The most important aspects of quality of life for New Zealand adolescents with physical disabilities

Margot Andrew

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Primary Supervisor: Nicola Kayes

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Attestation of authorship

"I hereby declare that the submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning"

Signed:

……..

Margot Andrew
29 February, 2008

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Abstract

Background

Improving quality of life (QoL) is increasingly identified as an important outcome of health and social care. Accurate measurement of QoL is important for young people because it can be used to help understand their needs, to evaluate interventions, to identify at risk adolescents and to enable education and health organisations to plan and monitor programs. Research exploring QoL from the perspective of adolescents with physical disabilities is limited, particularly from a New Zealand perspective.

Aims

The purpose of this qualitative study was:

(i) To explore the most important aspects of quality of life (QoL) for New Zealand adolescents with physical disabilities, from the perspective of the adolescents themselves, their families, teachers and therapists.

(ii) To compare findings with existing measures of adolescent QoL.

Methods

The study utilised a methodology as approved by the WHOQOL group (Geneva), and derived by the DIS-QOL Project, 2005, (Lead centre: The University of Edinburgh). Six focus groups were held: two with adolescents (including one group of Maori and Pasifika adolescents), two with parents and one group each of teachers and therapists. The recruitment process used purposeful sampling aiming to get variation in age, gender, ethnicity, type and severity of disability. The focus groups were tape recorded and transcribed verbatim. Data was analysed manually using content analysis, constant comparison and negative case analysis to establish themes and categories.

Findings

Four key themes emerged from the data regarding the most important aspects of QoL for adolescents with physical disabilities: (1) to be recognised as an individual; (2) to have autonomy; (3) to have meaningful relationships; and (4) to have purposeful opportunities (to contribute and achieve in society). When compared to existing adolescent QoL measures, some aspects of these themes

were supported. However, several fundamental components of QoL highlighted by the participants were not considered in these measures including: to be seen as an individual and have an identity outside that of being a person with a disability, to have the opportunity to make choices and be supported in those choices, to have a voice in the community and to have privacy.

Significance

This study contributes to the body of knowledge regarding what New Zealand adolescents with physical disabilities consider to be important in terms of QoL. It also contributes to the body of knowledge regarding the perspective of Maori and Pasifika adolescents with physical disabilities. The findings have identified areas not addressed in current adolescent measures of QoL and can be used to contribute towards developing a conceptual framework for QoL for adolescents with physical disabilities. This framework could then be used to develop measures which can then be validated in this population.

This study also shows the importance of working in partnership with young people. Research that does not include adolescents in the generation of ideas has the potential to miss concerns critical to their development.

CHAPTER ONE: INTRODUCTION

The purpose of this qualitative study was to explore the most important aspects of quality of life (QoL) for New Zealand adolescents with physical disabilities, from the perspective of the adolescents themselves, their families, teachers and therapists. This chapter provides a brief overview of the study and outlines the structure for this dissertation.

Improving QoL is increasingly identified as an important outcome of health and social care. For adolescents, QoL encompasses a multidimensional approach that emphasises the holistic nature of the adolescent and the uniqueness of QoL as experienced by each individual (Meuleners & Lee, 2005). Knowledge about what matters most to adolescents with regards to QoL is important for societies to help improve adolescents' well being and prepare them for a constructive adulthood. QoL measures organise constructs that can be used for evaluating dimensions associated with a life of quality, providing direction and guidance in providing appropriate service (Schalock, 1996). They can be used to help understand an adolescent's needs and goals, to evaluate specific interventions and to identify patient sub populations at risk for psychological and behavioural problems (Koot & Wallander, 2001; Spieth & Harris, 1996). They also enable health practitioners to plan, monitor and evaluate health and quality of care.

Adolescents with physical disabilities face unique issues of restricted physical movement and, in some cases communication difficulties. In addition, some have educational, vocational and recreational challenges to deal with at a time when they are vulnerable to a decrease in function as they get older (Haberfellner, 2001; Steele et al, 2004). Furthermore, advancements in medicine have resulted in reduced mortality rates and increased lifespan for this population (Plioplys, 2003). This means that adolescents are living with the consequences of their impairment for longer. It is important that advances in medical care also result in a correspondingly good QoL and that parents, educators, clinicians and policy makers understand the factors that promote or inhibit the QoL and health of adolescents with physical disabilities.

Research exploring QoL from the perspective of adolescents with physical disabilities is limited and as a result existing QoL measures for this population are potentially flawed. Firstly, most current adolescent QoL measures draw on measures developed for adults or research done in healthy adolescent populations. Secondly, there are a number of methodological inconsistencies such as what constitutes the age of adolescence, lack of consensus as to the definition of adolescent QoL and Health Related QoL (HRQOL) and lack of consultation with adolescents during the construction of measures. Thirdly, there is a distinct lack of New Zealand research from the perspective of young people with physical disabilities and their parents and a lack of research that includes the perspectives of teachers and therapists.

A better understanding of what matters to young people should contribute to the development of more conceptually sound, meaningful and responsive measures of QoL. Current lack of knowledge about New Zealand adolescents with physical disabilities represents a major limit to shaping social policies, designing programs and conducting youth work (Ministry of Youth Affairs, New Zealand, 2005). An understanding of New Zealand adolescents' perspectives will impact on health promotion initiatives and targeted interventions for this group. It would also inform practice for clinicians, teachers and health and education policy makers.

This study used qualitative methodology to explore the perspective of New Zealand adolescents with physical disabilities regarding QoL, as well as the perspectives of their families, teachers and therapists. It utilised an approach as approved by the World Health Organisation QoL group (Geneva) and derived by the DIS-QOL Project, 2005, (Lead centre: The University of Edinburgh). The adolescents with physical disabilities are defined in this study as young people with physical disabilities between the ages of 13 and 21 (13 being the average age for commencing secondary school in New Zealand and 21 being the compulsory age for the end of secondary education). The term "physical disabilities" was used as a generic term to reflect the characteristics of adolescents who have a reduced physical capacity (including, for example, conditions such as cerebral palsy, spina bifida, muscular dystrophy & acquired brain injury), but excludes those with sensory disabilities (sight and hearing).

The structure of this dissertation is as follows:

- Chapter one: Introduction
- Chapter two: Current literature is reviewed to provide background knowledge and a rationale for the methods used in the research. As the topic of QoL is very broad, the literature review briefly explores definitions of QoL and then examines the conceptual framework of QoL research to provide a general overview for the study. Most of the literature on adolescent QoL has been related to the development of measures and so the literature review also provides a summary of current measures for adolescent QoL assessment and examines methodological issues in their development. There is currently no published research on QoL issues for New Zealand adolescents with physical disabilities.
- Chapter three: The methodology, study design and methods used to ensure the validity and reliability of the research are described.
- Chapter four: The findings of the study are given.
- Chapter five: The findings are discussed in relation to current literature and the strengths and limitations of the current study are discussed. Implications for educators, clinicians, researchers and policy makers are considered and recommendations for further research suggested.

CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

The purpose of this qualitative study and Master's dissertation was to explore the most important aspects of quality of life (QoL) for New Zealand adolescents with physical disabilities, from the perspective of adolescents and their families, teachers and therapists.

This literature review will provide an overview of how QoL and Health Related Quality of Life (HRQOL) are defined and conceptualised. Gaps in current research regarding QoL for adolescents (and its measurement) will be discussed. The intention is to provide background knowledge and rationale for the methods used in the research. The aim of the research was to examine concepts of adolescent QoL from a New Zealand perspective, not to evaluate adolescent QoL measures. However, as most of the published research around adolescent QoL has been related to the development of measures, a brief overview of current measures will be given. Finally, methodological issues in conceptualising and measuring QoL for adolescents will be discussed.

A literature search was conducted online through several databases (MEDLINE, CINAHL, PsycINFO and Scopus from 1990-2007) to obtain articles pertaining to the concept of quality of life (QoL) and to identify assessments, instruments or tools to measure adolescent QoL and their related literature. The following search terms were utilised: quality of life, health-related quality of life, well-being, paediatrics, child, adolescent, review, assessment, and measurement.

Other strategies were used to ensure that key literature was not missed. These included: searching the above databases with the names of the authors of selected measures, reviewing reference lists from all retrieved articles and contacting some authors of published papers by email.

2.2. Conceptual framework of QoL research

The World Health Organisation's (WHO) commonly quoted definition of QoL is "an 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, expectations,

standards and concerns" (WHO, 1993, p153). The definition of QoL however, is still evolving as it is a multidimensional concept which includes both health and non-health issues. Janse et al (2004) describe it as including physical, emotional, mental, social, and behavioural components and comment that it refers to how an individual's total existence is perceived. Wallander, Schmitt and Koot (2001), describe it as a combination of objectively and subjectively indicated well being in one's culture. It is generally accepted that QoL refers to a broad range of human experiences related to one's overall well-being and that by its very nature, is idiosyncratic to the individual, but intuitively meaningful and understandable to most people (Revicki et al, 2000).

The term Health related Quality of Life (HRQOL) is often used to refer to QoL within the specific context of health, and has been described as a subset of QoL (Spilker & Revicki, 1996). HRQOL focuses on how health related issues and illness impact on areas of life that are important to an individual. Leidy, Revicki and Genesté (1999) described HRQOL as a subjective perception of the impact of health status, including disease and treatment, on physical, psychological, and social functioning and well-being. The term well-being is also being increasingly used as an umbrella term to cover functional status, health status, QOL and HRQOL (WHO, 2001).

Assessments of QOL and HRQOL reflect subjective personal valuations of daily experience. Considerable debate exists around the use of HRQOL as a measure, as QoL is a holistic concept and it is difficult for an individual's perception of QoL to be separated into that which is influenced by a disease and that which is influenced by all current and past experiences (Wallander, Schmitt & Koot, 2004).

A review of generic and disease-specific QOL measures for adolescents and children by Eiser and Morse (2001) showed substantial variations in the definitions of QoL and HRQOL and, although the domains were often the same, the way these were put into operation differed. Eiser and Morse felt these discrepancies were due to differences in the way QoL was conceptualised and assessed suggesting an urgent need to determine how far currently available

measures of QoL really assess the same underlying construct (Eiser & Morse, 2001).

Two main conceptual models of QoL have been proposed – the Utility model and the Health Status model (Spieth & Harris, 1996). The Utility model is derived from economic theory, and is used to compare alternative treatments – a single score is used to evaluate Quality Adjusted Life Years (QALYs). However, the use of a single score does not allow examination of the effects of health treatment on different QoL domains and does not reflect the real experience of living with disease or disability (Kaplan & Anderson, 1990, McPherson et al, 2004). In contrast, the Health Status model generates a number of separate subscale scores for each different domain of QoL measured and so tends to reflect the general experience of living with disease or disability. However generic versions of this model can be less responsive to changes in a person's health, are time consuming and the multiple subscale scores make cost benefit analysis difficult.

The original WHO concept of QoL includes six core domains. It is a broad-ranging concept, incorporating "a person's physical health, psychological state, level of independence, spirituality, social relationships, and their relationship to salient features of their environment" (WHO, 1993, p.43). These domains have evolved over time. The WHO also has a classification system for health and functioning (The International Classification of Functioning, Disability and Health [ICF]). The ICF provides a conceptual framework and common language for describing human functioning and disability and classifies individual functioning at the levels of (a) body functions and structures and (b) activities and participation (WHO, 2001). The ICF however, does not measure perceived satisfaction with performance.

As Table 1, taken from Raphael (1996), illustrates, QOL can be divided into disease specific and condition specific HRQOL concepts. Other QoL concepts have also been developed for specific groups of people.

Table 1: Conceptualisations of QoL (Raphael, 1996)

Approach	Focus	Definition
Health-related	Persons with diseases	Quality of Life represents the functional effect of an illness & its consequent therapy upon a patient, as perceived by the patient (Schipper et al, 1990).
	Persons with disabilities	Qualify of Life is recognized as a concept representing individual responses to the physical, mental & social effects of illness on daily living which influence the extent to which personal satisfaction with life circumstances can be achieved (Bowling, 1991).
Social Diagnosis	Persons in communities	The adjustment & life satisfaction of community members (Grenn & Kreuter, 1991).
Developmental Disabilities	Persons with developmental disabilities	QOL is the outcome of individuals meeting basic needs & fulfilling basic responsibilities in community setting such as family, recreational, school & work (Schalock, 1990).
Social Indicators	Societies or communities	Statistics of direct normative interest that facilitate concise, comprehensive & balanced judgments about the conditions of major aspects of society (Andrew & Whitney, 1976).
Centre for Health Promotion	Adults and adolescents	The degree to which a person enjoys the important possibilities of his/her life (Raphael et al, 1996).
Lindstrom Model	Children/Adolescents	Quality of Life is the total existence of an individual, a group or society (Lindstrom et al, 1993).

It is currently acknowledged that there is a need to reach conceptual consensus regarding adolescent QoL (King et al, 2006; Wallander et al, 2001). Two conceptualisations have been suggested regarding adolescents: Lindstrom (1993) and Raphael (1996) (see Table 1). For the purposes of this

study, Raphael's (1996) definition of QoL will be used, "the degree to which a person enjoys the important possibilities of his/her life". QoL from this understanding refers to the notion of holistic well-being, such as the perceived importance of physical health, where one lives and spends time, having friends, and access to education and work (Raphael, 1996). As pointed out by Meuleners and Lee (2005), this definition has a multidimensional approach that emphasises the holistic nature of the person and the uniqueness of QOL as experienced by each individual. This model includes both health and social determinants among adolescents. In comparison, Lindstrom's model is concerned with environmental and health determinants only and lacks a multi dimensional approach.

2.3. Measurement of QoL

HRQOL assessment measures are now routinely used to evaluate the human and financial costs and benefits of different health programmes and medical interventions. Two types of assessments are used to measure QoL – generic and condition specific. Generic assessments are designed to be applicable to all population subgroups and consider all of the relevant QoL domains that are likely to be affected by the condition (Waters et al, 2005). Generic measurement is most useful for comparing the HRQOL of adults, adolescents and children who have different chronic health conditions or for comparing those with chronic illness to physically healthy people (Koot & Wallander, 2001; Levi & Drotar, 1998). Generic assessments are used to aid in resource allocation across conditions. A disadvantage of generic measures is that, as they are broad measures, they are not always sensitive to small improvements in QoL, and in some cases, do not capture change at all (Spieth & Harris, 1996).

Condition specific assessments are designed to be applicable to one group and are highly responsive to changes in condition or to effects of a treatment (Bjornson & McLaughlin, 2001). They are most likely to provide information that is clinically relevant because they are able to capture small improvements. However, they are criticised for not allowing comparisons across illness groups (Eiser, 1997; Spieth & Harris, 1996). Condition specific HRQOL measures for adolescents and children have been developed for conditions such as asthma, cancer, epilepsy, cerebral palsy, spina bifida and diabetes.

Osman et al (2000) administered a generic and a disease specific questionnaire to 396 patients with asthma, aged sixteen to fifty two, and found that although both questionnaires were able to capture the impact of asthma on QoL, the condition specific measure was better able to discriminate those who would seek help for their asthma symptoms. Another respiratory based study compared responses of ninety seven individuals on generic and disease specific measures and found the disease specific measures to be more sensitive to changes (Singh et al, 2002).

De Wit and colleagues reviewed the clinical utility of available generic and diabetes specific HRQOL questionnaires suitable for use in adolescents with type 1 diabetes (DeWit et al, 2007) and found that the generic measures: The Pediatric QoL Inventory (PedsQL) and the the Kindl Questionnaire for measuring HRQOL in children & adolescents, (Kindl-R), were the most suitable instruments as the condition specific measures needed further research to establish responsiveness.

2.4. An overview of current measures for QoL measurement in adolescents

The WHO has recommended that when choosing measures suitable for adolescents and children, the instruments should be developmentally appropriate, adolescent/child centred with positive health enhancing aspects of QoL stressed and the results should be cross culturally acceptable (WHO, 2001). Other considerations in reviewing measures include evidence of acceptable reliability and validity, and ability to detect change (Flett & Stoffell, 2003). Sound psychometric properties are prerequisites for using any measure (Flett & Stoffell, 2003).

Six reviews have explored a range of generic and condition specific QoL measures in adolescents and children (DeWit et al, 2007 [generic & diabetes specific]; Eiser & Morse, 2001 [generic and condition specific]; Harding, 2001 [generic]), King et al, 2006, [generic], Livingstone et al, 2007 [cerebral palsy]; Rajmil et al, 2004 [generic]). These recent reviews were large and appeared comprehensive. The reviewers noted there to be a lack of measures designed

specifically for use with adolescents and, as a result, measures designed for use with both children and adolescents were included in all these reviews.

One measure that was not included in any of the reviews is the Kidscreen measure (KS-52) as this was published in 2006; too late to be included (Ravens-Sieberer, Erhart, Bullinger and the European KIDSCREEN and DISABKIDS Group, 2006). The KS-52 was developed to provide a generic measure of HRQOL in healthy and disabled children and adolescents and was constructed and pilot tested using the data of more than 3,000 European children and adolescents. While it appears to be a promising instrument for both clinical and epidemiological settings, it is still a very new measure and so research regarding its validity, reliability and responsiveness is ongoing. It is designed to be used by adolescents and children, rather than adolescents alone. Only four of the measures reviewed (KS-52, VSPA, YQOL-R and QOLPAV) used focus groups or interviews to determine the characteristics of the measures thus leaving some question as to how well current QoL measures address factors of importance to young people.

King et al conducted a comprehensive review of QOL measures for adolescents and children and found that the content of QOL items varied greatly from measure to measure and that while none of the measures could be rated as "excellent" due to limited documentation to determine clinical utility or having had only preliminary evidence of reliability and validity, most could be rated as "good" (King et al, 2006). Rajmil et al (2004) examined ten measures of HRQOL for children and adolescents looking at three broad domains considered important in of HRQOL measurement (physical, social and psychological) and found that there was substantial variation in content. Livingstone et al (2007), in reviewing trends in QoL and HRQOL for adolescents with cerebral palsy, found limited research for this population as did Eiser and Morse (2001). A summary of the generic QoL measures discussed in these reviews are summarised in Table 2.

Table 2: Generic QoL Measures Available For Use with Adolescents

Measure	Domains	Respondent	Targeted Age Group	No of Items	Reliability established	Validity established
KS-52 KIDSCREEN-52 (Ravens-Sieberer et al, 2006).	physical wellbeing, psychological well being, moods & emotions, self perceptions, autonomy, parent relations & home life, peers & social support, school environment, bullying, financial	1. healthy & disabled children & adolescents 2. parent proxy	8-18	52	Yes	Yes
KINDL (the Kindl Questionnaire for measuring HRQOL in children & adolescents) (Ravens-Sieberer & Bullinger, 1998).	psychological well-being, social relationships, physical functioning everyday life activities	Children & adolescents	8-16	24	Yes	Yes
Peds QL: Pediatric QOL Inventory (Varni, Seid & Kurtin, 2001).	functioning: physical, social, emotional, school	Children & adolescents	5-18	15 core + modules	Yes	Yes
YQOL-S (Youth quality of Life) (Patrick et al, 2002).	self, relationship, environment, general QOL	adolescents	11-18	57	Yes	Yes
VSPA (Vecu et sante percue de l'adolescent) (Simeoni et al, 2000).	psychological well being, energy, friends, parents, leisure, school	adolescents	11-17		Yes	Yes
CHQ (Child Health Questionnaire) (Landgraf, Abetz & Ware 1996).	global, health, physical function role/social limitations, bodily pain/discomfort behaviors, mental health, self esteem, general health perceptions, change in health, parental impact, family activities, family cohesion	1. children & adolescents 2. parent proxy	5-18	87	Yes	Yes (but not supported for population level analyses)
QOLPAV (Quality of life profile-adolescent version) (Raphael et al, 1996).	physical health, psychological, social, environment, opportunities for growth & development: Being, belonging, becoming	adolescent	14-20	54	Yes	Yes
CHIP-AE Children's Health Inventory Profile,adolescent edition (Starfield et al, 1995).	Risks, discomfort satisfaction, disorders achievement, resilience	adolescent	11-17	153	Yes	Yes

As shown in table 2, of the generic measures available for use with adolescents, the KINDL, the PedsQL and the CHQ are considered appropriate for young children also. These measures focus primarily on functional status or the performance of daily activities (Starfield et al., 1995; Landgraf et al., 1996). The Children's Health Inventory Profile, adolescent edition, (CHIP–AE) has an emphasis on measuring discomfort/ illness specifically related to HRQOL. The two generic measures that appear to be most appropriate to measure QoL in adolescents are the QOLPAV (quality of life profile- adolescent version. [Raphael, 1996]) and the YQOL (Youth Quality of Life Instrument [Edwards, Huebner, Connell, & Patrick, (2002); Patrick, Edwards & Topoloski, 2002]). Both these measures were developed as generic measures for healthy and disabled adolescents. The VSPA (Vecu et Sante Percue de l'Adolescent) also shows promise. The VSPA is a French HRQOL measure developed specifically for adolescents and is designed to be used as a global HRQOL index. Finally, as highlighted above, the KS-52 measure is a seemingly comprehensive measure of QoL recently developed. It has been designed to address QoL in children as young as eight. The wide consultation that took place during its development suggests that it could have a strong conceptual framework and should not be discounted. As acknowledged by the above six reviews, these measures are accepted by experts in the field of adolescent QoL. The measures and their psychometric properties will now be described.

The Quality of Life Profile- adolescent version (QOLPAV), (Raphael et al, 1996). The QOLPAV is a generic QoL measure for adolescents aged between fourteen and twenty that was developed from the Canadian Centre for Health Promotion's framework for adolescent QoL (Zekovic & Renwick, 2003). It was initially developed from the adult Quality of Life Profile to provide a generic measure of HRQOL in healthy and disabled adolescents aged between fourteen and twenty years of age and subsequently extended to include participants as young as twelve (Bradford, Rutherford & John, 2002).

The measure consists of 54 items that examine QoL in three domains – being, belonging and becoming. These domains are further subdivided into nine sub domains each containing six items. "Being" refers to who the adolescent is as an individual; 'belonging' relates to concerns with the fit between the adolescent

and the environment; and 'becoming' refers to what the person does to achieve hopes, goals and aspirations. In addition, participants are asked to rate each item for importance and satisfaction using a five-point Likert scale. There are also nine questions relating to the degree of control the adolescent has over each of the nine sub domains (i.e. control over places where they spend time, who they spend time with, and access to the community, etc), as well as opportunity for improvement and change.

The QOLPAV was developed through a combination of focus groups (of healthy adolescents and guidance counselors) with participants being asked what the term quality of life meant to them and what areas of concerns were relevant to their age group. Items were then added by the authors from specific theoretical models. It has been shown to be reliable in terms of internal consistency (Cronbach's alpha = 0.83) and it consistently correlated with adolescent reports of their health status (Raphael et al, 1996). However, Koot and Wallander (2001) commented that validation to date for the QOLPAV is limited because of its focus on subjective rather than objective measures. Initial analysis did not support the specificity of the sub domains, which may indicate that the sub domains do not have differential predictive validity or that the measures against which they were validated were too brief or non specific to detect differences. Bradford, Rutherford and John (2002), used factor analysis to explore the underlying factor structure of the QOLPAV and found eight dimensions which were largely consistent with the QOL model proposed by Raphael et al, the exception concerned items from the sub domain of "spiritual being", which did not cluster together but dispersed across multiple factors. Furthermore, it was developed with healthy adolescents and has not been tested on a group of chronically ill or disabled adolescents (Koot et al, 2001).

The YQOL (Youth Quality of Life Instrument), *(Patrick et al, 2002).*

The YQOL seems to reiterate the two domains of the QOLPAV measure describing them as a sense of self (being); social relationships (belonging) and and adds two other domains: environment and general quality of life.

The YQOL has two versions: a long version designed for research and evaluation (YQOL-R); and a short version designed for completion by

adolescents: The Youth Quality of Life Surveillance Version (YQOL-S). A study of over two hundred young people, aged between twelve and eighteen years of age, with and without disability, by Patrick, Edwards and Topolski, 2002, found that the scales of the YQOL-R showed acceptable internal consistency (Cronbach's alpha=0·77–0·96); reproducibility (ICCs=0·74–0·85); expected associations with other constructs; and the ability to distinguish between known groups. They concluded that the YQOL-R showed sufficient validity to encourage further use.

The YQOL is a relatively new measure and further testing of reliability, sensitivity and responsiveness is required. The main strength of the YQOL is that it is a generic measure, adolescent centred and both healthy and disabled adolescents were involved in its construction.

Vecu et Sante Percue de l'Adolescent (VSPA), (Simeoni et al, 2000).

The VSPA is a generic HRQOL measure developed by the French Ministry of Health. It was developed to provide a generic measure of HRQOL in healthy and disabled children and adolescents aged between eleven and seventeen years of age. The measure consists of 40 items, divided into six dimensions (psychological well-being, energy, friends, parents, leisure, and school) and takes approximately 15 minutes to complete. There is also a shorter 12 item version - VSPA-12. Any professional can administer the VSPA but it is designed to be self administered by adolescents.

A validation study of the VSPA including over 2941 adolescents confirmed it's content and construct validity. It has been shown to be reliable in terms of internal consistency (Cronbach's alpha = 0.83) and test-retest results ($r = 0.69$; $p < 0.001$), (Simeoni et al, 2000). In addition the tests of validity previously published for the VSPA were replicated for the VSPA-12 and a test–retest correlation (4 weeks) of 0.745 was observed for the 12-item HRQL index in the target population ($n = 664$). Average scores for this shorter index closely mirrored the VSPA index (Sapin, Antoniotti, Simeoni, Clément, Khammar, & Auquier, 2004).

The VSPA is a new measure and testing of reliability, sensitivity and responsiveness are currently being evaluated. The main strength of the VSPA is that it is designed to be used as a discriminative, predictive and evaluative instrument and a global HRQOL index. It is currently only available in French.

Kidscreen-52 (KS-52), (Ravens-Sieberer et al, 2006).

The KS-52 is a generic measure of HRQOL. It was developed to provide a measure of HRQOL in healthy and disabled children and adolescents aged between eight and eighteen years of age. The measure consists of 52 items grouped in 10 dimensions (Kidscreen-52), as well as 2 shorter versions (KS-27 and KS-10). It measures ten HRQOL dimensions: physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance (bullying), and financial resources. The KS-52 is self administered by adolescents and children (though there is also a parent/ proxy version) and it is easy to administer.

The developers of Kidscreen-52 assessed convergent validity through the comparison of KINDL scores with Kidscreen-52 scores and correlation coefficients were high for those assessing similar constructs (x + 0.51- 0.68). To assess familial socioeconomic status, the family affluence scale (FAS) was used and to assess psychosomatic health complaints the Health Behaviour in School age children (HBSC) was used and correlation was at moderate to high levels. Good internal consistency of the Kidscreen-52 dimensions was found (Cronbach's alpha = 0.80–0.89), (Ravens-Sieberer, U., Erhart, M., Bullinger, M. and the European KIDSCREEN and DISABKIDS Group, 2006).

In addition, the KS-52 was administered to over twenty two thousand children and adolescents (eight to eighteen years) in thirteen European countries. Psychometric properties were assessed using the Classical Test Theory approach, Rasch analysis, and structural equation modelling (SEM). For the overall sample, Cronbach's alpha values ranged from 0.77 to 0.89. The intraclass correlation coefficients ranged from 0.56 to 0.77. The KS-52 was found to have acceptable levels of reliability and validity although further work is needed to assess longitudinal validity and sensitivity to change (Ravens-Sieberer et al, 2007).

The KS-52 appears to be a promising instrument for both clinical and epidemiological settings, however it is a very new measure and further research is required by independent researchers as to validity, reliability and responsiveness. It needs to be tested in clinical settings where clinical diagnoses and information about conditions is available and more studies are needed to improve score interpretation for its use in clinical practice. Unfortunately it also combines measurement of adolescents with children and risks missing issues specific to adolescents.

Condition specific QoL measures designed for adolescents and children with physical disabilities are summarised Table 3. Four of these measures were designed for adolescents with cerebral palsy, and one for spina bifida. The measurement of HRQOL in adolescents and children with cerebral palsy is part of an emerging discipline, as this is the largest group that presents with physical disabilities (Bjornson & McLaughlin, 2005). Livingstone et al (2007) found that QoL and HRQOL measurement posed significant methodological challenges and that there was a shortage of validated measures for adolescents and children with cerebral palsy. Only DISABKIDS and the CCP QOL-ch used focus group interviews with the adolescents to determine categories to be included in the measures. A number of other measures are currently being designed specifically for adolescents with cerebral palsy (Waters et al, 2007).

Table 3:
Condition specific QoL measures available for use with adolescents/children with physical disabilities

Measure	Domains	Respondent	Targeted Age Group	No of Items	Reliability	Validity
1. CCP QOL-ch (Waters et al 2006)	Cerebral palsy physical health, ADL, participation in regular physical & social activities, emotional well being & self esteem, communication, acceptance family & services	1. children 2. parent proxy	9-12 4-12	52 66	Yes	Yes
2. QoL Inventory DISABKIDS (2006).	7 condition specific modules including Cerebral palsy & idiopathic juvenile arthritis. Domains as per KIDSCREEN	1. Children & adolescents 2. Parents	8 – 16 (mean age 12.5)	26 - 44	New measure	New measure
3. LAQ- G (Lifestyle assessment questionnaire) (Jessen, Colver, Mackie & Jarvis, 1998)	Cerebral palsy physical independence, clinical burden, mobility, schooling, economic burden & social integration	parent proxy	4 - 5	6 domains	Yes	Yes
4. Spina Bifida HRQOL scale (Parkin et al, 1997)	Spina Bifida social, emotional, intellectual financial, medical, independence environmental, physical, recreational	1. children (parent proxy) 2. adolescent	5 – 12 13 - 20	50	Yes	Yes
5. CQ (caregivers questionnaire) (Schneider et al, 2001)	Cerebral palsy: personal care, positioning/ transferring, comfort & interaction	parent	5 - 12	29	No	No

.

2.5. Methodological issues in measurement of adolescent QoL

The area of QoL measurement for adolescents is at a relatively early stage and adolescent QoL measures have been largely developed from frameworks of adult QoL measures (Eiser, 1997; Spieth & Harris, 1996). They can be classified across three dimensions – the way the measure is conceptualised, the type of scores they produce and the range of concepts and population assessed (Levi & Drotar, 1998; Spieth & Harris, 1996). Methodological issues in measurement of adolescent QoL include:

Lack of agreement as to what constitutes adolescence

There is a lack of agreement amongst researchers as to what constitutes adolescence (Waters et al, 2005). Although it is generally accepted that adolescence begins at puberty, puberty is occurring earlier and adolescents are experiencing longer schooling and marrying later. As a result many are still transitioning into adult life through to their mid twenties (Arnett, 2000). Van Heeswyk (1997) described adolescence as comprising three distinct phases; early (twelve to fourteen), middle (fifteen to sixteen) and late (seventeen to nineteen). Of the QoL measures reviewed in this study, six were developed for use with adolescents and children. Some included children as young as eight and, with the exception of one measure (adolescents up to the age of twenty) all of the measures included up to the age of eighteen only (See Tables 2 and 3). Stages of physical and cognitive development influence perception of QoL and adolescents' perspectives on QoL change as they mature (Eiser, 1997; Speith and Harris, 1996,). This suggests measures that combine adolescents and children may not capture issues unique to adolescents.

Lack of agreement as to definitions of adolescent QOL and HRQOL

A review of generic and disease-specific HRQOL measures for adolescents and children by Eiser and Morse (2001) showed substantial variations in the definitions of HRQOL and, although the domains were often the same, the way these were put into operation differed. Eiser and Morse felt these discrepancies were due to differences in the way QoL was conceptualised and assessed suggesting an "urgent need to determine how far currently available measures of QoL really assess the same underlying construct" (Eiser & Morse, 2001).

The literature has debated whether adolescent QoL measures should equate QoL with disability or functional status, as this implies that adolescents with disabilities experience a lower QoL than those without (Patrick & Erickson, 1993). Some research suggests that QoL should not equate to functional status and this is a potential pitfall of some measures (King et al, 2006; Zullig, Vallois, & Wanzer Drane, 2005).

Lack of consultation with adolescents during the construction of QoL measures. There has been a distinct lack of consultation with adolescents during the construction of QoL measures (Fayers & Machin, 2000). Since starting this study, the KS-52 measure has been developed which used thirty six focus groups (146 children, 86 parents) during its construction (Ravens-Sieberer et al, 2006). However, although this measure is designed for adolescents and children the average age of the young participants in the focus groups was twelve and a half years (early adolescence). As discussed in the previous section, the majority of current measures available for use with adolescents were developed without any consultation with adolescents themselves which suggests that significant life issues for this age range could be being missed.

2.6. Aims of Objectives of the current study

The purpose of this qualitative study was:

(i) To explore the most important aspects of quality of life (QoL) for New Zealand adolescents with physical disabilities, from the perspective of the adolescents themselves, their families, teachers and therapists.

(ii) To compare findings to existing measures of adolescent QoL.

2.7. Conclusion

This literature review has provided some background to the development of concepts regarding adolescent QoL and its measurement. A review of current adolescent QoL measures (Tables 2 and 3) has highlighted the lack of measures designed specifically for adolescents although this is changing. Consultation with adolescents in the construction of the measures reviewed is lacking and no information was found pertaining to the views of New Zealand Maori or Pasifika adolescents. In addition, wide variance was found in the range of ages the measures applied to.

CHAPTER THREE: RESEARCH METHODOLOGY AND METHODS

3.1. Introduction

The focus of this chapter is the research methodology and methods used in this study. In the first part of the chapter, qualitative research is discussed and specifically the chosen methodology, focus group interviews; their strengths, limitations and their appropriateness for interviewing adolescents. Next the study design is described including participant selection and recruitment, data collection procedures and data analysis. Following this, the methods used to ensure the validity and reliability of the research are discussed.

3.2. Study Design

A qualitative methodology using an interpretive approach was used in both data collection and analysis (Patton, 2002). The principles behind such analysis, and the steps followed in this study are outlined below.

The research aim was to explore the most important aspects of QoL for New Zealand adolescents with physical disabilities, both from the perspective of the adolescents themselves and also from the perspective of their family, teachers and therapists; and to compare findings to existing measures of QoL. Qualitative research is concerned with developing concepts which help to understand social phenomena in natural (rather than experimental) settings, using the experiences and views of all the participants (Mays & Pope, 1995).

This study used focus group interviews as the principal source of data collection. Focus groups are a method of interviewing a group of participants on a topic to produce data and insights that would be less accessible without the interaction found in a group (Morgan, 1997). Open ended questions are used by the interviewer, with the focus on listening and learning from the participants. Group members can build on each others ideas in ways that are not available in a one to one interview, resulting in a more in-depth discussion of a subject. Focus groups allow the researcher to probe both the cognitive and emotional responses of participants while observing the underlying group dynamics (Heary & Hennessey, 2002). Furthermore, focus groups acknowledge

the participants as experts which mean they are more likely to respond honestly (Levine & Zimmerman, 1996). In addition they are an efficient data collection technique where the extent to which there is a relatively consistent shared view can be quickly assessed and a large amount of information can be gained in a relatively short period of time (Patton, 2002).

Qualitative research is well suited to investigating what adolescents think as it is not formally structured and provides the opportunity for adolescents to express themselves freely in their own words. Most adolescents are comfortable with group discussions as they are a regular part of school life (Detmar et al, 2006; Heary & Hennesey, 2002). Also the use of a group removes pressure on adolescents, who in a one on one interview might answer in a way that they think the interviewer wants to hear or be tempted to give any answer to fill in a blank (Lewis, 1992). In addition focus groups:

> "represent a viable way of minimizing or breaking down power differentials between the researcher and youth group members, as the adolescents outnumber the adult researcher" (Delgado, 2006, p149).

Focus groups also have some limitations that should be acknowledged including: (1) there is a possibility that a group setting may inhibit some participants as there is the potential for embarrassment or shyness. However, groups can also actively facilitate the discussion of some topics because the less inhibited members can "break the ice" for shyer participants and furthermore participants can provide mutual support (Kitzinger, 1995, p.300); (2) group discussions also raise ethical issues related to the disclosure of sensitive information to others and issues of confidentially. Individuals interviewed on their own have reported feeling more anonymous than individuals who have participated in focus groups (Fern, 1982); (3) intense group discussion may give rise to distress in individual participants (Heary and Hennessey (2002). It is important to ensure that strategies are put in place to help overcome such limitations. As such, the strategies adopted in this study are described in the data collection section.

Ethical approval

Ethical approval was obtained by the Northern Regional Health and Disability Ethics committee in New Zealand (see Appendix A).

Consultation with Maori

The research process adopted for this study was consistent with the Treaty of Waitangi principles of partnership, participation and protection (Orange, 1989). To ensure the needs of Maori would be addressed, ongoing consultation took place with Maori representatives: Mr Darren Nathan (Head of the Department of Maori studies, Mt Roskill Grammar School), Mrs Tuihana White (Awhina Kaiako, Mt Roskill) and Mr Tame Cassidy (Kaumatua, Mt Roskill) (see Appendix B), who also remained involved throughout the research process in an advisory capacity. In addition, consultation with the Orakei Marae had also taken place for the WHOQOL focus groups previously carried out by Professor McPherson and Mrs Kayes (see Appendix C). This consultation informed the study design and data collection procedures in the following ways: (1) Having a specific group for Maori and Pacific participants to give their views; (2) Having separate groups for the adolescents as sometimes young Maori will hold back and seek guidance from the older representatives if both old and young are included in the same groups; and (3) Recognising the importance of family/ whanau as a stakeholder by their inclusion in the focus groups.

Research setting selection

Morgan commented that the site of a focus group must balance the needs of the participants and the needs of the researcher (Morgan, 1997). Mount Roskill Grammar School, an Auckland-based multicultural high school, was chosen as the site for the interviews because it is centrally placed and totally wheelchair accessible for adolescents with physical disabilities. In addition, Mount Roskill Grammar School had a large, sound proof conference room available where the participants would be able to express their views in a comfortable environment that would be conducive to conversation.

3.3. Participant selection and recruitment

This research aimed to explore the most important aspects of QoL for New Zealand adolescents with physical disabilities, both from the perspective of the adolescents themselves and from the perspective of their family, teachers and therapists (Speech Language Therapists, Occupational Therapists and Physiotherapists).

Inclusion criteria:

Participants were eligible to take part if they: (1) gave consent to take part in the study; (2) conformed to the specified age range of the focus groups (adolescents with physical disabilities aged between thirteen and twenty one); and (3) met the profile of the specified focus group types (adolescents with physical disabilities, families of adolescents with physical disabilities, teachers and therapists who work with adolescents with physical disabilities).

Exclusion criteria:

Potential participants were excluded from taking part if they did not have the capacity to consent to, or adequately take part in, the group discussions (e.g. those with severe cognitive impairment, significant communication problems or dementia). Proxy respondents were not included and so all participants needed to be capable of self-report. Those with significant or severe physical illness (e.g. terminal illness) or serious and current mental illness (e.g. severe depression) were also excluded.

Sampling

Purposeful sampling was used to select participants for this study, aiming for maximum variation in age, gender and ethnicity in all groups; impairment type and level of disability in adolescent groups; and professional occupation in the therapist group (Mays & Pope, 2000). Purposeful sampling selects participants for a specific reason relevant to the research. Mays and Pope (2000) commented that "the sample needs to include the full range of possible cases or settings so that conceptual rather than statistical generalisations could be made" (p 52). This approach to sampling allows the researcher to deliberately include a wide range of types of informants and also to select key informants with access to important sources of knowledge (Mays & Pope, 1995). As such this was an appropriate sampling technique for this study and enabled adolescents with differing degrees of impairment to be included as well as parents with diverse views. It also meant that teachers and therapists who had wide experience with adolescents with physical disabilities could be selected. As these participants lived throughout greater Auckland, a sufficient cultural and socioeconomic spread was anticipated.

Group size and make up

Examination of the literature reveals some debate about the optimum size of focus groups: six to eight participants is common (Krueger & Casey, 2000; Vaughn, Schumm, and Sinagub, 1996) although some researchers have used as few as four participants (Kitzinger, 1995) and others as many as twelve (Fern, 1982). Morgan (1997) commented that small groups could be less productive, as they are more sensitive to dynamics among the participants, whilst larger groups pose difficulties for handling the discussion and keeping it on the topic, as well as making it harder for shy people to participate. Tang and Davis (1995) commented that the size of a group should first be determined by the aims of the research study. This study aimed to have a representative group of adolescents with physical disabilities and as such it included some adolescents with communication impairment. Therefore, smaller focus groups (maximum of six) were considered appropriate to ensure these participants had adequate time to engage in debate and, if needed, have technical assistance from the support person.

Originally four focus groups were planned consisting of two groups of six adolescents with physical disabilities (one group solely Maori and Pacific participants), one group of family members and one combined group of teachers and therapists who worked with adolescents with physical disabilities. However, there was considerable interest from families, teachers and therapists which resulted in two additional groups being formed so that there were six groups in total: two adolescent groups, two groups for family members and two separate groups for teachers and therapists (Speech Language Therapists, Occupational Therapists & Physiotherapists).

Recruitment Procedures

All potential participants were sent an information pack, which consisted of a participant information sheet, outlining the aims and purpose of this study, and a consent form (Appendices D & E). The information pack emphasised that participation in the study was entirely voluntary. Participants were asked to respond by returning a signed consent form to the researcher or the manager of the Mount Roskill Grammar School. People had the opportunity to contact the researcher or the supervisors to ask any questions before deciding whether or

not to participate. Once participants had responded by contacting the researcher or returning the consent forms, times were coordinated for the focus groups. Adolescent participants over sixteen were able to legally give their own consent, however one participant was fifteen and consent was obtained from both the participant and their parent.

3.4. Data Collection

Methods congruent with accepted standards for this method of qualitative inquiry, focus groups, as outlined by Flick, 2006, were used. Six focus groups were conducted over a period of four weeks. Each group lasted approximately one to one and a half hours. All of the focus groups followed a pre-prepared focus group outline although allowing discussion to flow according to what were important topics to the people in the groups (see Appendix F). The focus groups were recorded and transcribed verbatim. Prior to each focus group taking place, a test of the recording equipment was conducted. In addition, a back up tape recorder was kept in the room.

All of the focus groups were facilitated by the lead researcher (MA). During the focus groups, people were encouraged to participate and interact while leading questions were avoided. There was a risk that some participants might not have been prepared to communicate freely or fully if they perceived the focus group as being dominated by the facilitator or the other participants and so a specific effort was made to manage participants who dominated the conversation so that quieter members could have their say. Group members with communication difficulties were given sufficient time to convey their opinions and feelings.

Heary and Hennessey (2002) described two ethical issues specific to focus groups: (1) the fact that disclosures by participants are shared with all group members and not just the researcher, which could give rise to issues of confidentiality; and (2) that intense group discussion may give rise to distress in individual participants. Both of these issues were discussed at the beginning of each focus group. The meaning of and the need for confidentiality was discussed including seeking agreement that if participants could not disclose what was said in the group to others outside of the group, that they could not refer to specific individuals by name and that all group members were

responsible for maintaining confidentiality. The possibility that certain topics or issues might be sensitive or distressing for group participants was also discussed. For the adolescent groups a second facilitator, who was also a trained counsellor, was present to take additional notes and monitor the psychological well being of the adolescents. A support person was also present to assist with any issues arising from the physical disabilities of the participants (assistance with writing and clarification of unclear speech). Participants had also been advised in the information sheets that they could report adverse outcomes to the researchers or a Health & Disability Advocate and were also advised that they could withdraw at any stage if they wished.

At the start of each group the facilitator welcomed the participants and made a brief opening statement introducing the study, setting the scene for discussion and explaining the aims and objectives of the group. It was emphasised that the aim of the focus group was to get an in-depth discussion on the subject of QoL for adolescents with physical disabilities from a New Zealand perspective. Participants were encouraged to remain focussed on the generality of the subject and were asked to follow basic 'ground rules' for taped discussion (e.g. contributing one at a time, avoiding multiple conversations).

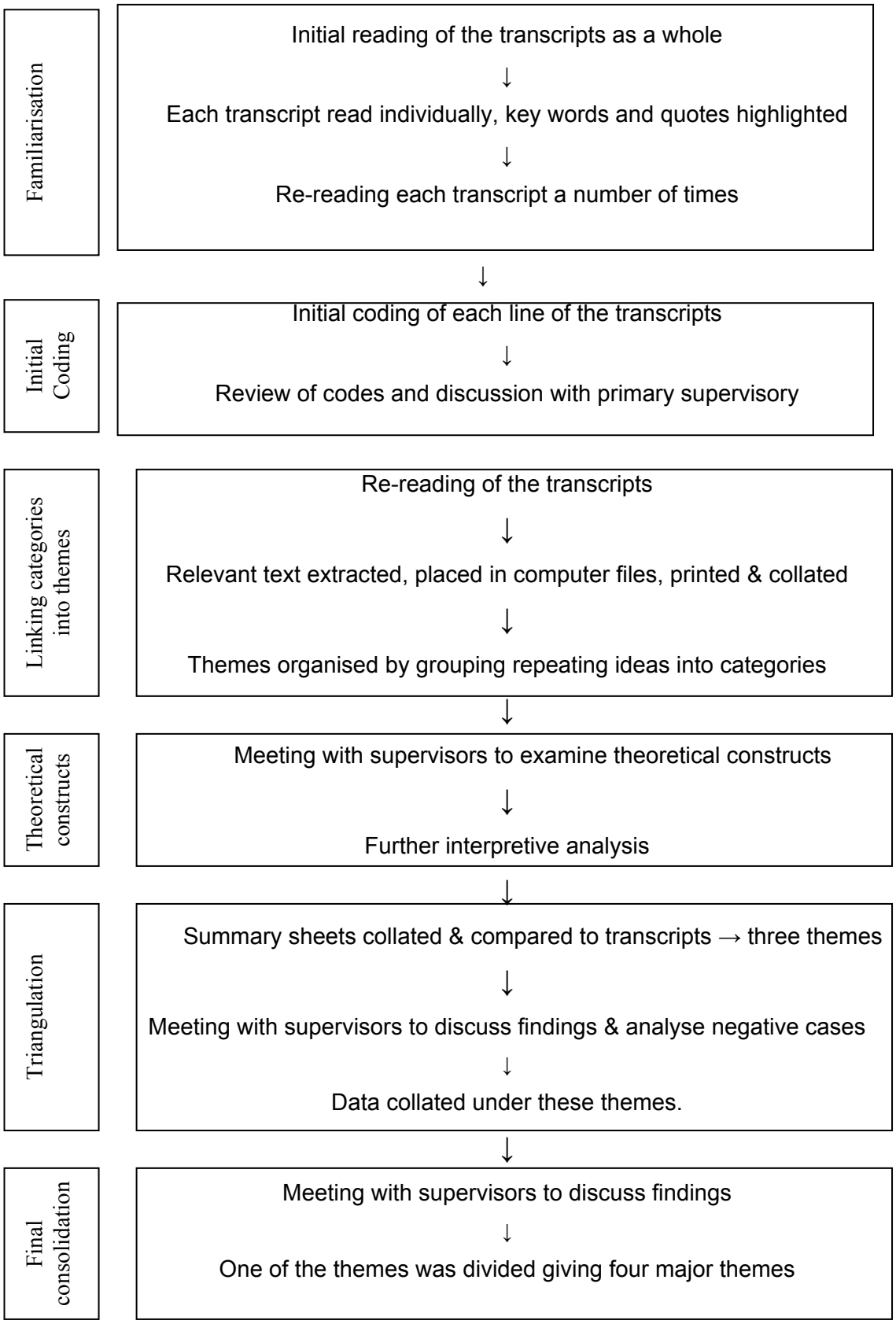
An opening round of self-introductions then took place with each participant invited to say a few brief words about themselves. This exchange formed the basis for the information sharing and exchange of ideas that followed in the discussion. Participants were then asked to individually record up to ten (or more if desired) QoL themes on section A of a prepared form (Appendix G). A few minutes were given for this task and participants were then invited to share their key themes one or two at a time, going round the group until all the lists were exhausted. The extent of consensus and/or diversity was noted and discussed, and an opportunity for the generation of additional themes was provided, as participants own views resonated with that of other group members to produce new insights. Set prompts were used throughout to facilitate discussion around the subject, including stimulus questions such as: What do you understand by the term quality of life? How do you think your lives compare with other teenagers that don't have a disability? How do you think your lives could be improved? After a fifteen minute refreshment break,

participants were asked to review the list of QoL themes drawn up individually and invited to make additions to their lists (if desired) in the light of the focus group discussion, noting these in section B of the record form (Appendix F). This provided participants with the opportunity to review their spontaneously generated themes previously noted in section A, together with any themes prompted by the group discussion. Next, each person was asked to rank their top three facets of QoL for adolescents with physical disabilities, bearing in mind all the issues discussed, and to add these to section C of the record form. This task was designed as a closure exercise: to enable participants to reflect back on the themes mentioned in the focus group discussion; to stimulate consideration of both their own contributions and those of other group members; and to encourage each person to make an individual determination about the relative importance of some of the key themes. The participants were then invited to share their top three themes with the group. Participants were given a final opportunity to contribute any additional thoughts on the discussion topics, and a final request was made to consider if anything has been missed. A brief summary of the key points that had emerged from the focus group tasks and discussion was given by the facilitator and checked with the group. Finally, participants were thanked for taking part in the focus group discussion.

3.5. Data analysis

The method of data analysis for this study was wholly qualitative, focusing on content analysis to derive important categories and themes. A theme is an implicit topic that organises a group of repeated ideas (Auerbach & Silverstein, 2003). Content analysis is a procedure for the categorisation of verbal or behavioural data, for purposes of classification, summarisation and tabulation. The content can be analysed on two levels – a descriptive account of the data or an interpretive analysis which is concerned with what was meant by the response, what was inferred or what was implied (Hancock, 1998). As outlined in figure1, the data analysis process for this study followed six phases: familiarisation, initial coding, linking categories into themes, examination of theoretical constructs, triangulation and final consolidation. The data was analysed manually.

Figure 1: Audit trail of data analysis



Familiarisation

Initially transcripts were read as a whole to become familiar with the data, after which each transcript was read for a second time, highlighting key words and illustrative quotes. Relevant text was selected without having pre set ideas in mind. The text was then searched for repetition (or challenge) of ideas. The transcripts were re-read a number of times to become more immersed in the data, and to aid the identification of emerging themes.

Initial coding

After this initial phase of analysis, each line of the transcript was coded. Analysis of the transcripts and the codes applied to one adolescent group and one family group was reviewed by the primary supervisor and any disagreements over categories were discussed and a consensus reached.

Linking categories into themes

Subsequently, each transcript was reviewed and coded separately and relevant text was extracted and computer files were created to combine data from each focus group under specific themes. The data was printed and collated on large sheets of cardboard, with the comments attached individually. The data was read, re-read and re-organised and constant comparison between groups took place throughout (Patton, 2002).

Examination of theoretical constructs

A meeting with supervisors was held to examine emerging themes and discuss theoretical constructs. This meeting identified that initially the themes generated were descriptive rather than interpretive. Different meanings of particular responses in the focus groups were discussed, as were possible interpretations. As a result, analysis began to move from a descriptive to an interpretive level, which is an accepted process in qualitative analysis (Patton, 2002).

Further analysis included re-reading the data to develop an interpretive understanding of the findings, to look for patterns and to identify other possible themes and sub themes. Responses between the groups were compared.

Triangulation

Summary sheets from the participants were collated and compared to the data and three existing themes emerged. Negative cases were analysed.

Final consolidation

A further meeting was held with the primary supervisor to discuss findings and to examine consistent and inconsistent responses between the focus groups and to synthesise the responses. The categories and themes were logically consistent and reflective of the data. The data was then re-examined to look for any additional themes and sub themes that did not fit with themes identified to date. Analysis of negative cases was discussed.

A final meeting was held with both supervisors to discuss findings and to examine consistent and inconsistent responses between the focus groups and to synthesise the responses.

3.6. Criteria for qualitative research

Trustworthiness ensures the quality of the findings and increases the reader's confidence in the findings - this requires that there be logical connections among the various steps in the research process from the purpose of the study through to the analyses and interpretation (Hancock, 1998). There has been considerable debate about methods of achieving trustworthiness using the concepts of validity and reliability, as these concepts were originally developed for use in quantitative research (Flick, 2006). It is now generally accepted however that the terms can be applied to qualitative research but that they need to be operationalised differently to take into account the distinctive goals of qualitative research (Mays & Pope, 2000).

Validity

Validity is the degree to which the research method measures what it is supposed to measure – has the researcher really understood what people mean when they describe their experiences attitudes and behaviours (Koot & Wallander, 2001). Validity is underpinned by the quality of the data collection, analysis and data interpretation. Mays & Pope (2000) described the ways of achieving validity in qualitative research to include triangulation, respondent

validation, clear exposition of methods of data collection and analysis, reflexivity, attention to negative cases and fair dealing. In this study validity has been demonstrated by all of the above, which will be discussed in more detail below, with the exception of respondent validation. Respondent validation or "member checking" is when the investigators account is compared to those of the research subjects, and their reactions to the analyses are then incorporated into the study findings (Mays & Pope, 2000). Respondent validation was not used in this study because if any of the adolescents with physical disabilities also had mild cognitive impairment, an inability to remember precisely in the process of respondent validation could have been distressing.

Triangulation

Triangulation refers to a method of data collection where information is deliberately obtained from two or more different independent data sources (e. g. interviews on the same subject with different groups of people) and can also be used to refer to the results from two or more different methods (such as interviews or observation) of data collection (Mays & Pope, 1995). The researcher looks for patterns of convergence to develop or corroborate an overall impression (Mays & Pope, 2000). Triangulation also occurs when two different researchers independently code the same interviews and compare results. Denzin and Lincoln (2003) further extended the concept of triangulation by describing it as being multi-faceted and a means of displaying multiple realities simultaneously. In this study, triangulation was achieved using several of these methods: (1) data was collected from a range of participants and six different groups discussed the same subject; (2) two different methods of data collection were used and compared (interviews and written summaries); (3) independent assessment of two transcripts was completed by the researcher and a skilled qualitative researcher and coding of data was compared.

Clear exposition of methods of data collection and analysis

The methods used in research unavoidably influence the participants and so a clear description of the methods of data collection and analysis is important (Mays & Pope, 2000). In the current study, thorough and systematic checking back with the interview transcripts was done, and an "audit trail" established (see Figure 1).

Reflexivity

Qualitative research assumes that the researcher is an integral part of the research process. Reflexivity of the account refers to sensitivity to the ways in which the collected data has been shaped by the researcher and the research process (Mays & Pope, 2000). Before commencing the study, the primary investigator (MA) deliberated about prior assumptions held on the topic and biases that might have been brought to the research. The fact that the primary investigator had worked as a physiotherapist with two of the adolescents previously meant that when collecting the data, it was important that extra care be taken to maintain clarity and distance between that role, that of researcher and those researched.

Traditionally a physiotherapist's role consists of administering treatments and suggesting to their client what the best practice is for their condition. A focus group discussion requires that information is generated from the participants themselves and the role of the researcher is very subtle. Having a focus group outline to follow meant that it was possible to maintain the role of facilitator rather than be diverted into directional behaviour. In addition, for the facilitator of focus groups, there sometimes can be a dilemma between giving control to the group and possibly hearing less about the topic of interest or taking direct control over the group and possibly losing the free-flowing discussion that was the original intent of the group interview. An effort was made to allow the discussion to flow naturally and prompts were only given when necessary to keep the participants on the topic of QoL. In the parent focus groups there was considerable discussion about quality of care issues, which was allowed to continue as it was obvious that they felt quality of care impacted on QoL.

Written comments were made during each focus group and a diary was also kept. The likely impact of the methods used on the data obtained was assessed and sufficient data was included in the reports of the study to provide evidence that the analytical criteria were met.

Attention to negative cases

A related analytical and presentational issue is concerned with the thoroughness with which the researcher examines "negative" or "deviant" cases

- those in which the researcher's explanatory scheme appears weak or is contradicted by the evidence (Mays & Pope, 2000). Negative cases were explored in the data analysis phase. More discussion of such cases is discussed in depth throughout the findings section of this dissertation (See Chapter Four).

Fair dealing

Mays and Pope (2000) described a process called “fair dealing” where the research design incorporates a wide range of different perspectives so that the viewpoint of one group is never presented as if it represents the sole truth about any situation. Fair dealing was incorporated in my study design by having two focus groups of adolescents as well as having focus groups of parents, teachers and therapists. Fair dealing was also used in data analysis by discussing my analysis of the focus groups with the two supervisors.

Reliability

Reliability is a central concept in measurement. The main ways in which qualitative researchers ensure the retest reliability of their analyses is in maintaining meticulous records of interviews and observations and by documenting the process of analysis in detail (Mays & Pope, 1995). The study, if repeated among a different sample, should generate the same range and diversity and the same explanatory understanding underpinned by the quality of sampling, the quality of data collection and the quality of analysis and interpretation. In this study, reliability was ensured by data collection and analysis being carefully described and by having an independent assessment of two transcripts by a skilled qualitative researcher and a comparison made. Reliability was further ensured by participants in all the six focus groups being adequately described, by documenting the physical disabilities of the adolescent groups and by describing the setting (See Chapter four).

In addition to the issues of reliability already discussed, Flick (2006) described how the reliability of the researcher establishes credibility. The researcher has been co author of two published research papers, including one on adolescents with physical disabilities (Andrew et al, 2004).

Mays & Pope (2000) also spoke of ways of ensuring the quality of qualitative research to include: the relevance of the research (is it adding to an existing body of knowledge), context description (can the reader relate the findings to other settings), sampling (did the sample include the full range of cases so that conceptual rather than statistical generalisations could be made), data collection and analysis and reflexivity of the account (methods used on the data obtained). Efforts were made to ensure all these criteria have been met in this research, as can be seen in the methodology outlined above. In addition the relevance of this research has been demonstrated in the literature review (Chapter 2) and it has added a New Zealand adolescent perspective to an existing body of knowledge about QoL for people with physical disabilities.

3.7. Summary

This chapter has outlined the methodology for the study. In the first part, the rational for choosing qualitative methods was discussed. Next the methodology of focus group interviews, their strengths and limitations and their appropriateness for interviewing adolescents was discussed. Ethical approval was acknowledged. Consultation with local Maori was described and the research setting was described. Following this details were given of participant selection and recruitment including eligibility criteria, sampling group size and makeup and recruitment procedures. Data collection was then described including Data collection procedures were next described. Following this, data analysis was described. Finally the way in which validity and reliability were ensured throughout the study was described.

CHAPTER FOUR: FINDINGS

4.1. Introduction

In this chapter the participants' characteristics will be described and a general overview of the dynamics of the focus groups given. The findings from the focus groups will be reported on and explored in depth. Each theme will be described individually, using the voices of the participants, and links to the other themes will be discussed. Finally, the findings will be compared to a range of existing measures of adolescent QoL.

4.2. Participant characteristics

Six focus groups were held: two adolescent groups (one Maori and Pasifika group and one mixed nationalities group), two family groups and two professionals groups (one group of teachers and one group of therapists). Tables 4, 5, and 6 display the participant characteristics of each of these groups.

As shown in Table 4, the adolescents presented with a range of disabilities, from mild to severe. These included cerebral palsy (spastic diplegia, quadriplegia and ataxia), spinal muscular atrophy and generalised low tone. Four of the adolescents had communication difficulties including dysarthria (facial muscle weakness), pseudo bulbar palsy (unilateral facial muscle paralysis) and there was one non verbal adolescent who used a communication device. In addition the adolescent groups demonstrated diversity in, age (ranging from fifteen to twenty years of age) and ethnicity. There was a gender imbalance in the two adolescent groups with the Maori and Pasifika group having one female and five males and the mixed nationality group having four females and one male.

Table 4: The demographics of the adolescent groups

Group		Maori & Pacific (n=6)	Mixed Nationalities (n=5)
Gender	Female	1	4
	Male	5	1
Age	Mean (yrs)	18	17
	Range (yrs)	15 – 20	16 – 18
Ethnicity	NZ European		4
	NZ Maori	3	
	Pasifika	3	
	Other		1
Speech difficulties		3	2
Level of Disability	Severe	3	3
	Mild	3	2

A range of family members took part in the two family focus groups, as seen in Table 5, although the majority of the participants were mothers (n=6; 75%). The remaining two participants were one father and one female sibling. As they were recruited separately to the adolescents, only two parents had a son/daughter also taking part in the research. Two parents of Maori and Pasifika ethnicity initially consented to take part in the research but on the day of the focus group one parent was unavailable due to illness and the other withdrew, reporting that they were too shy to participate. As a result all participants in the two family focus groups were of New Zealand European descent.

Table 5: The demographics of the family groups

Group		Group 1 (n=5)	Group 2 (n=3)
Gender	Female Male	4 1	3
Age	Mean (yrs) Range (yrs)	45 20 – 57	49 47 – 52
Ethnicity	NZ European	5	3
Relationship to participant	Mother Father Sibling	3 1 1	3

Table 6 shows the demographics of the teacher and therapist groups. These groups did not demonstrate diversity in ethnicity (all were of New Zealand European ethnicity) or gender (only one male participated in each group) which reflects the demographics of therapists and teachers in general. A diverse range of therapists participated in the therapist focus group with representation evenly divided between three disciplines. One therapist had a physical disability.

Table 6: The demographics of the professional groups

Group		Teachers (n=6)	Therapists (n=7)
Age	Mean (yrs) Range (yrs)	54 46 – 64	46 23 – 63
Gender	Female Male	5 1	6 1
Ethnicity	NZ European	6	7
Type of professional	Speech Language Therapists Physiotherapists Occupational Therapists	N/A	2 2 3

4.3. The dynamics of the focus groups

The focus groups with adolescents were challenging to facilitate, particularly due to communication difficulties experienced by some participants. As noted in the methodology (Chapter three, p 22), two support people; one a trained counsellor, were present to assist these students to take part in the group discussions. This additional support was helpful in facilitating the groups. All of the students appeared keen to have their opinions heard. Some students exhibited shyness during the focus group, with one boy saying "my mind just went blank" on completion of the group. Stimulus questions included: what do you understand by the term QoL, what do you like about your life, what makes you happy, how could your QoL be improved, how do you think your life compares with that of others (see Appendix F).

In the four focus groups with adults, conversation flowed well and did not require a great deal of researcher intervention. Families welcomed the opportunity to discuss the most important aspects of QoL for adolescents with physical disabilities and wanted to keep talking after the focus group concluded. One parent left the room and then returned to make a very impassioned statement about an issue that was important to them that had not been discussed by the group. Both teachers and therapists demonstrated enthusiasm for the topic of the research in their groups. Subsequent to their groups the principal investigator (MA) was asked to share research articles and speak to staff at a school that had decided to make the research topic their focus for staff in-service for the year. In addition, one participant emailed further information that they thought would be relevant to the research.

4.4. The most important aspects of QoL for New Zealand adolescents with physical disabilities

As the main objective of this research was to explore what the most important aspects of QoL are from the perspective of adolescents with physical disabilities, emphasis will be given to the "voices" of the adolescents. The data from the other groups, such as family members, therapists and teachers, is discussed in relation to how it supplements the adolescent view or to highlight a tension between the views of different groups. Each adolescent is identified by a pseudonym.

In analysis of the data, seventeen key components were determined that were organised into four themes: to be recognised as an individual, to have autonomy, to have meaningful relationships and to have purposeful opportunities. Each theme will be discussed in turn, followed by data exploring whether these themes and key components are reflected in existing measures of adolescent QoL.

To be recognised as an individual

Being recognised and valued as an individual, rather than being seen primarily as a person with disabilities, was a strong theme in the focus group discussions. The adolescents had a vision of being accepted for who they were; one got vigorous agreement from the group when she said:

> "I don't want to be seen as a person in a wheelchair, I want to be seen for who I am - not for my physical limitation, for me" (Jenny, aged 20).

This young woman perceived that she was primarily identified by others as a person with a disability, while she wanted to be acknowledged as a human being. For most of the adolescents, disability appeared to be integrated into their core identity and so whilst they believed that their disability was how they were identified by others, they saw other aspects of their self as their key identifying features:

> "Tell people we, inside, are no different to anyone else, we are people first and people with disability second" (Jenny, aged 20).

The desire to be recognised and valued by others as an individual was evident with comments such as "show positive things about you" and "show the good things people with disability do". The adolescents did not see disability as their key identifying feature but felt that social, moral and cultural factors gave true meaning and quality to lives and that many factors make up being a human. One adolescent expressed this by saying:

> "All your experiences affect who you are" (Michael, aged 17).

Some of the students expressed that their backgrounds reflected who they were as individuals:

"Where you come from affects you differently" (Sarah, aged 15).

The Maori and Pasifika group of adolescents had a strong identity with their culture and saw it has having a strong impact on their lives and who they were. A very dysarthric Samoan girl said slowly, with great gravity:

"I am proud, proud to be Samoan" (Mary, aged 17).

When asked if they saw themselves first as a person with a disability or first as a member of their culture, five of the six Maori and Pasifika participants said they identified with their culture primarily. One Maori student said:

"A sense of being important in my life for the quality of my life as to who I am, my culture is a bigger thing and the whole family feels the same. It is very strong in the family values" (Charles, aged 18).

As disability was integrated into their identity, having a disability did not equate to having a health problem for the adolescents. For one male, the pain he experienced as a result of his physical disability was so much a part of his everyday life, his core identity, that he did not see it as an issue that affected him overall:

"Good health is very important but I can put up with the pain" (David, aged 17).

One parent commented that his son was viewed as unwell simply because he had a disability:

"The thing that does piss me off is that we come under the Ministry of Health and it is just a huge organisation to deal with all sorts of bureaucracy and J is not sick. J doesn't have any health issues and it is just the wrong government department that oversees the disability" (Father).

The need to be seen as an individual, rather than an individual with a disability, was described by one teacher as being about acknowledging the whole individual:

"Who you are and where you sit within the framework of all these things, I actually see as a much bigger element with all the emotional, social, spiritual, everything… being, actually, when I use being - well I don't narrow it just to health, it's actually the whole person" (Teacher, female).

The ability to be an individual without others' attitudes impacting on their ability to be seen as a 'human being' generated much discussion with comments such as:

"People should treat you how they would like to be treated" (Paula, aged 16).

The young people also articulated thoughts about their experiences of dealing with prejudice and discrimination:

"Many times people have called me handicapped, stuff like that, it made me feel horrible" (Sue, aged 17).

Prejudice and discrimination impacted on their view of themselves within the social order of society:

"I think teenagers with disability are a lower minority, very often you sort of are forgotten or overlooked or that sort of thing" (Paula, aged 16).

The teenagers did however seem to have developed resilience towards discrimination:

"We have to deal with things that other people our age haven't had to handle like prejudice, discrimination, like we grow up mentally a lot faster. I think we get a lot more mature out of necessity, we have to deal with situations" (Sue, aged 19).

However, there did seem to be a tension between the need to be seen as an individual and the reality of the disability. Parents commented about the lack of understanding about disability on the part of organisations that were meant to be of assistance. One mother frustrated in her attempts to obtain support from a government department tried to explain how things were for her saying:

"I said to them listen, disability doesn't go away, this is it for life for us" (Mother).

Interestingly though, there appeared to be a discriminatory attitude within the disability community itself which was exhibited between adolescents with different levels of disability. One participant, referring to her more disabled peers,, said:

"You are stuck with them" (Mary, aged 17).

Another agreed, saying:

"Yeah it is embarrassing" (Sue, aged 19).

These adolescents did not really see disability as their key identifying feature and did not like being grouped with others just because they also had a disability. Although these adolescents wanted to be seen as individuals, human beings, rather than people with disability, they continued to identify their peers as people with disability. The parents spoke about the apparent discrimination sometimes exhibited towards each other, depending on the type or severity of disability each individual had, with one mother saying:

"The disabled community itself has a part to play in it as well, because there is almost a division between the able and the disabled, they segregate themselves" (Mother).

Another parent supported this view, indicating that he felt there is a hierarchy within those with a physical disability and related it to levels of communication ability:

"What happens quite often is that people who are able to express themselves well are perhaps the least disabled and they kind of move off and they forget about the others who are quite disabled" (Father).

Interestingly a teacher commented that there were times that even teachers were guilty of discrimination:

"We have our own insidious forms of put-downs. Look at the feeding room, we're not a zoo, but we send our kids to the "feeding room" at lunch time and we are on "feeding duty". We are in fact encouraging this sort of institutionalisation. And then we expect our kids to go out into the community and be treated differently" (Teacher, male).

The desire to be seen as an individual is linked to the issue of being accepted in their own community and in the wider community. The comments of the adolescents about discrimination impacting upon their ability to have a good quality of life reflected that they felt devalued by society. Some of the adolescents even spoke about the need to have television advertisements to promote understanding of disability. There was a strong call for more understanding of disability, one adolescent commented:

"I feel that New Zealander's understanding of disability is lacking immensely" (Michael, aged 17).

One young woman gave a personal reason for wanting to improve awareness of disability:

"New Zealander's understanding of people with disability needs to be raised to the next level, more forums, more hearing from us like we are doing now. We could set up some kind of peer programs or friendship programs To tell people we inside are no different to anyone else" (Jenny, aged 20).

One young man elaborated on this, inferring that although New Zealand has a policy regarding disability, it is not put into practice well:

"They could start by implementing the disability strategy and using it" (John, aged 15).

Another young woman indicated that she felt there was not enough consultation with young people saying:

"I would like to express my feelings to the government right now, from my point of view and then … I would actually like one day to go down to Wellington and meet with the Health and Disability commissioner" (Sue, aged 19).

"We need a stronger voice; there are not enough people with disabilities as our representatives" (Paula, aged 16).

When asked if they felt the programs the school ran for other students to promote disability awareness made any difference to the level of understanding they experienced, one commented:

"Not really, because when you are at school there are much higher influences so like with things like that, a lot of people just sit there and don't care" (Sarah, aged 15).

The theme of being recognised as an individual is linked to the theme of autonomy, particularly the importance of the right to have freedom as an individual recognised by others freedom of choice, of movement, of personal space, of speech and financial freedom. Being seen as an individual rather than primarily as a person with a disability is also inter-linked to the ability to have meaningful relationships with able bodied and disabled people:

"A sense of being valued**,** to me, is the absolute foundation stone for this whole area. If people are not valued for what they are, for who they are, irrespective of their level of ability or disability, then they have no quality of life" (Mother).

To have autonomy

Autonomy is defined by the New Zealand Oxford Dictionary (2005), as the right of self government, personal freedom or freedom of will. The adolescents in this study spoke a great deal about the importance of having personal freedom:

"Freedom in life is very important" (Jenny, aged 20).

"Just to feel that you can do what you want to do" (Sarah, aged 15).

Four categories emerged under this theme: freedom of choice, freedom of movement, freedom of speech and financial freedom. The findings showed that the adolescents had a strong desire to have freedom of choice - to make decisions regarding their own lives and to have the physical supports to do so. One young woman highlighted that the ability to make her own decisions was a key factor of autonomy for her by saying:

"For me freedom is about making my own decisions" (Jenny, aged 20).

It seemed that the opportunity to be consulted about choices and options was an important factor as another teenager commented:

"Making my own decisions is so important …. Even if the final decision isn't exactly what you want you still have a chance to be consulted" (Sarah, aged 15).

This was echoed by another adolescent who said:

"The ability to make your own decisions or a least have a say" (Paula, aged 16).

One teenager's comment reflected the transition stage adolescents are in and that there is a balance between freedom of choice and support:

"I like to be offered choices but sometimes the choices are hard and it is nice to have someone else to do it sometimes" (Sue, aged 19).

A teacher provided some insight on this when she commented:

"I think this is a huge problem with our adolescents who have lives of protection and other people making decisions for them and suddenly they have

got to determine who they are. It's very difficult for them to cross that bridge and then become independent, determining their own future" (Teacher, female).

Some adolescents believed that having choice equates to having opportunities, as expressed by one young woman:

"It's not the type of thing I would do if I had a choice because like I say, going back to having opportunities, I wouldn't want to stay at school any longer if I had a choice" (Jenny, aged 20).

In order to receive an additional substantial benefit towards assistance, this young woman was required to stay at school until she turned twenty one. She reflected on how having no choice or control over the requirement to remain at school to access additional benefits affected her ability to remain with her friends, her able bodied peers, and limited the opportunities available to her – particularly social opportunities.

When the adolescents were asked who they felt were the most helpful for facilitating them to make choices, out of parents, teachers and therapists, they only mentioned the contribution that they felt teachers made and perhaps this was because most of their time at school was spent with the teachers. In their focus groups, the teachers expressed clearly that their contribution to facilitating a good QoL was to enable the adolescents and skill them to make choices. They highlighted that the main issue was ensuring that the adolescents were in control when they made the decisions (whether they could physically carry out the decision or needed to get other people to do it) and that the consequences of making their own choices was followed through:

"Even though we might perceive that it might be in their best interest, as soon as we make a decision on what we perceive to be their best interest then we are taking power away from them and there is a very, very fine line here. So we have to expose students to a range of experiences without taking away their power to make the decision" (Teacher, female).

Overall the parents also acknowledged the need for adolescents to be given the opportunity to make choices:

"For her to be given choices - I think people see someone in a wheelchair and they think, oh they don't know anything and in fact they do" (Mother)

However one of the teachers commented negatively about the students having autonomy:

"Our students tend to be terribly egocentric about everything and I notice that some of our more disabled students, they are the centre of their life, much more than normal adolescence" (Teacher, female).

This teacher felt that the students with severe physical disability were so focussed on getting their own needs met, that at times prevented them from seeing beyond their own situation. However, this comment can be seen as either reflecting the effort that adolescents with severe physical disability need to exert to achieve autonomy or as a reflection of a personal bias on the part of the teacher. Independence was linked to the right to personal choice:

"I am thinking of just any teenager, but to be challenged and therefore to make choices themselves and to try things without someone rescuing them or telling them not to do things - teenage years are a time for experiencing things isn't it" (Teacher, female).

Parents, teachers and therapists all felt that facilitating/ enabling young people with physical disabilities to make choices, was an important part of their role and yet the adolescents clearly felt that they were not being given enough opportunities to make their own choices.

Freedom of choice was also closely linked to freedom of movement and being able to create opportunities. All of the adolescents who had power chairs spoke of them as representing physical, and to some extent psychological, freedom. One student commented on how great it was:

"To be able to go off and do my own thing" (David, aged 17).

Another added to this saying:

"You don't have to rely on other people to push you and you can go where you want" (Michael, aged 17).

When asked if they felt psychological freedom was closely linked to physical freedom, all the adolescents vigorously agreed. They expressed that power wheelchairs were an extension of who they were, with numerous comments such as:

"Wheelchairs are like another part of your body so it is really important that it works" (John, aged 15) and "My wheelchair is essentially my legs" (Jenny, aged 20).

Interestingly the students with mild physical impairment also saw physical freedom as very important and spoke of the importance of having a drivers licence:

"Now I have got my learners I want to get my restricted so I can get out" (Charles, aged 18).

"Driving your self means freedom" (Adam aged 17).

The importance of physical freedom for establishing friendships and opportunities was summarised well by one therapist who said:

"One student went away and he wasn't able to access his power wheelchair, one of the main things he missed most about NZ was his power wheelchair. I think it enabled him to access more things, be more independent and pursue friendships (Therapist, female).

In addition, therapists stressed that for a good QoL adolescents need lifestyle appropriate wheelchairs:

"At the moment our legislation is that the government will provide wheelchairs for inside use only - which is not going to be much use to some of our young men who would normally be out in a car or a motorbike" (Therapist, female).

An unexpected finding that was linked to the desire to have freedom of movement was the strong desire of the adolescents with severe physical disabilities to be able to achieve privacy – literally to be able to get away to have some time to be completely on their own:

"For me I guess privacy is a big thing, because of the level of support I myself need, I have always got somebody around. I never seem to be on my own because I need someone there all the time, so my privacy is very important" (Jenny, aged 20).

Another supported this comment acknowledging the need for free time to think without interruptions:

"When I am able to be left on my own, I do like to do so because it is the only time I have to think about things and I like to think about where I am heading in my life" (David, aged 17).

What was interesting about this and what is complex about QoL, is that at times there appears to be a tension between the things that are important to people. For example, the severely disabled adolescents had a strong desire to connect to others and have meaningful relationships but this was balanced by the strong need to have the ability to have times when they were completely on their own - a concept which was actually extremely difficult for them to achieve. Natural tension is the reality of life but it seems that having a physical disability further complicates this. Teachers and therapists acknowledged that adolescents have a need for privacy but said their high physical dependency levels caused practical issues:

"The sense of modesty and keeping yourself private and private places on the body is a really hard one to accept because they have got non-family dealing with very intimate areas of their life and so we are saying you have to

cover things up yet the next minute they need to go to the toilet and they are not covered up at all" (Therapist, female).

A mother talked about the lack of male caregivers available and the difficulties this posed for males:

"I feel quite sorry for the males that are disabled because there are very few male caregivers and so they are being lumbered with female caregivers and especially in your teenage years that has got to be embarrassing" (Mother).

Another aspect of autonomy that was discussed by the adolescents was the need for freedom of speech. This was very strongly expressed by adolescents in both groups, at both a personal level (the physical ability to be able to communicate) and at community level (being able to present your views to others – which is interlinked with being an individual). One male forcefully said:

"It is important to be able to communicate" (John, aged 15).

The reason why being able to communicate was so important to QoL was eloquently summarised by a young woman who said:

"Communicating is so important to make sense of your world" (Sarah, aged 15).

For the very disabled adolescents, communication was seen as a major challenge, second only to mobility issues:

"Communication is a second major problem" (Charles, aged 18).

Finding a way to express complex ideas is difficult for students with speech limitations:

"If you are challenged with your ability to communicate, letting people know about pain, where it is, how long it has been going for, what causes it and relieves it, is a very difficult thing to do" (Teacher, female).

At the conclusion of one of the adolescent focus groups, one of the young women asked for a copy of my "report" to pass the information on to other people. When I asked if she thought I had covered most of the things that were important to young people she said "Yeah, having a voice". Freedom of speech, not only the physical ability to communicate but also to have "a voice" and an opinion that was heard by others, was so important to all of the adolescents interviewed – especially those with dysarthria and the nonverbal student.

Although therapists stressed the need for communication devices to be available, communication devices were seen as posing several significant challenges. Communication through a communication device is slow and dependent on the skills of the programmer - it may not have subtleties of meaning (e.g. shades of emotion like frustration, disappointment) and there can be a temptation by parents and therapists to "sanitise" the language whereas the language should be age appropriate. A teacher commented:

> "A communication device should be really accessible to them with an age appropriate vocabulary." (Teacher, male).

> "To give them the opportunity to initiate conversations rather than us putting words into their mouths… so to speak a lot of the time students with communication devices often just say yes – a bit like learned helplessness, just agreeing is easier" (Teacher, male).

Financial freedom was another category that emerged from the focus groups. The right to control their own money (benefit) was seen as important and linked to freedom and independence:

> "Independence is really important, having independence from my parents… I don't have to say I need money for this" (Sarah, aged 15).

Another teenager linked the need for financial independence to being seen as an individual:

"Money is important, because if we have no money we have no rights" (John aged 15).

In the transition between childhood and adulthood management of money can present challenging situations as all the adolescents with physical disabilities receive benefits and the transition between parents managing the money and the adolescents managing it can be problematic:

"The problem with a lot of these kids is that they become chattels within the family and they become a source of income just for their benefit and so the restrictions are further made on them because the parents don't want to give them the right to determine their own future" (Teacher, male).

Almost all of the teachers and therapists talked about how important it was that they allowed students to have autonomy or freedom, however one teacher spoke of how this was not happening:

"I think a lot of our kids have become less self reliant because we have taken over too much of the responsibility and made too many of the decisions and not given them enough opportunity to risk themselves" (Teacher, male).

The importance of having autonomy was a key theme throughout all of the focus group discussions and is interlinked to being seen as an individual. Without personal freedom, particularly freedom of choice and freedom of speech, it is difficult to express yourself as an individual. The need to "have a voice" and an opinion that was heard by others was interlinked to the need to be an individual despite discrimination. In addition autonomy is needed for an individual to be able to experience meaningful relationships and purposeful opportunities. In addition freedom of movement, for people with disabilities, is strongly linked to the ability to socialise and experience meaning relationships as well as participate in purposeful opportunities.

To have meaningful relationships

The adolescents in this study made it very clear that, like most teenagers, it was important for them to have friends.

"It would work even better if I had more friends" (John, aged 15).

Meaningful friendships provide opportunities, as one adolescent said:

"With friends you can get out and do stuff" (Charles, aged 18).

As well as friendship providing opportunities, the most discussed aspect of friendship was the emotional support that friends offered:

"I have always thought that you also need friends that do have disabilities and friends that don't… basically it gives another aspect to support. I have found whether you have friends that understand what disability is…they are going through the same things and also the complete opposite side of the coin they might not know so much but they are still friends" (Sarah, aged 15).

"They are always there for you and they accept you and you know you can get support from them" (Sarah, aged 15).

One mother spoke of the difficulty her son had forming meaningful friendships and tried to arrange for a paid "buddy" for her son, poignantly saying that:

"The ultimate desire for a mother's heart is that it would transfer into a genuine friendship" (Mother).

One young woman commented on the importance of being like everyone else, when talking about friendships:

"Having friends is giving us the opportunity to be like everybody else" (Mary, aged 17).

At one stage during an adolescent discussion about friendships there was considerable talk amongst the male participants about girls, with laughter, embarrassment and each person saying it was the others turn to speak. However, they all clearly felt that having a girlfriend was very important. Some indicated that they had a girlfriend, whilst others said they wished they had one.

I asked one young male, who had said he had a girlfriend, if that contributed to his QoL and he replied “definitely”. Another, rather ruefully, commented “It hasn’t worked for me”, meaning that although he would really like a relationship with a girl he was having difficulty forming one. Interestingly, the girls in the focus groups did not discuss the subject of boyfriends.

This theme of having meaningful relationships links with the theme of being seen as an individual rather than as a person with physical disabilities, a therapist commented on this:

> “People with disabilities are seen as not sexual as well, a lot of caregivers and professionals skirt around that and don’t see that side, the choice side and the holistic side of being a sexual being with all the feelings and fantasies and dreams” (Therapist, female).

As well as talking about friendships and relationships with the opposite sex, the adolescents also acknowledged that family were important. One male stated that both:

> “Friends and family are important” (Joshua, aged 17).

When asked which was the most important to him, he indicated that both were rated of equal importance because of the support they provided:

> “They [family] can read my mind, know what I need without me having to ask” (Michael, aged 17).

Another adolescent referred to the stability and constancy of support his family unit provided:

> “My family is important to me because they help me along the way they are always there and in times of struggle I can always count on them” (Charles, aged 18).

Most of the participants acknowledged that their family gave unconditional support and for some, including John aged 15, this related back to the importance of being seen as an individual rather than a person with disability:

"They don't treat me different; they don't give me special treatment. They treat me like all my brothers and sisters; they treat me like a normal 15yr old" (John, aged 15).

Another factor valued by the adolescents was that their family saw their uniqueness as individuals because their background was understood by their family:

"If you have got certain beliefs that other people don't understand or believe are right for yourself they will help you with that" (Sarah, aged 15).

At first there appeared to be some disparity between some of the adolescents on the importance of family support. Though most acknowledged the importance of family support to their QoL, two said family support was not important:

"Not really" (Mary, aged 17),

"Family is not such a major thing for me now, but my friends are really important though" (David, aged 17).

However, further discussion after the group highlighted the fact that these two students did value family support but felt that their families did not offer the type of support they sought from them. Specifically, both these students felt that the parents did not provide emotional support and they controlled how the students' benefits were to be spent.

Interestingly the adolescents mainly spoke about support provided by friends and family, although one adolescent acknowledged the support teachers provided saying: teachers saying:

"You don't really have to ask for help because the teachers know about you, they actually offer before you ask" (John, aged 15).

The importance of having a relationship with somebody else and being able to transition away from dependence on their parents and eventually create their own family unit, was also discussed in depth by parents, teachers and therapists. One teacher commented:

"For normal adolescents it [having relationships] is a huge part of their lives, and with our kids there are severe restrictions. It must lead to quite a lot of distress and depression amongst adolescents with disability. I don't think we do enough to help them work through a lot of the issues. We've still got the opinion that people with disability; well maybe they don't need that sort of thing" (Teacher, female).

Whilst the adolescents' discussion focussed on personal relationships, the parents were concerned with the importance of establishing meaningful relationships with caregivers and supporting organisations. The parents wanted their family member to have an ongoing relationship with people in one organisation rather than numerous organisations so that their adolescents were treated as individuals:

"The coordination of services and the provision of support are not very good - you just need one solid organisation that can cover all bases - as long as they have a lifetime disability you are a lifetime client of that company. So that they know you intimately and they know the client intimately" (Mother).

A good example of how lack of continuity of care can impact on teenagers was given by one mother who talked about the difficulties she encountered obtaining appropriate and meaningful support around issues of her son's awakening sexuality:

"There were some sexuality issues I wanted to talk to them about and the guy came around and I had to reveal all the most intimate details of J's life. The next thing this guy has left and gone somewhere else without any help and then

the next thing I get a phone call - oh I am the next case worker how is this problem going? Has it been resolved yet? We want to close our files; I can close the file can I? And I said yeah fine..." (Mother).

The discussion about continuity of care and developing meaningful relationships with caregivers led to some discussion of quality of care in general and this father highlighted that sometimes the wider government structures and policies impact on the provision of continuity of care:

"This sort of work is very, very important; these people come in at a very personal level to someone's life. There is often a high turnover and it is very difficult to allow someone to come and help with those very personal cares so I think there needs to be greater remuneration but it also needs to be notched up. These people need to be recognised" (Father).

A major concern for the parents was for future QoL for their young people:

"And a big worry is if you disappeared off the face of the earth tomorrow who will step in?" (Mother).

This comment illustrates the very valid reason parents have for wanting to establish meaningful relationships with external agencies. The theme of having meaningful relationships on both a personal and organisational level was closely related to the theme of being acknowledged as an individual. The young people also linked to autonomy and the ability to make individual choices to this theme. They wanted to have relationships with caregivers and organisations rather than interaction with these groups mainly being through their parents. Without self determination it is difficult to establish meaningful relationships with caregivers and support agencies.

To have purposeful opportunities

A strong theme that emerged from all of the participants, in all of the groups, was the need for purposeful opportunities for adolescents with physical disabilities - to experience life, to make a contribution and to establish a sense of self worth:

"We need to have the same rights, the same opportunities as our peers" (Sue, aged 19).

"Having opportunities to be like everybody else" (Sarah, aged 15).

"I believe that we should be seen for who we are not just seen as people in a wheelchairs, we need to have the same rights the same opportunities as our peers "(Sarah, aged 15).

The adolescents in the study, and their parents, placed great emphasis on the need for participation in everyday occupation that was meaningful:

"He has got to participate in society; I would like to think that he will be able to work, have a home and have a partnership" (Mother).

For many of the young people, being part of a social community, having a social life and enjoying it was what adolescence was all about. One young woman described QoL as:

"To have a life which is good and that we can do things that we have always wished, such as it might just be the simple things - going out, socialising" (Jenny, aged 20).

Another said:

"I love to be out there with everybody else as much as I can, despite my physical limitations" (Joshua, aged 18).

One student with dysarthria expressed that she would like more opportunities for socialising out of school with people that did not have disabilities and a comment from a parent supported the need for this:

"I think as a parent if I was to do this again I would look for more opportunities for normalisation, I don't know that we have done that particularly

well um I guess we have but going to the pub and stuff we do it sometimes but it is about being able to let go as well" (Father).

This father was acknowledging that in order to give his son the opportunity to socialise in the company of non disabled adolescents, he needed to be able to "let go" and provide the chance for autonomy, rather than acting as a barrier to his son accessing opportunities. Another parent also acknowledged the difficulty she had in facilitating her daughter's access to opportunities saying:

"I should have given C the opportunity of experiencing things other than family "(Mother).

The opportunity for socialising linked with the ability to establish meaningful friendships outside of the family and parents expressed concern about the lack of opportunities available. One mother commented about her physically disabled son, when talking about her able bodied daughter:

"My daughter went to a school disco yesterday - why can't our kids socialise like that?" (Mother).

Therapists supported the need for opportunities for socialisation saying:

"For adolescents with physical disabilities; socialisation is the motivation for wanting or needing a whole range of skills that add to their QoL" (Therapist, female).

Three of the adolescents had part time jobs and they spoke eloquently about the significance of them, including providing meaningful occupation, financial independence and the opportunity for forming friendships:

"A good thing about a job is it helps you get a better life and it helps you earn money, the best thing for me about it… oh I stutter,…the best thing for me about it is that I am not at home doing nothing …..It is something I like.
It saves being at home" (John, aged 15).

"When I was thinking about all sorts of jobs, what could I get and I started feeling keen about it started breaking my neck for it like being keen, really keen, I wanted to do it" (Adam, aged 17).

"I work with CCS in various capacities, I am meeting lots of different people and you get to know various different sorts of people" (Paula, aged 16).

One teenager acknowledged the importance of the computer to him, in providing something to do. The need for purpose in life was a common theme with comments such as:

"I hardly have anything to do" (Joshua, aged 17).

"Sometimes being at home is just boring" (Michael, aged 17.

"Having fun and things to do is important" (Mary, aged 17).

Others commented that there needs to be an alternative to paid employment as a gainful way of spending their lives:

"More sheltered environments providing a community program are needed so that people who are not productive enough can move into that" (Sibling).

The parents spoke of the frustrations that arose as their children got older as there are no coordinated adult services for people with disabilities in New Zealand:

"D is now 18 …and we are falling into a big black hole" (Mother).

They also spoke of government initiatives which did not support QoL issues for adolescents with physical disabilities:

"I think the government has put our kids at a huge disadvantage bringing in this minimum wage thing. I really do. I think they have shot the kids in the foot

and disadvantaged them especially closing down the sheltered workshops" (Mother).

The provision of a realistic wage for people with disabilities in supported work environments was seen initially as removing discrimination, however in reality it meant that supported work environments became non viable financially and less opportunities were available for paid employment.

It was very evident that the adolescents wanted the opportunity to be able to have training in life skills to facilitate opportunities for participation. Therapists felt that social skills and life skills training were very big issues and should be put in place for every student, almost ahead of academic work. Two of the teenagers were living away from home and one mentioned that she needed help and support, when asked if she would feel comfortable saying what sort of help she needed she said she needed help with everything, including cooking and how to manage money. She felt that to engage with her able bodied flat mates, she needed to be able to contribute in a practical way. One teacher explained why training in life skills was important for adolescents with physical disabilities by referring to the lack of opportunities some had when they were younger saying:

"They just miss out on all of those types of early childhood experiences and things like taking them to the supermarket because life is hard and difficult and I think that's why they miss out that they are seen as being unnecessary in the scheme of the big picture of managing life" (Teacher, female).

There was considerable debate among all groups about the challenges of transitioning from school and moving into a purposeful life. The need to be able to leave school when it was age appropriate was discussed. Adolescents who have very high physical needs qualify for development funding over and above the normal benefits if they stay at school until they are twenty one (an extra $17,000 a year for life). As a result it is difficult for these adolescents to leave school with their non disabled peers, and illustrates that rigid government policies can get in the way of accessing opportunities at an appropriate and

meaningful time. One student commented that she had to remain at school until she was twenty one:

"If you leave early you don't get it, and if you don't access it within one year you lose it. With my personal circumstances, university and tertiary institutions don't have the support that someone in my position might need, they don't actually have people to do the simplest of things and that is why I am still at school today, to get a special lot of funding to be used for that help at tertiary level" (Jenny, aged 20).

Parents wanted their adolescents to have the opportunity to participate in their community to the full extent of their ability. What is interesting however is that adolescence has its own values and culture. Adolescents with physical disabilities have a lack of opportunities for risk taking in the same way that "able bodied" adolescents can. A teacher referred to the difficulty of providing opportunities for adolescents with physical disabilities to take risks:

"I think a lot of our kids have become less self reliant because we have taken over too much of the responsibility and made too many of the decisions and not given them enough opportunity to risk themselves" (Teacher, male).

In the focus groups, parents acknowledged the need for adolescents with physical disabilities to extend their boundaries and experience risk. One parent gave the example of risk taking as being involved in motor sports:

"Just to be involved in the activities that everyday teenagers would do. Now in our house they are motor racing mad. J (husband) has been down to a couple of the go-kart places when D was a little bit smaller and asked to book the whole place out for an hour and they said no, Health and Safety rules" (Mother).

However, this example of what a parent considers to be risk taking for their son with physical disabilities would not be seen as risk taking by an able bodied adolescent. The freedom to have opportunities to take risks is difficult for

adolescents with physical disabilities. In addition, as seen in the above example, some government policies which are initiated can prove to be punitive.

To be able to have purposeful opportunities is clearly linked to the adolescents being recognised as individuals with their own potential – not being identified as adolescents with physical disabilities but to being the same as their able bodied peers. It is also linked to the ability to have autonomy, self determination and freedom of choice. The young people indicated that it was not only important to have something to do they wanted to have choice and availability of options. Being able to experience purposeful opportunities is also a way for meaningful relationships to be established.

4.5. Comparison of the findings to existing adolescent measures of QoL

As highlighted in chapter two, the QOLPAV and the YQOL, are currently the most widely accepted generic measures to use for measurement of QoL in adolescents with physical disability and so their conceptual basis will be examined against the core findings of the current study. The comparison uses only the ten perceptual items of the YSQOL-S (designed to be completed by adolescents) and does not include the contextual items (designed to be completed by proxy). Van Heeswyk (1997) has argued that adolescence can be seen as comprising three distinct phases; early (12–14), middle (15–16) and late (17–19). The QOLPAV as originally devised by Raphael et al. (1996) could be viewed as a measure of middle to late adolescents' QOL and suitable to be compared to this study, where the age of the adolescent participants ranged from fifteen to twenty. The KS-52 is also included in this comparison as it is a newly developed measure in this field and appears to be a comprehensive measure, although it must be noted that it is designed for use with both adolescents and children. This comparison does not include the VSPA as this measure is not yet translated into English. On the whole, these measures covered many of the core components of QoL discussed by the young people in this study. However, as can be seen in Table 7, there were some gaps in their measurement, which are discussed in more detail below in relation to each of the four themes.

Table 7: Comparison of the findings to adolescent QoL measures

	The current study 2007/ 8	QOLPAV (Raphael) 1996	YQOL- S (Patrick) 2002	KS- 52 (Ravens-Sieberer) 2006
QoL DOMAIN	**Individual**	**Being**	**Sense of self**	**Individual**
Key components	Seen as an Individual	No	No	No
	Social acceptance	No	Yes	Yes
	Culture	No	No	No
QoL DOMAIN	**Autonomy**	**Not a specified domain**	**Autonomy**	**Not a specified domain**
Key components	Financial	Yes	No	Yes
	Choice	Yes	Yes	No
	Speech/ Voice	No	No	No
	Mobility	Yes	No	No
	Privacy	No	No	No
QoL DOMAIN	**Meaningful Relationships**	**Belonging**	**Relationships**	**Relationships**
Key components	Friendships with peers	Yes	Yes	Yes
	Family support	Yes	Yes	Yes
	Support services	No	No	No
QoL DOMAIN	**Purposeful Opportunities**	**Becoming**	**Environment**	**Environment**
Key components	Life skills	No	No	No
	Transition	Partially	No	No
	Employment	Yes	No	No
	Leisure/Social	Yes	Yes	Yes
	Risk taking	No	No	No

To be recognised as an individual

The adolescents in this study talked at length about the desire to be seen as an individual, rather than to be seen for their physical disability. This was not acknowledged by the above three measures, which instead included components such as physical and psychological well being to describe an individual's sense of self. The young people in the study also referred to not only gaining acceptance as an individual but to others gaining an understanding of them as a person and of what their disability involves. As seen in Table 7, the YQOL-S and KS-52 measures did address this category of having social

acceptance however the QOLPAV measure did not cover this aspect. In addition, for the Maori and Pacific students in this study, culture had far more relevance to who they were as a person than their disabilities, highlighting the importance of culture in QoL. However, the relevance of culture to QoL was not acknowledged in any of the three measures. The developers of the KS-52 measure conducted thirty six focus groups over twelve European countries to ensure it was cross culturally applicable. However, despite including a question about spirituality; they did not include a question about the importance of culture. Likewise, the YQOL- S included the statement "My personal beliefs give me strength" which encompasses spirituality but not cultural identity.

To have autonomy

In this study, all of the participants (adolescents with physical disabilities, parents, teachers and therapists) saw having autonomy, and the supports necessary to achieve it**,** as important. Current generic measures of QoL for adolescents do not include questions to examine the concept of autonomy in depth, with the exception of the QOLPAV. The QOLPAV does not have a specific domain for autonomy, however it does contain nine questions that relate to the degree of control the adolescent has over each of its nine sub domains (e.g. control over places where they spend time and who they spend time with). Within these nine items the key components relevant to autonomy articulated by the participants in the current study (financial, choice, speech/voice and mobility) were all covered adequately. The YQOL-S partially covers autonomy by examining whether the young people feel their parents allow them to participate in important decisions (choice) but does not attempt to cover any of the other categories such as freedom of speech, freedom of movement or financial freedom. The KS-52 has one item labeled autonomy, however this does not examine the ability to be an individual and have control over how they want to live their life, but rather is referring to whether the adolescent has opportunities to create social and leisure time and as such does not cover autonomy. While the above measures do acknowledge mobility and communication as supports to adolescents, only the QOLPAV considers financial resources and the control the individual has over them as a means to achieve autonomy, as the young people in the current study indicated. In this study, the participants highlighted that the need to have a voice and the need

for mobility were also important to achieve privacy which was not considered by any of the existing measures.

To have meaningful relationships

The young people in this study made it very clear that it was important for them to have meaningful relationships. Questions about relationships are covered in all of the four measures with the KS-52 being particularly comprehensive, having sections that examine relationships with parents and the atmosphere at home as well as examining the nature of the respondents' relationships with other children/adolescents and social acceptance (bullying). However the parents in this study also spoke of the importance of having meaningful relationships with support services and how continuity of care can have an important impact on QoL both in the present and future. This was not covered by any of the existing measures.

To have purposeful opportunities

Opportunities for social and leisure time was covered well in all the existing measures of QoL, however, this was just one aspect of opportunity that was discussed by participants in this study. In addition to social and leisure time opportunities, participants discussed opportunities for paid employment and alternatives to paid employment; opportunities to learn practical skills/ life skills; the process of transitioning from school to paid employment or an alternative; and opportunities for risk taking (and learning through risk taking). None of these findings are addressed in the QOLPAV, YQOL or KS-52 measures although the QOLPAV has a category: planning for a job or career.

4.6. Conclusion

In this chapter the participant characteristics have been described and a general overview has been given of the dynamics of the focus groups. The findings about the most important aspects of QoL for New Zealand adolescents with physical disabilities have been described. Negative cases have been analysed and the major differences between the perspectives of the different groups given. Finally, a comparison has been made between the findings and current generic assessments used to measure adolescent QoL.

CHAPTER FIVE: DISCUSSION

5.1. Introduction

In this chapter the principal findings will be summarised and discussed in relation to current QoL literature and examined from a New Zealand perspective. The strengths and limitations of the study will be reviewed. The significance of the findings will be discussed including implications for educators, clinicians, researchers and policy makers. Recommendations for further research will be made. Finally the reflections of the researcher will be given.

5.2. Summary of the principal findings

This qualitative study has explored the most important aspects of QoL for New Zealand adolescents with physical disabilities, from the perspective of the adolescents themselves, their families, teachers and therapists. In doing so it has filled a gap in current knowledge. The four themes from this study regarding the most important aspects of QoL for New Zealand adolescents with physical disabilities were: to be recognised as an individual, to have autonomy, to have meaningful relationships and to have purposeful opportunities. When compared to existing measures, some aspects of these themes were supported, however, several fundamental components of QoL highlighted by the participants were not considered including: to be seen as an individual and have an identity outside that of being a person with a disability, to have the opportunity to make choices and be supported in those choices, to have a voice in the community and to have privacy.

5.3. Discussion of the findings in relation to literature

As noted in the literature review, there is a lack of research specific to QoL and HRQOL in adolescents, as distinct from research that combines adolescents with children. Each key theme from the findings will now be discussed in relation to current QoL literature.

To be recognised as an individual

Adolescence is acknowledged as a time when adolescents move towards increasing independence and achieving a sense of identity (Erikson, 1963;

Lindstrom, 1993). However adolescent literature does not consider the difficulties someone with a disability has in establishing this identity. Hallum (1995) spoke about the negative effects that society can have on adolescents with disabilities, as it places importance on strength and appearance. There was much discussion by the adolescents in this study about the desire to be seen as an individual rather than to be seen for their physical disability. They referred not only to gaining acceptance as an individual but also to others gaining an understanding of them as a person and of what their disability involves.

Reviews of QoL and HRQOL among adolescents with physical disability, specifically cerebral palsy, have found that functional status, as measured by measures such as the Gross Motor Function Classification System, did not correlate consistently with measures of psychosocial wellbeing (Schneider et al, 2001). Furthermore a study by Chow, Lo and Cummings (2005), comparing the self-perceived QOL of adolescents with and without disabilities, found that the two groups were not significantly different in subjective QoL scores. Although these findings should be taken with caution (due to limitations of current measures) they suggest that aspects unrelated to physical disability seem to have more impact on QoL scores than the disability itself. This supports the finding of this study that adolescents with physical disabilities do not define themselves by their disability.

Adolescents in the study also expressed that they felt that discrimination impacted upon their ability to have a good quality of life. What was interesting was that discrimination was also in evidence within the focus groups, with the mildly impaired participants saying that it was embarrassing to be put with the more severely impaired. This apparent discrimination may in part be due to the process of identity formation that occurs in adolescence, with friendships being formed and reformed amongst peers.

All participants saw psychological well being as important (manifested by the importance of being seen as an individual) and placed less emphasis on their physical health. This supports research by Zullig et al (2005) which suggests that QoL, in the context of high school adolescents, is based largely upon self-

reported mental health and to a lesser extent on self-reported physical health. In addition, asking adolescents how they feel about their health is different from asking them how they perceive their QoL because although people may feel their health is poor, their quality of life may be excellent or vice versa (Bradley, 2001). The adolescents in this study reflected this when they said that the pain scale measurement was irrelevant for their QoL. One student said "good health is important but I can put up with the pain", indicating that pain was a relative constant in his life, distinct from an overall concept of wellness. It was not that he underestimated good health but rather that he did not see aspects of his disability as relevant to his health status. Meuleners and Lee (2005) used structural equation modelling to examine the dimensions of HR-QOL relevant for adolescents and children and found that the amount of control the adolescent perceived they had over their life, had a significant positive impact on QOL. Another study by Meuleners et al, 2003, found no significant difference between healthy and chronically ill adolescents in their perception of QOL, which may provide evidence that adolescents with a chronic condition can adapt to their conditions remarkably well and do not view their circumstances negatively.

Linked to the theme of being recognised as an individual, was the importance of culture to QoL. All of the participants in the Maori and Pasifika group strongly acknowledged that culture had far more of an impact on their individual identity, than their disability. This finding acknowledges the wider contexts that have an impact on adolescents' lives in New Zealand, particularly cultural values and principles embodied in the Treaty of Waitangi. Eiser and Morse (2001) commented on the lack of culturally appropriate adolescent QoL measures and further research is required to establish how the relevance of culture can be included in QoL measures.

To have autonomy

Self determination was described by Schalock (1996) as one of the eight core principles of QoL. A study including over three hundred able bodied and physically disabled adolescents by Meuleners and Lee (2005) showed that the amount of choice or self perceived control an adolescent had was significantly and positively related to their QOL. Historically, freedom of choice has been

recognised as important for people with physical disabilities, as reflected in the independent living and disability rights movements of the 1970s and more recently, in the move towards self advocacy, authority over resources and involvement in policy, as evidenced by The New Zealand Disability Strategy (2001) and The Youth Development Strategy, Aotearoa (2005).

Although all of the participants in this study acknowledged the importance of freedom of choice, the adolescents clearly felt that they had poor freedom of choice in many areas. What was interesting in this study is that both the adolescents with mild impairment and the adolescents with severe impairment wanted the same things regarding self determination – control over their lives with freedom of movement, speech and finances. The parents, teachers and therapists in the study felt that they were facilitating independence, whilst the adolescents themselves strongly felt that they did not have autonomy. However, the practical issues experienced by the more physically disabled young people (such as communication and mobility difficulties) meant that achieving any level of autonomy was often difficult. In the focus group discussions, parents contributed some insight to this when they commented on not only the difficulty of providing opportunities for freedom of choice for their more physically disabled youngsters but also the difficulty of allowing them to have negative consequences as a result of such freedom.

In addition, the literature on self-determination suggests that parenting styles impact on children's acquisition and development of self-determination skills and that parents' of children with disabilities provide fewer opportunities for them to practise making choices and decisions (Bannerman, Sheldon, Sherman, & Harchik, 1990; Zhang, 2005). As such parenting styles are likely to continue into adolescence and beyond, they impact on the adolescent's perceived autonomy.

To have meaningful relationships

Having meaningful relationships was important to the adolescents in the study. Detmar et al (2006) when examining the use of focus groups in the development of the KS-52 found that for both younger and older adolescents, social functioning, including the relationship with peers, was a more important

aspect of QoL than physical function. What is interesting about this and what is complex about QoL, is that at times there appears to be a tension between the things that are important to people. For example, the severely disabled adolescents had a strong desire to connect to others and have meaningful relationships but this was balanced by the strong need to have the ability to have times when they were completely on their own, something that adolescents with physical disabilities find very difficult to do due to their support requirements.

In rehabilitation programs, the emphasis has often been upon independence from the assistance of others, especially physical assistance, and this is reflected in the many functional outcome measures used by therapists. King et al (2000) commented that the ongoing emphasis from birth, on achieving optimum physical function and the delay in introducing power wheelchairs to children because of this can contribute to poor social integration and interfere with social development. Power wheelchairs are often only introduced if all other methods fail to achieve independent walking and yet they provide a means for children and adolescents to explore their environment, feel in control, make choices and achieve independence and socialisation. The literature is now beginning to suggest that early independent mobility provided by wheelchairs is a means of facilitating socialisation thus improving QoL (Bottos et al, 2001; Palisano & Lally, 2007).

In this study adolescents appeared to be focussed on the present and how engaging in meaningful relationship would impact on their QoL now, whereas the parents were looking ahead to the future, reflected in the parent's desire for their son or daughter to engage in meaningful relationships that would ensure they were supported into the future. As such, parents perceived relationships with professionals, such as caregivers, therapists and people from government agencies, to be important so that ongoing support could be provided. Parents appeared to believe that support and meaningful engagement with professionals contributed to a good quality of life for their adolescents and as such, caregivers should be recognised and remunerated well to prevent high turnover and to account for the stresses that such a role involved. In addition they emphasised the importance of having an ongoing relationship with one

organisation. These findings supported a cross-sectional study by McGavin (1996) of fourteen adolescents with physical disabilities and their parents. In this study McGavin reported that adolescents and their parents had different views, with the adolescents more concerned with the present and parents more concerned about implications for the future. Hallum (1995) spoke of the role that paediatricians should have in easing the transition of an adolescent, who is dependent on others for physical care, into adulthood. However, the parents in my study commented that after their family member turned twenty one "it was as if they fell into a big dark hole" because they were no longer under the care of a paediatrician. As disability was a life long condition the parents wanted to be under the care of one organisation for life, ensuring continuity of support (including funding, equipment and personnel), especially in the transition from secondary school.

To have purposeful opportunities.

Disability is now seen as a social construct involving an interaction of the person and their community, reflecting a move toward the identification of participation as an important dimension of health (Stewart & Rosenbaum, 2003). The WHO International Classification of Functioning model (2001) proposes that people with disabilities should be helped to have participation in everyday occupations that are meaningful to them. For the young people in this study, purposeful opportunities included paid employment or alternatives to work on transitioning from school and also purposeful occupation in leisure time.

A study by Donkervoort et al (2007) of over one hundred young adults, aged between sixteen and twenty, with cerebral palsy and without severe learning disabilities found that a significant number of them were restricted in daily activities and social participation. These problems were mainly attributable to restricted gross motor functioning and a low level of education. However participation for both the mildly and severely impaired adolescents in this study was extremely important. They wanted not only paid employment or alternatives to work on transitioning from school but also purposeful/ meaningful occupation in leisure time. Comments such as "I need something to do" came up frequently in the focus group discussions. This did not appear to reflect that

the adolescents were unhappy – rather they wanted to occupy themselves with something that had meaning. One young male explained that his part time job was important because it meant not only did he have something to do but it was a way for him to meet other people.

It is well documented that for adolescents with physical disabilities, participation decreases as they mature and often they feel socially isolated (Edwards, Patrick & Topoloski, 2003; King & Cathers, 1996; Varni et al, 2005). A study, of nearly six thousand able bodied and physically disabled people by Van Campen and Idema (2007), which examined whether people with physical disabilities who participate in society are healthier and happier, found that these constructs are much less closely related than is often assumed and that higher participation by people with disabilities is not associated with higher subjective well being. Thus rather than the "amount" of participation being key, it seemed that the "quality" and nature of that participation as purposeful was key to these young people.

Specific measures of participation are beginning to be developed, however the findings of this study suggest that items regarding participation should be included in QoL measures for adolescents as they are important in terms of adolescent development and relevant to clinical work and research.

5.4. Strengths and limitations of this study

A major strength of this study is that it has furthered our understanding of what the most important aspects of QoL are for New Zealand adolescents with physical disabilities, both from the perspective of the adolescents themselves and also from the perspective of their family, teachers and therapists. Previously there has been no documentation of what matters most in terms of QoL for New Zealand adolescents with physical disabilities. A further strength is that it included a group of Maori and Pasifika adolescents with physical disabilities in order to explore aspects unique to their cultural perspective. Consultation with this population has not previously been explored in the literature.

A strength of the methodology was that participants were able to freely discuss the topic rather than using a structured questionnaire approach. Studies on

QoL for people with cerebral palsy face methodological issues due to communication difficulties of participants and sometimes people with poor verbal skills are excluded from research (Bjornson & McLaughlin, 2001; Livingstone et al, 2007). This study included some adolescents with poor verbal skills and from the findings of the study, it was clear that these adolescents had a strong desire to “have a voice” and to have their opinions heard.

As highlighted in chapter two, focus groups have some limitations such as the possibility that a group setting may inhibit some participants; however the participants in this study appeared to provide mutual support for each other, particularly with allowing time for the students with poor verbal skills to convey their opinions. Group discussions also raise ethical issues such as disclosure of sensitive information to others and issues of confidentially. These issues were discussed at the start of each focus group and confidentiality issues were respected by the participants. The possibility that certain topics might be distressing for group participants was also discussed. Strategies that were included to help overcome this included having a second facilitator, who was also a trained counsellor, present to monitor the psychological well being of the adolescents.

Whilst the research design aimed to recruit a diverse range of participants in order to get a breadth of experience, there were some limitations to the samples, particularly in obtaining a cultural mix in the parent, teacher and therapist groups. Despite the limitations in the sample, qualitative methodology does not aim to produce generalised findings but rather aims to develop a conceptual understanding – hence the lack of a representative sample is in fact not as important as it would have been had a quantitative approach been used.

5.5. Significance of the findings

The findings show that young people with physical disabilities want to be seen as individuals, in the context of their whole lives, not as people with a disability. The findings also show the importance of working in partnership with young people. Research that does not include adolescents in the generation of ideas has the potential to miss concerns critical to their development. Accurate measurement of QoL is clearly important because it can be used to help

understand an adolescent's needs and goals, to evaluate interventions, to identify at risk adolescents and enable education and health organisations to plan and monitor programs for adolescents. Our findings suggest that current measures do not adequately capture what is important to adolescents and so new measures with a better conceptual basis should be developed.

The implications of these findings for teachers is that promoting self determination as an educational outcome should be used to empower adolescents with physical disabilities to make choices and to have some degree of control over their lives. Self determination skills such as decision making, problem solving, goal setting and attainment, self management, self advocacy and leadership, can be supported and programs can be introduced that use adult mentors with disabilities to teach self-efficacy, empowerment and psycho-social adjustment (Doll, Sands, Wehmeyer, & Palmer, 1996; Powers et al, 1996). More emphasis should be placed on opportunities made available through technology to increase the successful participation of people with disabilities in challenging academic programs such as those in science, engineering, mathematics, and technology (Washington University, 2002).

There are also implications from these findings for therapists working in education. The findings suggest that the ultimate goal of any therapy program should arguably involve enhancing QoL by promoting a strong sense of self in adolescents and by facilitating participation at school and in the community. Therapists need to really listen to the adolescent and provide them with the opportunity to have choices and the freedom to make them and be supported. In addition, therapists need to facilitate participation in the wider community in preparation for the transition from school. Physiotherapists can encourage adolescents to participate in sports groups and join fitness centers to develop partnerships prior to leaving school. Occupational therapists can work with adolescents in the home and speech language therapists can work with adolescents in the community. To support adolescents, occupational goals should be focused towards occupations that are meaningful (Hocking, 2003). The process of transitioning from school should include exploring purposeful opportunities in the wider community for adolescents with severe physical disabilities, as well as involvement with their own cultural groups.

For services outside of education further work is needed to promote an understanding of disability, particularly among young people. More opportunities should be provided for autonomous decisions and actions by adolescents with physical disabilities and their families. For example caregivers could be employed by the adolescents and their families rather than being employed by an agency. Better coordination of health, education and social services seems needed (or at least desired) for people with disabilities. In addition adolescents wish to experience quality relationships with the people they view as important in their lives, including professionals such as case managers, youth workers and caregivers.

It is interesting that the concepts of having a voice (in the family, at school, and in the community) and having privacy were such strong concepts - if services, education and rehabilitation, do not enable adolescents to have a voice in their community and to have privacy, they are missing something relevant for them.

Currently there are anomalies in the New Zealand system between government policies and the reality experienced by youth with disabilities, as discussed by the participants in this research. The impact that current New Zealand policies have on QoL issues for New Zealand adolescents with physical disabilities will now be briefly discussed with specific reference to the Youth Development Strategy, Aotearoa (2005).

The Youth Development Strategy, Aotearoa (2005), acknowledges that the key to youth development is giving young people an opportunity to exercise control. The New Zealand Disability Strategy (2001) also promotes the principles of autonomy and participation for people with disabilities. Recent years have seen deinstitutionalisation of people with physical and intellectual disabilities into community based houses, inclusion of children with disabilities into their local schools, and the closing of sheltered employment situations. However the New Zealand situation is complicated by discrepancies that hinder autonomy and participation particularly in the process of transition from adolescence to adulthood. One example is that although the New Zealand Disability Strategy acknowledges the principle of autonomy, organisations rather than individuals, are given control of funding for housing and care. The New Zealand Ministry of

Social Development has only six official providers of community programs for people with disabilities and funding for participation in these programs cannot be allocated to the individuals or their families to administer. This prevents an individually tailored mix of community options for people with disability. In addition, people with disability are housed in community houses with other people with disabilities, rather than being facilitated to live in the community with non disabled people.

The Youth Development Strategy, Aotearoa (2005), commented that a number of different and key social environments (family/ whänau, school, training or education, work, peer group and community) provide young people with support, skill development, social connections, socialisation, a sense of purpose and achievement as well as many other factors that promote their development. The New Zealand Accident Compensation Corporation has a system of a case manager for each client – this ensures that all aspects of rehabilitation are coordinated, but also means that over time, the case worker builds an on going relationship with the client. However, currently adolescents with physical disabilities lack a coordinated system for health, education and social needs.

The New Zealand Ministry of Education (NZ MOE) has a policy of integration of adolescents with physical disabilities into their local schools (NZ MOE, 1999). Some schools have centres attached that offer physiotherapy, speech language therapy and occupational therapy as well as extra educational support. A 2007 report on integrated effective practice by the NZ MOE recommended inter-agency and professional collaboration to avoid problems during transition from school. However, adolescents and parents spoke of frustrations encountered in the process of transitioning from school and felt that current structures were limiting adolescents with disabilities from participating with their able bodied peers. In addition, the parents in this study spoke of the marked lack of inter-agency collaboration.

Surprisingly, despite all the functional rehabilitation experienced from birth, the adolescents wanted more training in practical skills to help their QoL. This study showed a conflict between therapists and teachers in achieving a balance between practical skills and academic learning. The transition process for

adolescents who are dependent on others for physical care is challenging, as they need to establish supported but independent lives and need therapist involvement beyond merely supporting the educational process. Specialised therapy is required to facilitate use of computer and networking technologies to increase independence, productivity, and participation in both education and employment:

"Of all the new technologies, on line communications has the strongest potential to break down the barriers and inequities encountered by students of different socioeconomic, racial, linguistic and disability backgrounds." (Washington: CAST, 1995, p23).

In addition some programs aimed at achieving greater participation of people with disabilities in employment and communities, such as Workbridge, will only assist once students have left school. A key finding from the Pacific Disability Research Project (2002) was that in New Zealand there is a vacuum of services for teenagers with disability who leave school and strategic focus is required particularly for Pacific Island youth.

The Ministry of Education's operational protocol for occupational therapists and physiotherapist working with students with physical disabilities is to support students in the context of their learning environment and to assist others to meet the student's individual learning achievements (MOE & HFA, 1999). However, as described by Simmons-Carlsson (2005), therapists working in education are part of an emerging culture and need to develop a unique model of service delivery that is different to the biomedical model and that facilitates the challenging process of transitioning from school.

This study highlights the need for adolescents with physical disabilities, particularly Maori and Pacific adolescents, to inform health, education and social development policy and service development.

5.6. Recommendations for further research

Further research is needed to validate the findings of this study in both qualitative and quantitative settings. It is important to extend and corroborate the findings to contribute to best practice for New Zealand school based education. Further research could be done with ethnic specific groups facilitated by a researcher from the same ethnicity, to understand the implications of the strong identity with culture that the Maori and Pasifika adolescents had. In addition further research could be facilitated by a researcher who was an adolescent with a physical disability.

The adolescents in the study wanted more research done in New Zealand, on ways to facilitate an understanding of disability. Studies are needed on ways to enable the voice of adolescents with physical disabilities to be heard, particularly the adolescents with communication difficulties. More studies are needed on how parents, educators and therapists can best increase self determination skills for adolescents with severe physical disabilities. Research on QoL issues from the perspective of Maori and Pacific teachers and therapists would also add insight to the findings from this study.

There is a need for further research to determine best practice for New Zealand school based therapy. Further study is needed on the move by therapists from a biomedical model focussed on treatment of impairment, to a social model, particularly exploring long term effects. Studies are needed to explore the role therapists could play in facilitating and supporting transition from school to purposeful opportunities. As acknowledged by Simmons-Carlsson (2005), further research is also required related to capturing the students' voice in relation to school therapy services and how they experience the culture. Studies are also needed to examine the interface between the New Zealand Ministries of Education, Health and Social Services in their provision of services to adolescents with physical disabilities.

The findings from this study can be used to contribute towards developing a conceptual framework for QoL for adolescents with physical disabilities. This framework could then be used to develop measures which can then be validated in this population.

5.7. On reflection

As a physiotherapist, I found the role of researcher very different to the role of a clinician. In using focus groups, the participants were the experts – in contrast to a physiotherapist's traditional role as an expert in rehabilitation. At times I found the process of research overwhelming – particularly in view of the size of the topic. However doing qualitative research about QoL issues has helped me to focus more on the things that are important to the people I work with and has broadened my perspective as well as providing the participants with an opportunity for reflection on the topic of QoL. Subsequent to the focus groups I was asked to share research articles and speak to staff at a school that had decided to make the research topic their focus for staff in-service for the year. In addition, one participant emailed further information that they thought would be relevant to the research. This highlights an enthusiasm and interest for the topic which leaves me with no doubt as to its importance to the participants and my colleagues. As a practitioner, understanding what is important for adolescents with physical disabilities has influenced me to move beyond the biomedical model of treatment to a social model, aiming more towards facilitating participation for adolescents at school, at home and in the wider community. I have enjoyed involving young people in choice and decision making regarding lifelong heath options.

At present, in specialised education centres in New Zealand, there is considerable debate about the ethics of providing supported eating services to students with dysphagia. Some speech language therapists feel that they would be professionally incompetent and legally liable if they knowingly fed a student with dysphagia. However, adolescents with dysphagia feel they have the right to choose to be assisted to be fed rather than having compulsory tube feeding. One surprise in my research was that there was no mention of these issues in the focus group discussions (although before the start of one focus group, a mother said she would not be discussing it as it was too painful for her). However, on reflection, I realised that this debate is really about choice – the right of the adolescents to choose to be fed rather than intubated (despite the possibility of choking or developing aspiration pneumonia) and to be supported in that choice. This highlights the strength of qualitative research – often what we think is important to people and what actually is important to

people are two different things. Had I used a quantitative approach I may have simply have had answers to things that I expected rather than a more comprehensive understanding of what is important.

5. 8. Conclusion

This study contributes to the body of knowledge regarding what New Zealand adolescents with physical disabilities consider to be important in terms of QoL. and identifies areas not addressed in current adolescent measures of QoL. The implications of this study can be summarised as the need for parents, educators, therapists and policy makers to work in partnership with adolescents to hear their voice and acknowledge their concerns. In conclusion, this quote succinctly summarises the relevance of this research:

"Qualitative modes of inquiry can offer an adolescent - centred view into this complex world. This view may allow us to better work with youth - to draw on their strengths, build on their idealism, and guide them toward safer behaviours. Our vision of the direction for adolescent health is likely to be clearest when adolescents serve as our guides, for they best understand the prose and the poetry of their lives." (Rich & Ginsberg, 1999, p3).

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Appendix A: Northern X Regional Ethics Committee Approval

Health and Disability Ethics Committees

Northern X Regional Ethics Committee
Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Private Bag 92 522
Wellesley Street, Auckland
Phone (09) 580 9105
Fax (09) 580 9001

Email: pat_chainey@moh.govt.nz

21 June 2007

Ms Margot Andrew
Auckland University of Technology
60 Ranfurly Rd
Epsom
Auckland

Dear Margot

NTX/07/05/043 **The most important aspects of quality of life for adolescents with physical disabilities and their families: PIS/Cons V#3, 8/06/07**
Principal Investigator: Ms Margot Andrew, Auckland University of Technology

Thank you for your letter received 13 June 2007enclosing the required changes.

The above study has been given ethical approval by the **Northern X Regional** Ethics Committee. A list of members of this committee is attached.

Approved Documents

- Participant Information Sheet/Consent Form V#3, dated 8 June 2007.
- Information Sheet/Consent Form for Teenagers V#3, dated 8 June 2007-06-21 Core Socio-demographic Information – Teachers/therapists V#2 dated 23 May 2007

Certification
The Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report
The study is approved until 31 January 2008. A final report is required at the end of the study. The report form is available on http://www.newhealth.govt.nz/ethicscommittees (Information for Researchers - Progres Reports) and should be forwarded along with a summary of the results. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Requirements for SAE Reporting
The Principal Investigator will inform the Committee as soon as possible of the following:

- Any serious adverse events occurring during the study worldwide which are considered related to the study.

All SAE reports must be signed by the Principal Investigator and include a comment on whether he/she considers there are any ethical issues relating to this study continuing due to this adverse event.

Amendments
All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Pat Chainey
Administrator
Northern X Regional Ethics Committee

Cc: Mr Charles Grinter, Ethics Co-ordinator, AUT

Appendix B: Mt Roskill Kaumatua consultation

Re: MARGOT ANDREW and her proposed MHSC dissertation: The most important aspects of quality of life for New Zealand adolescents with physical disabilities.

I sat in consultation with Darren Nathan HOD Maori Dept at Mt Roskill Grammar School November 2006 and with Whaea Ely his other class room teacher to make sure the Kaupapa of the thesis respected the rights and traditions of the local iwi. After the thesis was drafted the Tangata whenua was advised of appropriate information that came out of the study and private requests were respected. The Kaumatua were consulted and their input considered during the stages of the draft so that talking to the local tribal members within this area and other tribal members could be sanctioned. We all believed that in the scheme of things that by using our indigenous comments it would enhance and enrich the thesis. We know now that it is a great project and that this study will benefit our people and other cultural groups as well as Margot Andrew.

T White

Tuihana White
22 Nov 2006
Ngati Kahungunu
Ngati Harakeke

Appendix C: Orakei Marae Consultation.

Orakei Marae Consultation
Representative: Te Puna Tamahai
Wednesday 12th July

Project Title: Quality of Life (QoL) in Disability – contributing towards a measure of quality of life (QoL) that includes factors people with disabilities consider important

Notes from Meeting:

General Feedback

Understand the difficulties of measuring outcomes and feel that measuring quality of life may actually be easier to measure in Maori – matching the principles with the outcome.

Therefore this opportunity is particularly important to help ~~help~~ health professionals learn what principles actually matter most to Maori.

Focus Group ideas?

Instinct says that group would be better, but might be important for individuals to have the option to contribute individually as well. Include this option in consent.

Older and Younger together?

Sometimes the young will hold
They seek guidance from the

(Videt Wolfe)

Consultant Name: TEPUNA TUMAHAI	**Signature:**
Position: REPRESENTATIVE ORAKEI MARAE – NGATI WHATUA.	**Date:** 12/07/06.

Consultant Name: DELWYN TUMAHAI	**Signature:**
Position: ORAKEI MARAE CO-ORDINATOR, SOCIAL SERVICES	**Date:** 12/07/06.

Appendix D: Information pack for adolescents
(Information sheet & consent form)

Information Sheet

Quality of Life for Adolescents with Disabilities
What matters most?

You are invited to take part in a research project to find out what matters most to teenagers with a disability. To help you decide whether to take part, it is important you know why the research is being done and what taking part will mean for you. We hope this sheet answers some of the questions you may have. Please read the information carefully, or ask someone to read it with you if you wish. Please ask us if something doesn't make sense, or if you would like more information.

What is the project about?

We want to find out what matters most to teenagers with a disability. We especially want to know what things are important for enjoyment of life. We also want to find out what relatives, carers, teachers and therapists think is important to help teenagers with disability have a good quality of life.

Why is this research important?

This information may help to improve the quality of life of teenagers with disability in the future. Your views will help the researchers to develop a better understanding of how to measure quality of life.

Who will be involved in the study?

Three different groups of people are invited to take part: first teenagers experiencing disability and second relatives and carers and third teachers and therapists.

Do I have to take part? What will happen if I agree to take part?

You do not have to take part. Only take part if you want to tell us the things that you think are important. If you decide not to take part that is absolutely fine. If you change your mind at any time – that is also fine. If you do take part, you will join in a small group discussion with other people with a disability and two members of our research team.

This group interview will take about 1½ - 2 hours (with a refreshment break). We would like you to let us tape the interview so we remember what is said. Only the researchers will hear or read what is said. If you do decide to take part, we will ask you to keep this form and sign a consent form.

Why should I take part? What are the possible benefits of taking part?

We hope that our study will help us learn how to improve the services for a better quality of life for teenagers experiencing disability.

What happens to the information the researchers will collect?

All information collected and your contribution to the group discussion will be confidential. That means no information about you that could be linked to you will be written in the report of the study. Researchers will explain to all participants that what each person says should not be talked about outside the group, but this cannot be guaranteed.

Will anyone be told that I am taking part in the study?

You don't have to tell anyone you are taking part in the study. However, you may choose to tell carers/support workers or someone like your doctor if they are helping you with things at the moment. The researcher will not tell anyone you are taking part without asking your permission.

Who is organising the study?

Researchers at AUT University in Auckland are leading the study. Margot Andrew is completing the study as her Masters of Health Science Dissertation.

Who has reviewed the study?

This study has received ethical approval from the Northern X Regional Ethics Committee.

What will happen to the results of the study?

The results of the study will be included in a Masters of Health Science dissertation. We also would aim to publish results for other health and social professionals to read. You will not be identified in any way in any written or verbal report of the study.

Compensation

In the unlikely event of a physical injury as a result of your participation in this study in this study you may be covered by ACC under the Injury Prevention Rehabilitation and Compensation Act. ACC cover is not automatic case will need to be assessed by ACC according to the provisions of the 2002 Injury, Prevention, Rehabilitation and Compensation Act. If your claim is accepted by ACC you still may not get any compensation. This depends on a number of factors such as whether you are an earner or non earner. AA usually provides only partial reimbursement of any costs and expenses and there may be no lump sum compensation available. There is no cover for mental injury unless it is associated with physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office or the investigator.

How can I find out more about the study?

If you would like more information about the project, or if would like to talk a bit more about what you will be asked to do if you agree to take part, please contact:

Local Principal Investigator: Margot Andrew 09 6210050 (Physiotherapist)
Nicola Kayes 09-921 9999 ext 7309
Research Officer
Kathryn McPherson 09-921 9999 ext 7110
Professor of Rehabilitation
AUT University

If you have any queries or concerns regarding your rights as a participant in this research Study, you can contact am independent Health & Disability Advocate. This is a free service provided under the Health & Disability Commissioner Act.

Telephone (NZ wide):	0800 555 050
Free Fax:	0800 2787 7678 (0800 2 SUPPORT)
Email:	advocacy@hdc.org.nz

THANK YOU FOR READING THIS
WE HOPE YOU WILLTAKE PART IN OUR STUDY

V#3 8/6/07

CONSENT TO PARTICIPATE IN RESEARCH

Project Title:	The most important aspects of Quality of Life for adolescents with physical disabilities
Principal Researcher:	Margot Andrew
Address:	60 Ranfurly Rd Epsom Auckland
Telephone Number:	09 6233117

I have read and understood the information provided about this research project (Information Sheet dated 08 June 2007).

I have had an opportunity to ask questions and to have them answered.

- I understand that the focus groups (or interview) will be audio-taped or video-taped and summarised for discussion by the research team here in New Zealand.
- I understand that the summary of the group discussions will also be included in a Masters of Health Science Dissertation.
- I understand that the summaries may be used for a final report that is given to some government bodies here in New Zealand and overseas.
- Researchers will make every effort to help all participants understand that what each member of the group says should stay confidential but this cannot be guaranteed.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that my contribution to the focus group, interview or data notes will be deleted.
- I agree to take part in this research.

Please tick	Yes	No	
I wish to receive a summary of the findings of the research.			
I would like to have a family/whanau member or carer to help me take part			
I wish to take part but would like an interpreter			*If yes, what language?*

Participant signature: .....……..

Participant name: …….

Participant Contact Details (if appropriate):

……
……
……
……

Witness signature and name (if appropriate):

……

Date:

V#3 8/6/07

Appendix E: Information pack for adult participants
(Information sheet only - Consent form as in Appendix D).

Quality of Life for Adolescents with Disabilities
What matters most?

Information Sheet

Kia ora, talofa and hello. You are being invited to take part in this research project. This information sheet sets out answers to some questions you may have about the study. Please read the information carefully, or ask someone to read it with you if you wish. Please ask us if there is anything that is not clear, or you would like more information.

What is the project aboout? Why is this research important?

The project aims to contribute to knowledge about what teenagers with physical disabilities, their families and the professinals involved in their daily lives perceive to be the important aspects of quality of life for young people with disabilities. Information will be collected about the health, wellbeing and concerns of teenagers with physical disabilities through group interviews (small group discussions. It will also look at the views of relatives and carers and of professionals working with the teenagers. We hope to learn more about the factors that contribute to a high quality of life.

By taking part in the study you will provide valuable information about the experiences, preferences and needs of teenagers with disabilities. This may help to improve the lives of teenagers with disabilities in the future. Your views will help the researchers to develop a better understanding of how to measure quality of life.

Who will be involved in the study?

The separate group discussions will involve teenagers experiencing disability; their relatives and carers; and therapists and teachers working with teenagers experiencing disability. There is an exclusion criteria for people with serious physical or mental illness.

Do I have to take part? What will happen if I agree to take part?

It is up to you to decide whether to take part or not. If you decide to take part, you are still free to withdraw at any time, without giving a reason. If you decide not to take part, or withdraw from the study at any time, this will not have any negative consequences for you, and you do not have to give a reason. Once you have been part of the discussion though, you cannot withdraw your

information. If you agree to take part, you will take part in a single group interview (small group discussion) with a member of the research team.

This group interview will take about 1½ - 2 hours (with a refreshment break). There will be a general discussion about issues that affect quality of life. The group will have around 4 – 6 participants and two interviewers. We would like your permission for the group interviews to be audio taped: this will help us to analyse all the information discussed. The transcripts of the tapes will be used by the researchers only. If you do decide to take part, you should keep this information sheet and you will be asked to sign a consent form.

Why should I take part? What are the benefits of taking part?

Your views and experiences will help us to learn more about how to improve the quality of life of teenagers with physical disabilities. We hope the results of the study will improve social policy and mprove care and support of teenagers with disability.

When will the study take place?

The project will be carried out over a four month period between May 2007 and August 2007. A researcher will contact you about the date, time and place of the group interview you will attend.

What happens to the information the researchers will collect?

All information collected about you during the study, and your contribution to the group discussion, will be confidential to the project researchers and you will not be identified in any way in the written report of the study. Researchers will make every effort to help all participants understand that what each member of the group says should stay confidential, but this cannot be guaranteed.

Will anyone be told that I am taking part in the study?

In most cases there is no need for anyone to be told you are taking part in the study. However you may choose to tell carers/ support workers or someone like your doctor if they are helping you to take part in the study. The researcher will not tell anyone you are taking part without asking your permission.

Who is organising the study? Who is funding the research?

Researchers at Auckland University of Technology are leading the study. Margot Andrew is completing the study as her Masters of Health Science dissertation.

Who has reviewed the study?

This study has received ethical approval from the Northern X Regional Ethics Committee.

What will happen to the results of the study?

The results of the study will be included in a Masters of Health Science dissertation. The results will be published in professional journals also, and will be disseminated at appropriate conferences for policy makers, professionals and service users. However it is important to stress that you will not be identified in any way in any written or verbal report of the study.

Compensation

In the unlikely event of a physical injury as a result of your participation in this study in this study you may be covered by ACC under the Injury Prevention Rehabilitation and Compensation Act. ACC cover is not automatic. Cases will need to be assessed by ACC according to the provisions of the 2002 Injury, Prevention, Rehabilitation and Compensation Act. If your claim is accepted by ACC you still may not get any compensation. This depends on a number of factors such as whether you are an earner or non earner. ACC usually provides only partial reimbursement of any costs and expenses and there may be no lump sum compensation available. There is no cover for mental injury unless it is associated with physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office or the investigator.

How can I find out more about the study?

If you would like more information about the project, or if would like to talk a bit more about what you will be asked to do if you agree to take part, please contact:

Local Principal Investigator: Margot Andrew 09 6210050 (Physiotherapist)
Nicola Kayes 09-921 9999 ext 7309
Research Officer
Kathryn McPherson 09-921 9999 ext 7110
Professor of Rehabilitation
AUT University

If you have any queries or concerns regarding your rights as a participant in this research Study, you can contact am independent Health & Disability Advocate. This is a free service provided under the Health & Disability Commissioner Act.

Telephone (NZ wide):	0800 555 050
Free Fax:	0800 2787 7678 (0800 2 SUPPORT)
Email:	advocacy@hdc.org.nz

THANK YOU FOR READING THIS.
WE HOPE YOU WILLTAKE PART IN OUR STUDY.

V#3 8/6/07

Appendix F: Focus Group Outline

Part 1

Section 1: Introduction

At the start of each group, participants should be welcomed and the moderator should make a brief opening statement providing an introduction to the study, outlining the rationale for the focus groups and describing the methodology, setting the scene for the discussion topics, and identifying the aims and objectives of the group. Particular emphasis should be placed on the aspiration to obtain a wide range of perspectives on the dimensions that might be important in assessing the quality of life of adolescents with physical disabilities. It should be stressed that will be no 'right' or 'wrong' suggestions in this regard; that the task is to generate as many contributions as possible, all of which will be valued; and that the aim is to hear from everyone, in terms of both ideas and 'stories' which might exemplify various issues. However, participants should be encouraged to remain focussed on the generality of the target issues and to avoid over reference to specific individuals with disabilities who may be known to them.

As the discussions will be audio taped, participants should be requested to follow basic 'ground rules' for taped discussion (e.g. contributing one at a time, avoiding multiple conversations etc).

The participants in each group may or may not know one-another. Therefore the moderator should prompt an opening round of self-introductions, which will have the additional function of 'breaking the ice' by getting each participant to speak early in the procedure. Each participant should be invited to say a few brief words about themselves (e.g. their name, where they live, their occupation or daytime activity etc). This exchange will help to highlight the commonalities of participants that underpinned their selection for the group, and which forms the basis for the information sharing and exchange of ideas that will follow in the discussion.

Section 2: Quality of Life

Participants should be asked to reflect on their past experience of the topic of the *quality of life* of adolescents with physical disabilities, to consider the question of what contributes most to the quality of life of such individuals (within the educational context as well as within a health context), and to make a similar list of some of the key themes that come to mind. Group members should be requested to complete this task on an individual basis initially, and advised that more general discussion of the themes generated will follow. A few minutes should be given for the task and participants requested to record up to 10 (or more if desired) quality of life themes in section A of the prepared form (Appendix G).

This task is designed as a starter question and an orientation exercise: to raise participants' awareness of their own views on the topic (discouraging 'group think') and engage their individual commitment; and to provide a preparation for each person's first

individual contribution to the group discussion. *Moderators should be sensitive to the needs of some participants for assistance in relation to writing their lists in this task.*

Participants should then be invited to share their key themes one or two at a time, going round the group until all the lists are exhausted. The extent of consensus and/or diversity should be noted and discussed, and an opportunity for the generation of additional themes should be provided, as participants own views resonate with that of other group members to produce new insights.

Finally, participants should be asked to give their views of the contribution of different living conditions to overall quality of life; and invited to share examples from their own, or other people's, living situations (within the context of the confidentiality of the group). This section may be of particular importance (and also sensitivity) to the groups of adolescents with disabilities. Care should be taken to ensure that participants do not feel any need, or obligation, to disclose overly personal details, or to share any aspect of their own situation that they would prefer to keep private.

As the discussion of the task progresses, the moderator should note how the emerging quality of life themes link with the *WHOQOL* facets, in order that some of the related quality of life facets not yet mentioned can be introduced later in the flow of discussion.

Once again, stimulus questions can be asked by moderators to prompt the task and the subsequent free form discussion, for example:

- What do you understand by the term quality of life?
- What do you like about your life? What makes you happy?
- What is your living situation? What do you like / dislike about it?
- How do you think your life compare with that of others / adolescents with physical disabilities?
- How could your quality of life / that of adolescents with physical disabilities be improved?
- What would make your quality of life / that of adolescents with physical disabilities worse?

Break:

Refreshments should be offered. Some participants may be content to remain in the room; others may wish to have a breath of fresh air. Moderators should make clear that the break is short (essentially a comfort and refreshment break) and indicate when participants should return to the group.

Part 2

Participants should be reminded about the purpose of the focus groups and be provided with a brief introduction to the purpose of Part 2. A brief recap of some of the themes mentioned in earlier discussions may be helpful also.

Section 3: Review of Themes / Facets

Firstly, participants should be requested to review the list of quality of life themes drawn up individually during the introductory tasks in section 2 and invited to make additions to their lists (if desired) in the light of the focus group discussion, noting these in section B of the record form (Appendix G).. This will provide participants with the opportunity to review their spontaneously generated themes previously noted in section A, of the record form, together with any themes prompted by the group discussion which has particular resonance for them, in undertaking the closure task.

Subsequently, each person should be requested to consider their personal opinion of which themes ranked as the top three facets of quality of life for adolescents with physical disabilities, bearing in mind all the issues discussed, and add these to section C of the record form. This task is designed as a closure exercise: to enable participants to reflect back on the themes mentioned in the focus group discussion; to stimulate consideration of both their own contributions and those of other group members; and to encourage each person to make an individual determination about the relative importance of some of the key themes, in terms of a final statement. Then participants should be invited to share their top three themes with the group and once again the extent of consensus and/or diversity may be discussed.

Section 4: Summary of Discussion Points and Close

Participants should be provided with a final opportunity to contribute any additional thoughts on the discussion topics, and a final request may be made to consider if anything has been missed. The moderator should offer a brief summary of the key points that had emerged from the focus group tasks and discussion and check both the clarity and adequacy of this overview with the group.

Finally, participants should be thanked for taking part in the focus group discussion and for making so many useful contributions. (A few days after each focus group, a short letter of thanks should be sent to each participant also).

Appendix G: Quality of Life Themes Form

Quality of Life for Adolescents with Physical Disabilities.
What matters most?

Section A

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.

Section B: Additions to the above list

Section C: Top 3 facets

1.
2.
3.

V#2 16/4/07

Appendix H: Core Socio-demographic forms

Quality of Life for Adolescents with Physical Disabilities
What matters most?

CORE SOCIO-DEMOGRAPHIC INFORMATION: Teenagers

Centre: Maclean Centre Focus Group Number…… Date:

ABOUT YOU: *Please write in space OR put* [X] *a cross like this in the box as appropriate.*

Gender Male [ ] Female [ ]

Age (in years) [ ] **Date of Birth** [ ][ ][ ]
(dd / mm / yy)

Ethnicity Primary [ ] Secondary [ ]

Home location: (city / locality):
……/……
……

Education:
What is your highest level of educational achievement?

None at all [ ]
Special school [ ]
Primary school [ ]
Secondary [ ]
Tertiary (college/university) [ ]
Other (*please tell us*
……

Health status: *Are you currently ill or in poor health?* Yes [ ] No [ ]

If something is wrong with your health, what do you think it is?
……

……
……..……. illness / problem

How does this illness/problem affect your everyday life?
…….

……
…….

Disability status: *Do you have a disability/impairment?* Yes ☐ No ☐ *If yes*, for long have you had a disability/impairment? (*years*)

If you have a disability/impairment, how would you describe it?
.....

……
…….

What word (terminology) do you prefer to be used for this disability?
…….

How does your disability/impairment affect your everyday life?
.....

……..……
……

How would you classify your disability/impairment? Mild ☐ Moderate ☐ Severe ☐ Profound ☐

Please explain why you say this……
…….

Formal diagnosis / specific disability classification (*from clinician if available*)
……
……
……

Medicines: *Do you need regular medication or medical treatment?* Yes ☐ No ☐

If yes, what medication / medical treatment do you need?

V#1 23.05.07

Quality of Life for Adolescents with Physical Disabilities: What matters most?

CORE SOCIO-DEMOGRAPHIC INFORMATION – Parents/ carers

Centre: Maclean Centre Focus Group Number…… Date: ……/…..../……

ABOUT YOU: *Please write in space OR put* X *a cross like this in the box as appropriate*

Gender Male ☐ Female ☐

Age (in years) ☐ **Date of Birth** ☐☐☐

Ethnicity Primary ☐ Secondary ☐

Marital status Single ☐ Living with Partner ☐ Widowed ☐ Separated ☐ Divorced ☐

No. of children ☐ **No. of grandchildren** ☐

Education:
What is your highest level of educational achievement?

None at all ☐ Secondary school ☐
Special school ☐ Tertiary (college/university) ☐
Primary school ☐ Other (*please tell us what*) ☐

Occupation:
*What is your **main** occupation / daytime activity?*

Paid employment* ☐
Voluntary employment* (unpaid) ☐
Full-time education / further education ☐
Community-based activities ☐
Day centre / Day hospital ☐
Therapies programme (e.g. art, music, physiotherapy, occupational therapy) ☐
Home-based (e.g. homemaker) ☐
Retired ☐
None ☐
Other (*please tell us what)* ☐
……

*If you work, what is your occupation?……

V#1 23.05.07

Quality of Life for Adolescents with Physical Disabilities
What matters most?

CORE SOCIO-DEMOGRAPHIC INFORMATION – Teachers/ Therapists

Centre: Maclean Centre Focus Group Number Date:

ABOUT YOU: *Please write in space OR put* [X] *a cross like this in the box as appropriate.*

Gender Male [ ] Female [ ]

Age (in years) [ ] **Date of Birth** [ ][ ][ ]

Ethnicity Primary [ ] Secondary [ ]

Marital status Single [ ] Widowed [ ] Living with Partner [ ]
Separated [ ] Divorced [ ]

No. of children [ ]

Home location: (city / locality): ……

Education:
What is your highest level of educational qualification?

Occupation:
What is your occupation?

Teaching [ ]
Occupational therapy [ ]
Physiotherapy [ ]
Speech Language Therapy [ ]

Are you currently involved in further education? If so what? [ ]

V# 1 2 3/05/07