 2000; Grossman et al., 2000). This group was therefore also included in this research. Obsessive Compulsive Disorder (OCD) was included as repetitive or stereotyped patterns of behaviour are one of the diagnostic criteria in ASD (ICD-10; WHO, 1992; DSM-IV, APA, 1994). Lastly, Attention Deficit Hyperactivity Disorder (ADHD) involves many features similar to ASD, such as impairment in executive

function (Happe et al., 2006), and on this basis was also included in the research as a relevant disorder to ASD. The decision to include these disorders, and not others, was made by the researchers involved in the study, and as such involved application of clinical judgment and a degree of subjectivity on their part.

Ovid databases were used to identify QOL scales across the five disorders outlined above, which detected a total of nine scales covering 32 QOL items. Although this was considered to be an appropriate method, it did not necessarily identify all available research. Important QOL scales could have been missed, as well as research into QOL not published as yet. No scales were found to have been developed for assessing QOL in Personality Disorders or OCD, and only one in Bipolar Disorder and ADHD. Seven of the ten scales detected were therefore for the assessment of QOL in Schizophrenia, and as such the developed QOL-ASD is heavily based on the study of QOL in this disorder. Although having features in common with ASD, the two are widely different, which could be argued is a weakness of the QOL-ASD, however this is difficult to avoid with the lack of other disorder-specific QOL scales detected by the databases used. This could further have lead to features specific to ASD not being included, such as the special interests commonly found among people with ASD (Attwood, 2006).

Throughout the research presented in this thesis, an issue of language use emerged. When collating the thirty-two QOL items from the scales detected, the scales used a great variety of terms, and decisions had to be made by the researchers regarding the equivalence of these to compress them into categories, such as 'stigma' and

'strangeness', 'biological function' and 'physical health', and 'coping' and 'resilience'. Certainly not everybody will support these judgments. Similarly, in order to make the QOL-ASD as user-friendly as possible, some items were joined in a way that not everyone will agree with, such as 'psychological health' and 'mood', 'physical health' and 'energy levels', 'love' and 'sexual life', and 'access to services' and 'medication'. Furthermore, although every effort was made to ensure that the language used in the QOL-ASD was as concrete and clear as possible, it was found when administering the scale that some of the terms could be improved upon: 'justice' to 'fairness', 'truthfulness' to 'honesty' and 'society' to 'the community'. It was also found that a term like 'living situation' was ambiguous, as one participant commented that he was pleased with his physical living situation (his flat), but not with living on his own, without a partner. 'Relationships with friends' was another item receiving debate, as the term 'friend' was unclear to some, for example whether or not to include their outreach workers, which relates to the finding by Barnhill et al. (2001) that people with ASD commonly over-rate the quality of their connection with others. Lastly, the four response options decided upon, 'Poor', 'Fair', 'Good' and 'Excellent', meant that there was no middle option to choose. However, some respondents may have thought 'Fair' was the least committal response to give if unsure about the question, which may then cause a reported QOL below the actual QOL.

The thirty-two identified QOL items were reduced to twenty through a process of collating and ranking of items as to inclusions in other QOL scales and by the

researchers as to their relevance to ASD. As such, this was made on the basis of subjective, clinical judgment of a small group of people.

In the literature, there are recommendations that the content of QOL scales should if possible be obtained from the group whose QOL the measure aims to assess (McKenna, 1997). As such, focus groups could have been conducted with people with ASD and analysed using a qualitative method. The items of the QOL-ASD could then have been extracted from these results. However, clinical experience suggests that people with ASD struggle with lack of structure and open-ended questions, possibly due to the impaired imaginative abilities often found in ASD. This was supported by the fact that when posing the only open-ended questions in the assessment process of the QOL-ASD, asking for comments on the scale, not one person with ASD had any comment to give.

The QOL-ASD consists of twenty-one components of QOL, and gives each of these equal weight when summarising them into a single overall QOL score. This procedure contrasts to some others in the assessment of QOL, and has inherent limitations. As outlined in the Introduction, most measures of QOL are multidimensional, as QOL is generally considered to be a multidimensional construct. There are a few exceptions to this, where a single dimension or single item QOL measure has been developed, however most would disagree with the conceptualisation of QOL in such narrow terms (Dijkers, 1999). However, the simple adding up of the twenty items of the QOL-ASD is giving each item equal weight, which in itself is a value judgment on the part of the researchers. Another

method would have been for the researchers to allocate weights to the different dimensions as to their perceived importance, however this would have entailed a more active impositions of value judgements, which did not appear to the researchers to be a better approach. Yet another approach would have been to ask the respondents to allocate weights of importance to each dimension, which may have been more valid, however this would have required a more complex procedure, possibly too confusing for many people with ASD. Therefore, giving each item equal weighting was seen as the best procedure, and as the most appropriate use of the QOL-ASD may be in evaluating the effectiveness of interventions on the QOL of individuals with ASD in clinical practice, this seemed appropriate. Another issue with adding all items up to produce a single QOL score is that there could be significant differences in item scores pre- and post intervention getting lost from the overall score if they cancel each other out in value, for example physical health improving from fair to excellent and psychological well being deteriorating from excellent to fair. It is however hoped that if used as a clinical tool, the QOL-ASD would be used in a more informative way, not only paying attention to the total score, but also to any reported fluctuations on the individual items.

4.2 THE VALIDITY OF THE QUALITY OF LIFE – AUTISTIC SPECTRUM DISORDER (QOL-ASD) SCALE

4.2.0 Face/content validity

The face/content validity of the QOL-ASD was concluded to be good. This was based on the feedback forms received from the participants with ASD, their relatives and health care professionals within the field of ASD. All but one item, Romantic

and sexual life, received a mean score of Relevant to Very Relevant. QOL overall received the highest mean score, which would be expected. The items deemed to be most relevant to QOL in ASD were Psychological well being and mood, Living situation, Level of safety and security, Access to services and medication and Family relationships. The items deemed of lesser relevance to QOL in ASD were Degree of inclusion in society, Eating, Degree of truthfulness around you and Relationship with friends. It is interesting that the item on a significant other received the lowest score, as people with ASD often will state this to be one of the main desired goals for them to achieve happiness, along with employment and friends (Forrester, personal communication, 2007). However, most of the people with ASD included in this sample were single, and this may be seen as the least achievable of their goals. It could therefore be that they (and others around them) discounted this as important, in order to bridge the gap between desires and achievability.

The only qualitative comment received on the QOL-ASD was that it could have benefited from including an item on control over one's own life, which should possibly be included in any future versions of the scale.

4.2.1 Concurrent validity

There is no criterion measure or gold standard currently available for comparing assessment scales of QOL in ASD against. However, the widely used generic scales (EQ-5D; EuroQoL Group, 1990; WHOQOL-BREF; WHO, 1994) administered showed significant correlations between these and the QOL-ASD, which formed the basis for the conclusion that the QOL-ASD was found to have good concurrent

validity. The strength of these correlations was not anticipated by the researchers who, although choosing these measures as the best available, found them to be quite different to the QOL-ASD. The WHO-QOL BREF (WHO, 1998) included a variety of items not in the QOL-ASD, such as 'Acceptance of body shape', and also had quite different sets of response options. Similarly, the EQ-5D (EuroQoL Group, 1990) seem to be mainly a measure of physical abilities, and as such quite different from what the QOL-ASD aims to measure. Nevertheless, the results reported here suggest that the construct of QOL bridges these gaps between the measures used.

4.3 THE RELIABILITY OF THE QUALITY OF LIFE – AUTISTIC SPECTRUM DISORDER (QOL-ASD) SCALE

4.3.0 Test-retest reliability

Correlations between baseline and follow-up data on the QOL-ASD collected seven days after the initial interview were found to be excellent, resulting in the conclusion that the QOL-ASD was found to have good test-retest reliability. This may also be seen as a surprising result, considering that QOL is commonly thought to be a dynamic construct (e.g Carr et al., 2001), and also in light of the two interviews conducted with the participants with ASD being quite different in quality. The initial interview, unlike the second, was conducted with a member of Grampian Autistic Society present, who knew each of the participants prior to the research being conducted. It was a concern that the people interviewed could feel a certain obligation to be positive about aspects of their lives, so as not to be seen as ungrateful for the support they had received from the Society. However, this did not

appear to be the case, maybe due to the theory of mind deficits central to a diagnosis of ASD (Baron-Cohen & Wheelwright, 2004).

4.3.1 Internal consistency

The internal consistency of the QOL-ASD was found to be good. Some items showed a lower correlation with the total score, such as Access to services, but when these items were taken out, the overall consistency of the QOL-ASD did not improve. On this basis, it seems that all the items included in the scale are needed to measure QOL in ASD.

4.4 PROXY RATINGS OF QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

The agreement between the scores given by people with ASD on the QOL-ASD items and the scores given by their proxies on their behalf appeared not to be good, with the proxies generally giving lower scores overall. Indeed, statistically significant differences were found on Relationships with friends, Participation in leisure activities, Degree of justice around you, Degree of inclusion in society, QOL overall, and also total QO-ASD score. However, proxy data was only obtained from 10 participants, and as such whether or not to include proxy ratings in the assessment of QOL in ASD is unclear based on these results, and needs further investigation and consideration.

Whether people with a variety of disorders can accurately evaluate their own QOL has been a much debated issue, which has evolved around the use of subjective

versus objective entities (e.g. Lawton, 1994, 1997), and whether to use patient or proxy ratings, or both. It is generally agreed that because of the highly subjective nature of this concept, any appraisal of QOL should rely where possible on the perception of the individual person. Even so, Albert et al. (1996) stated that people with cognitive impairment cannot comprehend questions or report on subjective states, and have further concluded that while the subjective world of the person is not directly assessable, readily observable behaviours offer a basis for assessing QOL (Albert et al., 1996). However, as pointed out by Whitehouse (1998), the subjective world is not directly accessible for any individual, whether they have any cognitive impairment or not. Additionally, Lockwood (1987) has emphasised that people have what philosophers call 'privileged access' to their own lives, they know better than anyone else can, just what it is like to be them.

Direct respondent assessment is often not undertaken with people with cognitive impairments due to the presumed logistical and methodological issues with doing so (Stewart et al., 1996). However, inferring subjective QOL from external circumstances or 'objective' domains does not fully take into account the values, needs, and adaptations of individuals to various life circumstances (Flanagan, 1982; Sanifort et al, 1996). Furthermore, the use of proxies to measure QOL has inherent difficulties. These include characteristics of the proxy such as the nature of the relationship and time spent with the person assessed, the degree of objectiveness of the questions, and level of any impairment, which may influence the degree of correspondence between proxy responses and the responses of the person assessed (Magaziner et al., 1988; Zimmerman & Magaziner, 1994). Both relatives and

healthcare professionals have been found to frequently underestimate people's QOL (Sprangers & Schwartz, 1999). Furthermore, how people perceive behaviour and overt expressions of emotion varies. For example, Innes (1998) found that what behaviour staff in a residential home perceived as 'challenging', varied according to their relationship to the person, with behaviour displayed by residents already perceived as challenging being described as difficult, whilst similar behaviour by other residents with whom the staff had a better relationship, might be described as 'attempts to communicate'. Even if the proxy is someone who knows a person in depth and is concerned for the person's well being, they will be imposing their own subjectivity upon their judgments, which is likely to be affected by their own sense of well being. For instance, caregivers' own QOL has been found to be related to their perception of the QOL of terminally ill cancer patients (McMillian & Mahon, 1994).

The main argument that has been used by researchers and clinicians for using 'objective' measures or proxy reports to assess QOL for people with disorders like ASD is that due to their cognitive deficits or differences, the person cannot report reliably on internal states. They are thought to lack 'insight'. However, whether a person has insight or not, is typically based on what is defined as 'reality' by another person with greater power or status than the person (Cheston & Bender, 1999). This issue was reflected in the present study, where the two people with Classic Autism scored their QOL the highest of all participants, which could be explained by their apparent limited insight compared to the participants with AS. For these two participants, the greatest discrepancy between their own scores on the QOL-ASD and

the proxy scores were also found. This may suggest that for these two people there were aspects of their QOL they found to be good, about which people without ASD would have higher expectations. If this is the case, it relates to one of the issues core to the measurement of QOL in any group disadvantaged in our society, namely whether their expectations are too low or ours too high. Furthermore, is indeed ignorance of the possibilities for improvement bliss, or are we colluding with their disadvantaged place in society if we do not attempt to induce a change for the better?

Lawton (1997) has stated that emotions and moods have long been known to affect major aspects of the quality of daily life, and that these change from day to day and in rough synchrony with changing circumstances and daily events. If this is so, maybe the variability of responses is more of an issue than whether a person's perception of their QOL corresponds with ours, and as such the assessment of QOL may need to be conducted over a certain time-span rather than being a 'snap-shot' of one moment in time.

Another important issue in this regard is the function of denial. According to Chester and Bender (1999) denial can be functional and adaptive. These authors state that denial as a coping mechanism can protect the person against something that is too traumatic and overwhelming to deal with. Research has also shown denial as being linked to survival in women with breast cancer (Greer et al., 1979). The difficulty arises when the denial is no longer adaptive, but this might not be the case at the time of the QOL assessment.

4.5 GENERIC VERSUS CONDITION-SPECIFIC ASSESSMENT OF QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

The strong correlations detected between the scores on the QOL-ASD and the generic measures used, could be interpreted as meaning that a condition-specific measure is not needed to assess QOL in ASD, as this is well captured by existing generic measures. Comparisons with the control group revealed a significant difference on all QOL indices measured, with the exception of the WHOQOL-BREF (WHO, 1994) Environment and Social domains. This may suggest that these domains of the WHOQOL-BREF do not capture the overall lower QOL found for people with ASD relative to controls. Furthermore, when comparing the results with published population norms, significant differences were found for the WHOQOL-BREF (WHO, 1994) Physical, Psychological and Social domains and the EQ-5D VAS (EuroQoL Group, 1990), but not on the WHOQOL-BREF Environment and the EQ-5D Weighted Health State Index, possibly lending some support to the hypothesis that these scales do not fully capture QOL in ASD. The WHOQOL-BREF (WHO, 1994) also seemed complicated for some people with ASD to complete, due to the nature of some of the language and the varying response options. Some participants with ASD struggled with completing this scale, and for 4 of the 15 the completion of this scale had to be abandoned.

It could therefore be that the QOL-ASD is a more appropriate measure for assessing QOL in ASD, but due to the small numbers in the present study, this needs to be researched further. However, due to the brevity of the QOL-ASD, and the ease of

which it can be administrated and scored, it seems that it may be a useful tool for assessing QOL in ASD.

4.6 VALUE AND PHILOSOPHICAL ISSUES UNDERLYING THE QUALITY OF LIFE – AUTISTIC SPECTRUM DISORDER SCALE

QOL is an abstract concept, and fundamental values and philosophical issues are tied up in its definition and measurement (Dijkers, 1999). It therefore seems important to make the implicit judgments involved in developing a QOL scale explicit, and be aware of the choices informed by these. The QOL-ASD is a subjective scale, based on the developers' conviction that only the person assessed can judge the quality of his or her life. Objective QOL scales, however, are based on the assumption that what constitutes 'the good life' is universal. This approach, as well as going against the fundamental conceptualisation of QOL of the researchers involved in the development of the QOL-ASD, has been criticised as reductionistic and detracting from humanness (Draper, 1992).

In selecting the domains to be included in the QOL-ASD from the items detected in the searches performed, clear value judgments were made. These were all by educated health care professionals without ASD, which will have had an impact on their ranking of items' importance. It is to be hoped that their clinical experience within the field of ASD informed these judgments sufficiently, and it appears from the investigations into the face validity of the QOL-ASD that the items chosen were evaluated by the people with ASD, their relatives and other health care professionals in the field to be appropriate to assess QOL in ASD.

4.7 CONCEPTUALISING QUALITY OF LIFE IN AUTISIC SPECTRUM DISORDER

From the findings it appears that people with ASD attribute quality to their lives to a varying degree, and seem aware of this as a meaningful concept. Only one component of the suggested conceptual model of QOL in ASD (Figure 2, page 45) could be investigated in the study, namely the person's appraisal of their life situation, based on the discrepancy between their expectations and experience (Calman, 1984). As such, the results presented here only make a modest contribution to the effort to conceptualise QOL in ASD. Additionally, it may be that a group on the fringes of society, such as people with ASD, have differing value systems and expectations of their lives to the majority of people. This is important if it means that they have overly modest expectations from life, and as such report having a good QOL when there are aspects of their existence that could be improved upon that are beyond their awareness. This also relates to the question posed at the very beginning of this thesis, whether QOL is an objective entity or inherently subjective. The results from the feedback on the QOL-ASD presented above suggest that the sample perceived QOL to be subjective, depending on psychological well being and mood. As such, is the person's experience of their life the most valid, even if their expectation of life is excessively low compared to the general population? And furthermore, do we have an obligation to alter this expectation and attempt to improve people's lives in accordance with our own expectations? These must surely be questions central to any discussion of the concept of QOL. The inclusion of proxy data in the present study was done in an attempt to add another dimension to the person with ASD's subjective judgment of their QOL. However, as

described above, the results revealed poor correlations between proxy scores and the person with ASD's own scores on the QOL-ASD, and as such this is another area in need of further investigation.

As outlined in the introduction of this thesis, one variable that has been found to significantly predict QOL in ASD is time spent with friends (Craig, 1999). The results presented in this thesis found no significant differences in QOL between participants with ASD reporting having friends or no friends. However, number of friends and time spent with friends is not the same, and there is the issue of what the word 'friend' means to people, as outlined above. Furthermore, Renty & Roeyer's (2006) highlighted the positive impact on QOL of meaningful employment and engagement in ASD, as well as perceived availability of informal and formal support. The present study found no significant difference in QOL between participants presently employed compared to those unemployed. However, the small numbers involved could have affected these findings.

Jennes-Coussens et al. (2006) found that the majority of young men with AS included reported never having dated or having been in intimate relationships. This was similar to the findings of the present study, in which most participants with ASD included were single. It was however not possible to conduct a meaningful analysis of this, due to the numbers of the two groups being too unequal.

The descriptive data included also living situation, education and qualifications and diagnosis. No significant impact of these variables on the QOL of people with ASD

was detected here. A significant positive relationship was detected between age and total QOL-ASD score, suggesting that the older people with ASD in this sample experienced higher QOL. However, although significant the relationship was not strong, and considering the low number in this sample this may not necessarily be a meaningful finding.

4.8 CLINCIAL REFLECTIONS ON ASSESSING QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

The research team involved in the study described in this thesis was fortunate enough to have a member with in-depth prior knowledge of all participants. As well as ensuring that appropriate language was used with each individual and that all were approached with the invitation to participate in a way that was as anxiety-reducing as possible, this also meant that informed reflection could take place subsequent to the interviews. This led to some points worth mentioning. The person scoring the lowest on the QOL-ASD was EE. This is a man with AS, who craves what people around him have: a partner, friends and a driving license. However, mainly due to his marked egocentricity, these are aspects of life sadly unavailable to him. Compare this to the participant in the study with one of the highest overall scores, MB, who has Autism. He can only cope with limited contact with other people, and has no desire for friends or a partner. Scoring in the middle range on the QOL-ASD is CH, who is married with children, keeping a job until retirement age, and being able to initiate and maintain some friendships. CH's manifestation of AS is subtle, and he was only recently diagnosed with having AS after twenty years in mental health services. These examples illustrate individual differences among people with ASD

that appeared to be well captured by the QOL-ASD. In contrast, when comparing the low QOL-ASD score of EE, who would be described as 'active but odd' with that of GV, who had the highest QOL-ASD score of the sample, a difficulty is highlighted. GV would be described as 'passive' person with ASD, who attempts to be pleasant and compliant. His high score could be reflecting a desire to 'give the right answer', and does not reflect his recurrent severe depression. This is an issue with the QOL-ASD, as other measuring scales, which is problematic to address.

4.9 LIMITATIONS

A number of limitations with the research reported in this thesis are important to highlight. One is that only one part of the proposed conceptual model of QOL in ASD was investigated in this thesis (Figure 2), namely the person's appraisal of their life situation. As such, the proposed conceptual model can only be considered as a hypothetical model for consideration.

The work undertaken to validate the QOL-ASD scale, involved significant challenges. Numbers were low, which was particularly clear when dividing the sample into sub-groups for analyses, and as such any result must be interpreted with caution. Both the ASD group and the control group were self-selected. All participants in the ASD group were people already receiving services and the control group consisted of people belonging to a small rural community. As such, this sample may not be representative. Furthermore, there were significant differences between the two groups, the control participants were on average older, less lived alone and none with parents, more were married and employed. Focus groups were

not conducted due to the perceived unfeasibility of these, but could have added a valuable dimension both to the development of the QOL-ASD and the investigation into the face or content validity of the scale. Little qualitative data were received on the feedback questionnaires distributed. Semi-structured focus groups could have been more successful in gathering such information. In relation to concurrent validity, the best available measures were used. These generic scales (EQ-5D; EuroQoL Group, 1990; WHOQOL-BREF; WHO QOL group, 1998) have not been demonstrated to be valid or reliable for use with people with ASD. In terms of test-retest reliability, this was tested using a seven-day interval. It could be argued that this time should have been longer, however with the hypothesised dynamic nature of QOL, a time scale for expected stability is a difficult aspect to consider.

Several important aspects of validity were not investigated in the present study. In terms of construct validity, to what extent the construct of QOL, which the QOL-ASD aims to measure, is a real and concrete entity, as well as the salience of this scale to that construct, cannot be demonstrated empirically. Evidence can be sought to support it, however due to small numbers a Principal Component Analysis was not conducted. Both convergent and divergent validity and known group validity were deemed too difficult to include in the study, as this would have involved a significant added commitment from the people with ASD to complete yet more scales, for example of cognition and mood, which may have overloaded them. Furthermore, due to the time-scale in question, predictive validity and sensitivity to change were not investigated in this validation study, which is a further shortcoming of the research presented here.

In terms of the ethical issues surrounding the assessment of QOL raised in the Introduction, the main cause for concern was that the act of measuring QOL would raise an expectation in the participants that the researchers would be able to influence it (Higginson & Carr, 2001). Although it was explained to the participants that this was not the case, it could still be that some felt that through the act of telling about limitations to their QOL something would be done to improve their everyday lives.

4.10 IMPLICATIONS FOR PRACTICE

The research described has found some support for the value of QOL as a meaningful aspect of ASD. As such, this may be a variable of importance to investigate when developing treatment plans for people with ASD, as it is an inclusive concept, reflecting a variety of elements of everyday life. Some evidence has been found to suggest that the QOL-ASD is a valid and reliable scale, and its use in clinical practice can as such be cautiously supported. One important implication for clinical practice is the hopefulness underlying the proposed conceptual model of QOL in ASD outlined in this thesis. This would imply that health care professionals can have an important effect on QOL for people with ASD, not in terms of how they function physically, psychologically and socially *per* se, but the way in which these abilities are appraised to form a person with ASD's sense of their QOL. The findings reported here suggest that it is possible to produce a meaningful single index value for QOL in ASD. This is particularly important if QOL is going to be introduced as a routine part of assessments of people with ASD.

4.11 IMPLICATIONS FOR RESEARCH

The results from the validation study presented in this thesis must be considered with caution due to the small number of participants. However, this study could form a valuable basis as a pilot for a large-scale validation study of the QOL-ASD. As outlined above, as well as gathering further evidence on the validity and reliability indices investigated here, this should include investigations into the scale's construct validity, convergent and divergent validity, known group validity, predictive validity and incremental validity. Furthermore, any future research should use much larger samples to permit an investigation of factorial validity, and aim to establish the extent to which the scale is sensitive to clinically meaningful change in ASD. Additionally, whether or not to include proxy ratings in the assessment of QOL in ASD needs to be investigated further.

If a large scale study were to demonstrate that the QOL-ASD is a valid and reliable scale, then it could be used in further research to investigate empirically the conceptual model for QOL in ASD as suggested in this thesis in order to further explore the factors underlying QOL in ASD. The remit of this thesis was to investigate whether the QOL-ASD was a valid and reliable instrument for the measurement of QOL for adults with high-functioning ASD. Future research could explore the psychometric properties of this scale with children and adolescents with ASD, and also with people with ASD and a learning disability, as there are currently no self-report QOL measures for these groups.

4.12 CONCLUSIONS

It was found to be possible to develop a comprehensive scale for the measurement of QOL in ASD. Considering the validation study as a pilot, due to small numbers, the preliminary results suggest that the Quality Of Life –Autistic Spectrum Disorder (QOL-ASD) scale has good face/content and concurrent validity. It was also found to have good test-retest and internal consistency. The hypothesis that the QOL-ASD is valid and reliable scale can be therefore be cautiously supported by the findings reported here, and despite Aksoy's (2000) reservations, it does appear that QOL can be measured accurately and reliably. This study has demonstrated also that people with ASD can accurately report on their QOL. Therefore, as to the questions posed at the very beginning of this thesis, some evidence has been found to support the idea that QOL is inherently subjective, and that a tool can be developed to assess it that is perceived as meaningful by the group of people assessed.

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Appendix A:

Assessment Scales

ID:	Proxy:
Rater	Time

QOL-ASD

QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

Appendix A: Assessment Scale 134

please ( ) *circle*

1	Level of independence	**Poor**	**Fair**	**Good**	**Excellent**
2	Level of safety & security	**Poor**	**Fair**	**Good**	**Excellent**
3	Work (or educational) situation	**Poor**	**Fair**	**Good**	**Excellent**
4	Financial situation	**Poor**	**Fair**	**Good**	**Excellent**
5	Living situation	**Poor**	**Fair**	**Good**	**Excellent**
6	Participation in leisure acitivites	**Poor**	**Fair**	**Good**	**Excellent**
7	Access to services & medication	**Poor**	**Fair**	**Good**	**Excellent**
8	Family relationships	**Poor**	**Fair**	**Good**	**Excellent**
9	Relationships with friends	**Poor**	**Fair**	**Good**	**Excellent**
10	Romantic & sexual life	**Poor**	**Fair**	**Good**	**Excellent**
11	Physical health & energy levels	**Poor**	**Fair**	**Good**	**Excellent**
12	Psychological well-being & mood	**Poor**	**Fair**	**Good**	**Excellent**
13	Self-esteem	**Poor**	**Fair**	**Good**	**Excellent**
14	Ability to think and remember clearly	**Poor**	**Fair**	**Good**	**Excellent**
15	Ability to communicate effectively	**Poor**	**Fair**	**Good**	**Excellent**
16	Sleep	**Poor**	**Fair**	**Good**	**Excellent**
17	Eating	**Poor**	**Fair**	**Good**	**Excellent**
18	Degree of truthfulness around you	**Poor**	**Fair**	**Good**	**Excellent**
19	Degree of justice around you	**Poor**	**Fair**	**Good**	**Excellent**
20	Degree of inclusion in society	**Poor**	**Fair**	**Good**	**Excellent**
21	Quality of life overall	**Poor**	**Fair**	**Good**	**Excellent**

Thank you!

Feedback on the QOL-ASD

please ◯ *circle*

1	Level of independence	Not relevant	Somewhat relevant	Relevant	Very relevant
2	Level of safety & security	Not relevant	Somewhat relevant	Relevant	Very relevant
3	Work (or educational) situation	Not relevant	Somewhat relevant	Relevant	Very relevant
4	Financial situation	Not relevant	Somewhat relevant	Relevant	Very relevant
5	Living situation	Not relevant	Somewhat relevant	Relevant	Very relevant
6	Participation in leisure acitivites	Not relevant	Somewhat relevant	Relevant	Very relevant
7	Access to services & medication	Not relevant	Somewhat relevant	Relevant	Very relevant
8	Family relationships	Not relevant	Somewhat relevant	Relevant	Very relevant
9	Relationships with friends	Not relevant	Somewhat relevant	Relevant	Very relevant
10	Romantic & sexual life	Not relevant	Somewhat relevant	Relevant	Very relevant
11	Physical health & energy levels	Not relevant	Somewhat relevant	Relevant	Very relevant
12	Psychological well-being & mood	Not relevant	Somewhat relevant	Relevant	Very relevant
13	Self-esteem	Not relevant	Somewhat relevant	Relevant	Very relevant
14	Ability to think and remember clearly	Not relevant	Somewhat relevant	Relevant	Very relevant
15	Ability to communicate effectively	Not relevant	Somewhat relevant	Relevant	Very relevant
16	Sleep	Not relevant	Somewhat relevant	Relevant	Very relevant
17	Eating	Not relevant	Somewhat relevant	Relevant	Very relevant
18	Degree of truthfulness around you	Not relevant	Somewhat relevant	Relevant	Very relevant
19	Degree of justice around you	Not relevant	Somewhat relevant	Relevant	Very relevant
20	Degree of inclusion in society	Not relevant	Somewhat relevant	Relevant	Very relevant
21	Quality of life overall	Not relevant	Somewhat relevant	Relevant	Very relevant

Do you think this scale covers all the important domains for a person with ASD?____
If no, please expand. _____
Do you think any of the items no relevant for the QOL of a person with ASD?_____
If yes, please expand. _____
Do you have any additional comments about the scale?_____

Thank you!

Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

For office use			(Please circle the number)				
			Very poor	Poor	Neither poor nor good	Good	Very Good
G1 / G1.1	1.	How would you rate your quality of life?	1	2	3	4	5

For office use			(Please circle the number)				
			Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
G4 / G2.3	1.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

For office use			(Please circle the number)				
			Not at all	A little	A moderate amount	Very much	An extreme amount
F1.4 / F1.2.5	3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
F11.3 / F13.1.4	4.	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
F4.1 / F6.1.2	5.	How much do you enjoy life?	1	2	3	4	5
F24.2 / F29.1.3	6.	To what extent do you feel your life to	1	2	3	4	5

	(Please circle the number)				
	Not at all	A little	A moderate amount	Very much	An extreme amount
be meaningful?					

	(Please circle the number)				
	Not at all	Slightly	A Moderate amount	Very much	Extremely
7. How well are you able to concentrate?	1	2	3	4	5
8. How safe do you feel in your daily life?	1	2	3	4	5
9. How healthy is your physical environment?	1	2	3	4	5

wing questions ask about **how completely** you experience or were able to
n things in the last two weeks.

	(Please circle the number)				
	Not at all	A little	Moderately	Mostly	Completely
0. Do you have enough energy for everyday life?	1	2	3	4	5
. Are you able to accept your bodily appearance?	1	2	3	4	5
Have you enough money to meet your needs?	1	2	3	4	5
How available to you is the information that	1	2	3	4	5

office use		(Please circle the number)				
		Not at all	A little	Moderately	Mostly	Completely
	you need in your day-to-day life?					
1.1 / 5.1.2	14. To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

office use		(Please circle the number)				
		Very poor	Poor	Neither poor nor well	Well	Very well
9.1 / 1.1.1	15. How well are you able to get around?	1	2	3	4	5

e following questions ask you to say how **good** or **satisfied** you have felt about ious aspects of your life over the last two weeks.

office use		(Please circle the number)				
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
3.3 / 4.2.2	16. How satisfied are you with your sleep?	1	2	3	4	5
0.3 / 2.2.3	17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
2.4 / 6.2.1	18. How satisfied are you with your capacity for work?	1	2	3	4	5
6.4 / 3.2.2	19. How satisfied are you with your abilities?	1	2	3	4	5

For office use			*(Please circle the number)*				
			Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
F13.3 / F17.2.3	20.	How satisfied are you with your personal relationships?	1	2	3	4	5
F15.3 / F3.2.1	21.	How satisfied are you with your sex life?	1	2	3	4	5
F14.4 / F18.2.5	22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
F17.3 / F21.2.2	23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
F19.3 / F24.2.1	24.	How satisfied are you with your access to health services?	1	2	3	4	5
F.23.3 / F28.2.2	25.	How satisfied are you with your mode of transportation?	1	2	3	4	5

llow question refers to **how often** you have felt or experienced certain things last two weeks.

	(Please circle the number)				
	Never	Seldom	Quite often	Very often	Always
26. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

neone help you to fill out this Yes No
Please circle Yes or No)

ng did it take to fill out this

THANK YOU FOR YOUR HELP

Describing your own health today

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about
I have some problems in walking about
I am confined to bed

Self-Care

I have no problems with self-care
I have some problems washing or dressing myself
I am unable to wash or dress myself

Usual Activities (e.g. work, study, housework, family or leisure activities)

I have no problems with performing my usual activities
I have some problems with performing my usual activities
I am unable to perform my usual activities

Pain/Discomfort

I have no pain or discomfort
I have moderate pain or discomfort
I have extreme pain or discomfort

Anxiety/Depression

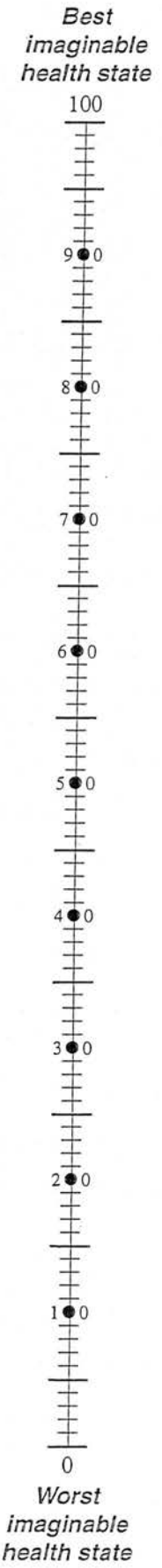
I am not anxious or depressed
I am moderately anxious or depressed
I am extremely anxious or depressed

Valuing your own health today

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today



Appendix B:

Letters/forms

NHS
Grampian

North of Scotland Research Ethics Committee (2)
Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558480
Facsimile: 01224 558609

11 June 2007

Dr Lene Forrester
Trainee Clinical Psychologist
Grampian NHS
Clinical & Counselling Psychology, Block A
Clerkseat Building, Royal Cornhill Hospital
Westburn Road
AB30 1PJ

Dear Dr Forrester

Full title of study: **A Validation Study of an Autistic Spectrum Disorder (ASD) - Specific Quality of Life Assessment Scale**
REC reference number: **07/S0802/26**

Thank you for your letter of 7 June 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

The favourable opinion is given provided that you comply with the conditions set out. You are advised to study the conditions carefully, in particular:

Condition 1: Annual Progress Report

Under the National Research Ethics Service (NRES) regulations NHS Research Ethics Committees are required to monitor research with a favourable opinion. This is to take the form of an annual progress report which should be submitted to the North of Scotland Research Ethics Committee (NOSREC) 12 months after the date on which the favourable opinion was given. Annual reports should be submitted thereafter until the end of the study.

Points to note:

- The first annual progress report should give the commencement date for the study. This is normally assumed to be the date on which any of the procedures in the protocol are

initiated. Should the study not commence within 12 months of approval a written explanation must be provided in the 1st annual progress report.

- Progress reports should be in the format prescribed on the NRES website (www.nres.npsa.nhs.uk/applicants/index.htm).
- Progress reports must be signed by the Principal Investigator/Chief Investigator.
- Failure to submit a progress report could lead to a suspension of the favourable ethical opinion for the study.
- Please note the Annual Progress Report is a short 3 page form which is extremely easy to complete.

Condition 2: Notification of Study Completion/Termination

Under the National Research Ethics Service (NRES) regulations researchers are required to notify the Ethics Committee from which they obtained approval of the conclusion or early termination of a project and to submit a Completion/Termination of Study Report. Researchers should follow the instructions on the NRES website (www.nres.npsa.nhs.uk/applicants/index.htm)

Points to note:

- For most studies the end of a project will be the date of the last visit of the last participant or the completion of any follow-up monitoring and data collection described in the protocol.
- Final analysis of the data and report writing is normally considered to occur after formal declaration of the end of the project.
- A Final Report should be sent to the NOSREC within 12 months of the end of the project.
- The summary of the final report may be enclosed with the end of study declaration, or sent to the REC subsequently.
- There is no standard format for final reports. As a minimum we should receive details of the end date and information on whether the project achieved its objectives, the main findings and arrangements for publication or dissemination of research, including any feedback to participants.
- Please note the Completion/Termination of Study Report need only be a summary document and should, therefore, be easy to prepare.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Application	5.3	22 March 2007
Investigator CV		
Protocol	1	18 December 2006

Statistician Comments		
Compensation Arrangements		28 July 2006
Questionnaire: WHOQOL-BREF	US	
Questionnaire: EQ-5D		
Letter of invitation to participant	Amended	
Participant Information Sheet: Participant	3	
Participant Information Sheet: Professional	3	
Participant Information Sheet: Relative/Friend/Carer	3	
Participant Consent Form: 3		06 March 2007
Participant Consent Form: 2		06 March 2007
Participant Consent Form: 1		06 March 2007
Co-investigator's CV: Tommy McKay		
CV of John Forrester		
Supervisor CV: Dr George C Murray		

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from http://www.rdforum.nhs.uk/rdform.htm.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:

https://www.nresform.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx

We value your views and comments and will use them to inform the operational process and further improve our service.

07/S0802/26	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

pp RS Venables

Dr Sheila A Simpson
Chair

GRAMPIAN
Autistic Society

Grampian Autistic Society ♦ 35-37 Carnie Drive ♦ Aberdeen ♦AB25 3AN
Telephone 01224 277900 ♦ Mobile 07835 844 554 ♦ Fax 01224 495580
Email john.forrester@classmail.co.uk

NAME
ADDRESS
ADDRESS
ADDRESS

Aberdeen, date

Dear NAME,

RE: QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

You are being invited to take part in a research study. Please read the attached Information sheet, before you decide whether or not to take part.

If you do decide to take part in the study, please contact Dr Lene Forrester on the address given in the Information sheet. Alternatively, you can contact me on the address above.

Thank you very much in advance.

Yours sincerely,

John Forrester
Training & Assessment Consultant

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NHS
Grampian

QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER
INFORMATION SHEET (3) – 07.06.07

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important that you know why this research is being done, and what taking part in it will mean for you. Please read this information carefully, and discuss it with somebody if you like. This could be a member of your family, your key worker or your GP. Ask us if there is anything that is not clear, or you would like some more information.

What is the purpose of the study?
Having Asperger's Syndrome, Autism or Autistic Spectrum Disorder has a big effect on people's lives, and helping improve the wellbeing of the person is important. One way of finding out if professionals are successful in doing this, is using an assessment scale in an interview. This means asking people questions about themselves and their lives. However, wellbeing (or quality of life as it is also called) is difficult to measure like this, and that is why we are now testing such a scale, to make sure that it measures what it is supposed to measure. This research study will be carried out over the next 3 months.

Why have I been chosen?
You are being invited to take part in this research study because you have some connection with Grampian Autistic Society, and we are hoping to include a total of 30 people in your situation in the study.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part, you will be asked to sign a consent form. You will still be free to withdraw at any time without giving a reason. Whatever you decide, any support you may be receiving from Grampian Autistic Society or anywhere else will not be affected.

What will happen to me if I take part?
If you choose to take part in the study, you will be interviewed for 10 minutes by two researchers (John Forrester and Lene Forrester). A second interview will then be arranged for one week later. This interview will be with only one researcher (Lene Forrester) and will last for 30 minutes. These interviews can either be done at Grampian Autistic Society's premises or in your own home if you would prefer. In the interviews, you will be asked some questions about yourself, your life, and how you are feeling. You will not have to answer anything you do not want to answer.

What are the possible disadvantages or risks of taking part?
There should be no risks involved in taking part in this study. If we, through our interviews, should discover that something about your situation needs addressing, this will be done by Grampian Autistic Society as appropriate.

What are the possible benefits of taking part?
We hope that taking part in the study will be an enjoyable experience for everyone involved, as we will

have an opportunity to discuss your experience of your current situation, and any help or support you may be receiving. By taking part in this study, you would be helping us to clarify what is important to people with Asperger's Syndrome, Autism or Autistic Spectrum Disorder, which would be of benefit to them and any professionals involved with them.

What happens if something goes wrong?

If you at any stage have concerns about aspects of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?

All information collected about you in this study will be kept strictly confidential, and it will have your name removed from it so that you cannot be recognised from it.

What will happen to the results of the research study?

When the study has been completed, you will be invited to a talk, presenting the results of the research.

Who is organising and funding the research?

This study is overseen by the University of Edinburgh.

Who has reviewed the study?

All the questions we are going to ask you and everything we do in this study has been found to be acceptable by the Ethics Committee in Grampian.

Contact for further information

If you have any questions or need any more information, please contact Dr Lene Forrester or Dr George Murray. Our contact details are:

Dr Lene Forrester
Clinical & Counselling Psychology, Block A
Royal Cornhill Hospital, Westburn Road, Aberdeen
Tel: 01224 557475
Email: lene.forrester@nhs.net

Dr George Murray
D.Clin.Psychol, University of Edinburgh
Medical School, Teviot Place, Edinburgh
Tel: 0131 6513972
Email: v1gmurra@staffmail.ed.ac.uk

THANK YOU VERY MUCH FOR READING THIS
AND FOR CONSIDERING TAKING PART IN THIS RESEARCH.

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QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER
INFORMATION SHEET (3) – 07.06.07

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important that you know why this research is being done, and what taking part in it will mean for you. Please read this information carefully, and discuss it with somebody if you like. This could be a member of your family or your GP. Ask us if there is anything that is not clear, or you would like some more information.

What is the purpose of the study?
Having Asperger's Syndrome, Autism or Autistic Spectrum Disorder has a big effect on people's lives, and helping improve the wellbeing of the person is important. One way of finding out if professionals are successful in doing this, is using an assessment scale in an interview. This means asking people questions about them and their lives. However, wellbeing (or quality of life as it is also called) is difficult to measure like this, and that is why we are now testing such a scale, to make sure that it measures what it is supposed to measure. This research study will be carried out over the next 3 months.

Why have I been chosen?
You are being invited to take part in this research study because you have a relative, friend or are providing support to a person with a connection to Grampian Autistic Society, and we are hoping to include a total of 30 people in your situation in the study.

Do I have to take part?
We were hoping that you may be willing to help us conduct this research. It is up to you to decide whether or not to take part. If you decide to take part, you will be asked to sign a consent form. You will still be free to withdraw at any time without giving a reason. Whatever you decide, any support your relative may be receiving from Grampian Autistic Society or anywhere else will not be affected.

What will happen to me if I take part?
You will find two questionnaires with this letter. If you choose to take part in the study, please complete the first one (entitled QOL-ASD) on behalf of _____ as best you can. (S)he has already been interviewed by us, and has agreed to you taking part in this study if you so wish. Then please complete the second questionnaire (entitled Feedback on the QOL-ASD), giving your opinion as to how important you think the 21 items of the QOL-ASD scale are for _____'s quality of life.

What are the possible disadvantages or risks of taking part?
There should be no risks involved in taking part in this study. If we, through our interviews, should discover that something about your relative's situation needs addressing, this will be done by Grampian Autistic Society as appropriate.

What are the possible benefits of taking part?

We hope that taking part in the study will be an enjoyable experience for everyone involved. By taking part in this study, you would be helping us to clarify what is important to people with Asperger's Syndrome, Autism or Autistic Spectrum Disorder, which would be of benefit to them and any professionals involved with them.

What happens if something goes wrong?

If you at any stage have concerns about aspects of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?

All information collected about you in this study will be kept strictly confidential, and it will have your name removed from it so that you cannot be recognised from it.

What will happen to the results of the research study?

When the study has been completed, you will be invited to a talk, presenting the results of the research.

Who is organising and funding the research?

This study is overseen by the University of Edinburgh.

Who has reviewed the study?

All the questions we are going to ask you and everything we do in this study has been found to be acceptable by the Ethics Committee in Grampian.

Contact for further information

If you have any questions or need any more information, please contact Dr Lene Forrester or Dr George Murray. Our contact details are:

Dr Lene Forrester
Clinical & Counselling Psychology, Block A
Royal Cornhill Hospital, Westburn Road, Aberdeen
Tel: 01224 557475
Email: lene.forrester@nhs.net

Dr George Murray
D.Clin.Psychol, University of Edinburgh
Medical School, Teviot Place, Edinburgh
Tel: 0131 6513972
Email: v1gmurra@staffmail.ed.ac.uk

THANK YOU VERY MUCH FOR READING THIS
AND FOR CONSIDERING TAKING PART IN THIS RESEARCH.

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QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER
INFORMATION SHEET (3) – 07.06.07

The limitations of using survival rates and symptom levels as the only outcome variables in clinical practice and research are becoming evident, particularly with people who have a lifelong and incurable disorder, such as autistic spectrum disorder (ASD). A more important indication may be whether an intervention has the result of making life more or less '*worth living*'. As such, quality of life (QOL) is increasingly seen as a key consideration in; evaluating services; the ethical debate regarding health care resource allocation; testing the effectiveness of new treatments; and the development of clinical guidelines.

What is the purpose of the study?
Factors contributing to QOL for people with ASD are not yet understood, and have to date received little attention. There is to date no ASD-specific assessment scale described in the literature. This is why we have now attempted to develop such a scale. The study of this scale will be carried out over the next 3 months.

Why have I been chosen?
You are being invited to take part in this research study because you are a professionals working within the field of ASD, and we are hoping to include a total of 30 professionals in the study.

Do I have to take part?
It is of course entirely up to you whether or not you choose to take part in the study, and you are free to withdraw your input from the study at any time.

What will happen to me if I take part?
As part of the validation process of the QOL-ASD scale, we were hoping that you would take ten minutes to read through the scale (entitled QOL-ASD), and then give your feedback on the attached questionnaire (entitled Feedback on the QOL-ASD) as to how relevant you think the __ (no.) items are to QOL in ASD. Please also to sign the consent form.

What are the possible disadvantages or risks of taking part?
There should be no risks involved in taking part.

What are the possible benefits of taking part?
By taking part in the study you would be helping to clarify what is important to people with ASD, and thereby benefiting them and professionals involved in their care.

What happens if something goes wrong?
If you at any stage have concerns about aspects of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?
All information that is collected in this study will be anonymised and kept strictly confidential.

What will happen to the results of the research study?
When the study has been completed, you will be invited to a talk, presenting the results of the research.

Who is organising and funding the research?
This study is overseen by the University of Edinburgh.

Who has reviewed the study?
All procedures employed in this study have been approved Grampian Ethics Committee.

Contact for further information
If you have any questions or need any more information, please contact Dr Lene Forrester or Dr George Murray on:

Dr Lene Forrester
Clinical & Counselling Psychology, Block A
Royal Cornhill Hospital, Westburn Road, Aberdeen
Tel: 01224 557475
Email: lene.forrester@nhs.net

Dr George Murray
D.Clin.Psychol, University of Edinburgh
Medical School, Teviot Place, Edinburgh
Tel: 0131 6513972
Email: v1gmurra@staffmail.ed.ac.uk

THANK YOU VERY MUCH FOR READING THIS
AND FOR CONSIDERING TAKING PART IN THIS RESEARCH.

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QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER
INFORMATION SHEET (4) – 04.09.08

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important that you know why this research is being done, and what taking part in it will mean for you. Please read this information carefully, and discuss it with somebody if you like. Ask us if there is anything that is not clear, or you would like some more information.

What is the purpose of the study?
Having Asperger's Syndrome, Autism or Autistic Spectrum Disorder has a big effect on people's lives, and helping improve the wellbeing of the person is important. One way of finding out if professionals are successful in doing this, is using an assessment scale. This means asking people questions about themselves and their lives. However, wellbeing (or quality of life as it is also called) is difficult to measure like this, and that is why we are now testing such a scale, to make sure that it measures what it is supposed to measure. This research study will be carried out over the next 3 months.

Why have I been chosen?
You are being invited to take part in this research study because you attend Arbuthnott Community Centre, which has been chosen as a site from which to recruit a comparison sample in a study conducted with people with Autistic Spectrum disorder. We are hoping to include a total of 30 people in the study.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part, you will be asked to sign a consent form. You will still be free to withdraw at any time without giving a reason. Whatever you decide, this will not affect you in any way.

What will happen to me if I take part?
If you choose to take part in the study, you will be asked to complete 4 short questionnaires. This should take about 30 minutes. You will also be asked to complete 1 questionnaire one week later, which should take about 10 minutes. The questionnaires will ask you some questions about yourself, your life, and how you are feeling. You will not have to answer anything you do not want to answer.

What are the possible disadvantages or risks of taking part?
There should be no risks involved in taking part in this study. If you, through completing the questionnaires, should feel that there is something about your situation that needs to be addressed, Lene Forrester will be available to discuss with you how to best take that forward.

What are the possible benefits of taking part?
We hope that taking part in the study will be an enjoyable experience for everyone involved,. By taking part in this study, you would be helping us to clarify what is important to people with Asperger's Syndrome, Autism or Autistic Spectrum Disorder, which would be of benefit to them and any professionals involved in their care.

What happens if something goes wrong?
If you at any stage have concerns about aspects of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?
All information collected about you in this study will be kept strictly confidential, and it will have your name removed from it so that you cannot be recognised from it.

What will happen to the results of the research study?
When the study has been completed, you will be invited to a talk, presenting the results of the research.

Who is organising and funding the research?
This study is overseen by the University of Edinburgh.

Who has reviewed the study?
All the questions we are going to ask you and everything we do in this study has been found to be acceptable by the Ethics Committee in Grampian.

Contact for further information
If you have any questions or need any more information, please contact Dr Lene Forrester or Dave Peck. Our contact details are:

Dr Lene Forrester
Angus Psychological Therapies Team
Booth House, Sunnyside Royal Hospital, Montrose
Tel: 01674 832252
Email: lene.forrester@nhs.net

Dave Peck
D.Clin.Psychol, University of Edinburgh
Medical School, Teviot Place, Edinburgh
Tel: 0131 6513972
Email: dfpeck@btinternet.com

THANK YOU VERY MUCH FOR READING THIS
AND FOR CONSIDERING TAKING PART IN THIS RESEARCH.

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QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

CONSENT FORM (3) – 07.06.07

I confirm that I have read and understand the information sheet dated 07.06.07 for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving a reason and without any support I receive from Grampian Autistic Society being affected.

I understand that all information collected about me in this study will be kept strictly confidential, and will have my name removed from it so that I cannot be recognised from it.

I agree to take part in this study.

Name of participant	Date	Signature
Name of researcher	Date	Signature

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QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

CONSENT FORM (3) – 07.06.07

I confirm that I have read and understand the information sheet dated 07.06.07 for the above study and have had the opportunity to speak with the researchers to ask questions if I have so wished.

I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving a reason and without any support my relative receive from Grampian Autistic Society being affected.

I understand that all information collected in this study will be kept strictly confidential, and will have my name removed from it so that I cannot be recognised from it.

I agree to take part in this study.

_____	_____	_____
Name of participant	Date	Signature

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QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

CONSENT FORM (2) – 01.05.07

I confirm that I have read and understand the information sheet dated 07.06.07 for the above study and have had the opportunity to speak with the researchers to ask questions if I have so wished.

I understand that my participation is voluntary and that I am free to withdraw my input from the study at any time.

I understand that all information collected in this study will be kept strictly confidential, and be completely anonymised.

I agree to take part in this study.

_____	_____	_____
Name of participant	Date	Signature

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QUALITY OF LIFE IN AUTISTIC SPECTRUM DISORDER

CONSENT FORM (4) – 04.09.08

I confirm that I have read and understand the information sheet dated 04.09.08 for the above study and have had the opportunity to speak with the researchers to ask questions if I have so wished.

I understand that my participation is voluntary and that I am free to withdraw my input from the study at any time.

I understand that all information collected in this study will be kept strictly confidential, and be completely anonymised.

I agree to take part in this study.

_____	_____	_____
Name of participant	Date	Signature