The development of a new instrument to measure Participation of adolescents with cerebral palsy

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Abstract

The World Health Organisation published the International Classification of Functioning, Disability and Health in 2001. It defines Participation as ‘involvement in life situations’. Instruments to measure Participation have been developed for children and adults, but none specifically for adolescents. Adolescence is a life stage with distinct patterns of Participation, and previous research has demonstrated that adolescents with disabilities have poorer Participation than the non-disabled population. Cerebral palsy (CP) is a significant cause of disability in adolescents, with affected individuals experiencing a range of different impairments of varying severity. CP was chosen as the exemplar condition for this study.

The aim of this study was to develop a measure of Participation for adolescents with CP. Semi-structured interviews with 17 adolescents, 12 with CP and 5 without disability, were used to elicit views of Participation to inform item generation. Focus groups with 8 of the adolescents allowed respondent validation and feedback on possible questionnaire items. The pool of 88 proposed items was revised following review by 17 experts, resulting in 92 items with a content validity index of 93%. Cognitive interviews were carried out with adolescents and carers. Field-testing with 107 young people with CP was used to examine reliability, construct validity and to enable item reduction. For 38 of these adolescents, a proxy report was obtained because the young person did not have sufficient cognitive ability to self-report.

Known-groups validity was demonstrated using correlation with impairment severity. Test-retest reliability was satisfactory for all domains, whilst internal consistency varied between domains. The instrument was shortened to 45 items.

This is the first instrument developed to measure Participation for adolescents with disability. Use of the instrument in research and clinical work will enable its properties to be better understood in different settings.

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Chapter 1. Introduction

1.1 Rationale for the study

“Participation” was introduced as a concept by the World Health Organisation in 2001, when it published the International Classification of Functioning, Disability and Health. It was defined as “involvement in life situations”. Since then, a number of measures have been developed that aim to measure Participation. Some have been designed for children and some for adults, but to date, none have been designed specifically for adolescents.

Adolescence is a distinct life stage between childhood and adulthood. It is time of specific developments in different areas of an individual’s physical, psychological and social functioning, but also has cultural significance. Young people with disabilities, exemplified by cerebral palsy, face challenges in their development and in their Participation in adolescent life and culture. Some of these challenges continue into adulthood.

It is increasingly appreciated that people with a variety of health problems are not simply interested in their symptoms and clinical functioning, but in the broader aspects of what they can do (Participation) and how they feel about their lives (Quality of Life). When choosing outcome measures, in both clinical and research situations, it is therefore important that we have methods of quantifying these concepts.

This study set out to develop an instrument to measure Participation in adolescents with disability, as such a measure does not currently exist and is needed in order to measure meaningful outcomes in this population.

Cerebral palsy (CP) is an umbrella term for a motor disorder caused by a non-progressive insult to the developing brain. Those with a diagnosis of cerebral palsy have a wide range of impairments, with a wide spectrum of severity. CP was therefore chosen as an exemplar condition for the purposes of this study.

1.2 Aims and Objectives

The aims of the study were:

- To obtain the views of adolescents with and without cerebral palsy about their involvement in life situations to inform the development of an instrument to measure Participation in adolescents with cerebral palsy
- To develop a draft instrument for which data could be obtained regarding its psychometric properties

The objectives of this study were:

- To carry out semi-structured interviews with a number of disabled and non-disabled young people to determine what they regard as the key elements of Participation
- To hold focus groups with young people who were interviewed for respondent validation and to provide feedback on comprehension and clarity of possible questionnaire items
- To combine these findings with a review of the literature on adolescent development and existing Participation instruments for other age groups to create an item pool
- To perform content validation of the item pool by asking a group of experts to complete a content review questionnaire by post
- To conduct cognitive interviews with adolescents and parents or carers to identify any areas of ambiguity or other difficulties in administration
- To establish reliability, including test-retest reliability, and construct validity; the latter by simultaneous administration of instruments measuring impairment
- To refine the instrument so that it has robust psychometric properties and is of an appropriate length

1.3 Structure of the research process and of the thesis

This research encompassed a number of discrete parts which were performed sequentially, but which together contributed to the development of an instrument. In order to present this in a logical manner, the thesis has been structured as set out overleaf in figure 1.1.

Chapters 2–6 provide the background and review of the literature on adolescence, cerebral palsy and the concept and measurement of Participation. Chapter 7 discusses the methodological underpinnings of the different parts of the study. Chapters 8–10 cover the methods, results and discussion of each individual part of the research. The overall discussion and conclusions are presented in Chapter 11.

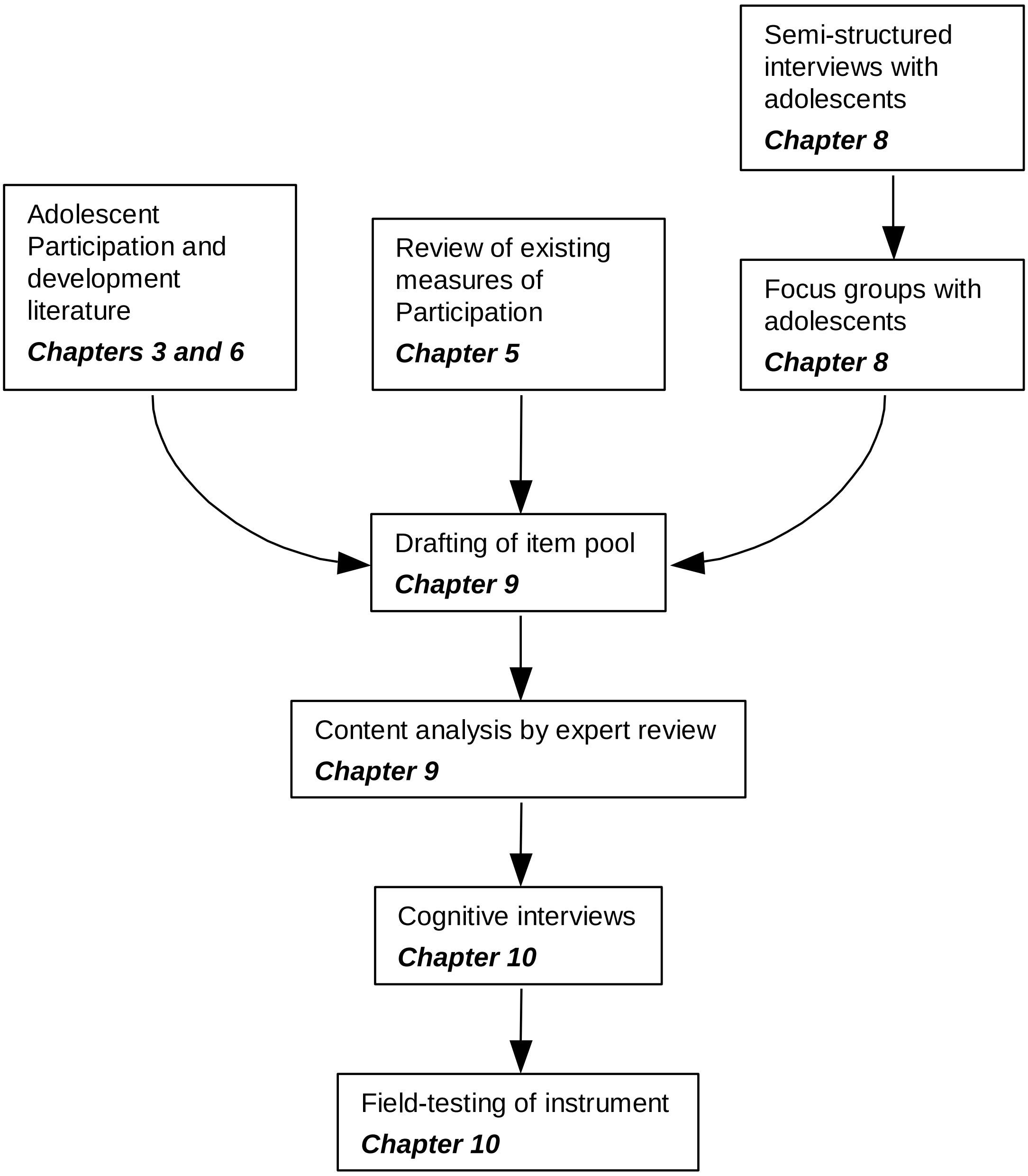

Figure 1.1 Overview of Research Process

Chapter 2. Cerebral Palsy

The aim of this research was to develop an instrument for use with adolescents with disabilities. In order to ensure that an instrument measures what is intended, it is important to involve people in the development who are similar to the intended respondents. Therefore in designing this research project, a choice had to be made about which group of young people with a disabling condition should be chosen to inform the instrument development. Cerebral palsy (CP) was chosen as an exemplar condition for several reasons. Firstly it is the commonest cause of significant motor impairment in childhood (Rosenbaum, 2003), and has a wide range of severity and associated impairments. Secondly, although children with the severest impairments do have a reduced life expectancy, most children with CP will live through adolescence and into adulthood (Hemming et al., 2006; Hutton and Pharoah, 2002; Strauss and Shavelle, 1998). Thirdly, a local population-based database – the North of England Collaborative Cerebral Palsy Survey (NECCPS) – provided a convenient source for recruitment.

In this chapter, I provide a brief overview of cerebral palsy. I outline the relevant epidemiology, and describe the impairments and health problems associated with CP. These are important to consider when investigating the Participation of people with CP, since impairments are known to affect Participation. An understanding of the effects of CP was also necessary when deciding which information should be collected during the field testing stage of the instrument development to further assess validity (see Chapter 7 for further details on the process of instrument validation). An additional consideration when planning the research was the particular challenges inherent in carrying out research with this specific population and so an understanding of CP and its effects on the adolescent were also important for this reason.

It is important that outcome measures for adolescents are self-reported where possible as the views of the individual are likely to be the most valid. For some this may not be possible because of intellectual impairment. In addition, self-reporting may be affected by psychological and emotional difficulties, as these may impinge on the way a person perceives themselves, as well as interprets questions asked of them. These impairments may also affect the engagement of individuals in the research process itself. I have therefore also reviewed the literature on cognitive and psychological problems arising in this population.

2.1. Definition

Cerebral Palsy is an umbrella term for a heterogeneous group of disorders. It is a clinical diagnosis, and there is no universal agreement on an exact definition, although there is broad agreement on what the term encompasses. Recently, a proposed definition was published following an International Workshop on the Definition and Classification of Cerebral Palsy (Bax et al., 2005):

> *"Cerebral palsy describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder."*

This definition has its critics (Badawi et al., 2006; Graham, 2006; Carr et al., 2005). Problems noted include the omission of some associated impairments; that activity limitation is socially, not biologically, determined; that some of the terms used lack clarity; and that a time limit, before which the insult to the brain needs to have occurred, has been omitted. However, judging by the number of papers citing this definition, it appears to have gained widespread acceptance.

Whilst concurring with the criticism over the inclusion of "activity limitation" and the appreciation of the need to set an upper age limit for the timing of the insult when defining a research population, I feel that it provides a reasonable descriptive definition.

2.2 Classification

A number of patterns of CP exist, depending on the part of the brain affected and degree of involvement. There is a spectrum of severity from mild unilateral involvement with minimal functional impairment to those with total body involvement. Terminology has been confusing (Colver and Sethumadhavan, 2003) but there is now a simple, consistent classification developed by a European Collaboration (SCPE, 2002).

The classification depends on whether one or both sides of the body are affected and whether the primary problem is one of spasticity (persisting velocity-dependent high muscle tone and hyperreflexia), dyskinesia (varying tone with abnormal involuntary movements) or ataxia (impaired balance). The dyskinetic group includes those with involuntary writhing movements and often decreased tone (choreo-athetosis) or slower, stiff movements with a tendency to increased tone (dystonia) (SCPE, 2002). The importance of delineating the type and pattern is in identifying possible aetiologies and therapeutic options and in providing prognostic information to families. Participation may also differ depending on CP type (Fauconnier et al., 2009).

Type of CP	**Unilateral spastic**	**Bilateral spastic**	**Dyskinetic**	**Ataxic**	**Unclassifiable**
Proportion %	30	50	7	6	7

Table 2.1 Proportion of types of CP as published by SCPE, 2002

A European study showed the proportion of the different types of CP to be as shown in table 2.1 (SCPE, 2002). Studies from other parts of the developed world show similar proportions (Cans et al., 2008).

An understanding of classification is necessary to interpret the results of studies involving people with CP and was used when selecting the sample used in the qualitative part of this project.

2.3 Epidemiology

The epidemiology of CP is important for this project in order to appreciate the importance of CP as a health problem and in determining how study samples compare to the wider CP population.

There is an increased risk to boys, with a male to female ratio of around 1.4:1 (Odding et al., 2006). This may be due to the greater biological vulnerability of the male brain to injury, particularly preterm (Johnston and Hagberg, 2007). The prevalence of CP also shows a social class gradient with UK prevalence of 3.33 per 1000 births in the most deprived quintile compared to 2.08 per 1000 in the least deprived (Dolk et al., 2001)

The epidemiology of CP has changed over the last few decades. The birth prevalence of CP in the UK is around 2–3/1000 (Pharoah et al., 1996). Although there have been changes over this period in certain groups, for example those of low birth weight (Dolk et al., 2006; Pharoah et al., 1996), the prevalence overall remains fairly static. Some severely affected children with CP die during early childhood but the majority now live to adulthood and the milder affected have a normal life expectancy (Hemming et al., 2006; Hutton and Pharoah, 2002; Strauss and Shavelle, 1998). This is likely to be as a result of improvements in a number of aspects of care in childhood and technological advances such as gastrostomy tubes (Strauss et al., 2007). Mortality in later adulthood is slightly higher than in the general population, with an excess of deaths related to respiratory, cardiovascular, oncological and neurological causes (Hemming et al., 2006). Mortality due to accidents is lower than in the general adult population (Hemming et al., 2006), a finding which may reflect lower levels of Participation in some life areas. In general then, concern about reduced life expectancy should not be an issue for most young people with CP. Looking forward to, and planning for future adulthood, is as important as for the general population, and with incidence rates unlikely to change significantly in the foreseeable future, cerebral palsy will continue to be a significant cause of motor impairment in adolescents.

2.4 Defining severity of cerebral palsy

As part of the assessment of the psychometric properties of the new instrument, I examined construct validity (see Chapter 7 for details) which reflects the degree to which the instrument is measuring what is intended. This entailed examining the relationship between Participation scores on the new measure and levels of impairment and for this it was necessary to categorise impairment severity.

A number of different methods have been used for this, depending on the purpose of the research. When looking at life expectancy, Strauss and colleagues (Strauss et al., 2007) defined the severe group as those with a motor impairment such that they were unable to stand or move themselves without support and were fed entirely by others. The rest were defined as "non-severe". The Surveillance in Cerebral Palsy in Europe (SCPE) group uses three levels of severity. Severe is defined as "unable to walk even with assistive devices AND with IQ<50", moderate as "able to walk without or with assistive devices and IQ<50 OR children unable to walk without assistive devices and IQ≥50" and mild as "able to walk without assistive devices and IQ≥50" (personal communication A Colver). The severe and moderate categories have been combined by some authors (Jarvis et al., 2005) to give two categories – "mild" and "more severe".

For my study, I chose to use the SCPE classification because when looking at Participation, it is important to consider the effects of both cognitive and motor impairment as possible barriers. I also measured the presence and severity of associated impairments in order to better describe the study population.

2.5 Measuring impairment

Tools have been developed to categorise both gross and fine motor function for children with CP. The Gross Motor Function Classification System (GMFCS) (Palisano et al., 2007; Palisano et al., 1997), designed by Palisano and colleagues in Canada, is widely used (Morris and Bartlett, 2004). It has 5 levels which range from the mildest (Level I) to the most severe (Level V). It is included in the Impairment Questionnaire in Appendix A. Studies have demonstrated its reliability and validity (Jahnsen et al., 2006;

Morris and Bartlett, 2004; Morris et al., 2004). It was designed for use in children up to the age of 18 years but has also been used in studies of older adolescents and adults with CP (Jahnsen et al., 2006; Sandstrom et al., 2004).

For the classification of fine motor skills, the Manual Classification System (MACS) (Eliasson et al., 2006) is modelled on the GMFCS, with 5 levels. It has been used less extensively than the GMFCS. The MACS was designed for children aged up to 18, but has also been positively evaluated with young adults (van Meeteren et al., 2010). Again, studies have shown reliability (van Meeteren et al., 2010; Eliasson et al., 2006; Morris et al., 2006b). The GMFCS and MACS fulfilled my need for valid, reliable tools to categorise severity of motor impairment, appropriate for use in the adolescent age group.

Most studies classifying cognitive impairment use IQ scores. These have the advantage of wide acceptance and familiarity. However, in the UK, IQ is not routinely measured and so many parents will not have this information. In addition, assessing intellectual ability may be a particular problem for those with severe motor impairment, because some tests of cognitive functioning are also dependent on motor skills (Sigurdardottir et al., 2008). The NECCPS uses three levels of functioning with IQ ranges in addition: unlikely to need special educational provision for intellectual deficit (IQ 80+); likely to need special educational provision for intellectual deficit (IQ 50–80); and severe learning difficulty (IQ about <50) (NECCPS, 2010). Similar descriptive categories were used when collecting data for this project, but phrased in simpler language to aid understanding by parents and carers (see Impairment Questionnaire in Appendix A).

The SCPE classification, which has been adopted by registers such as NECCPS, also includes classifications for sensory and other impairments. These were adapted for this study and are shown in the Impairment Questionnaire in Appendix A.

2.6 Impacts of cerebral palsy on body function and structure

In this section I look at the impairments caused by the underlying brain insult in CP and the sequelae of these impairments on other areas of body function. The major co-morbidities are sensory impairments, intellectual impairment, epilepsy, communication and feeding impairments. Depending on the type of CP, 25–80% of individuals have additional impairments (Odding et al., 2006), with those with spastic four limb CP having the highest burden of co-morbidities (Shevell et al., 2009).

Type of impairment	Estimated prevalence
Gross motor function	GMFCS Levels I–III 69%, Levels IV–V 31%[1]
Hand function	Mild–moderate 75%, Severe 25%[1]
Intellectual impairment	IQ<70 23–53% of whom 30–41% IQ<50[2]
Sensory impairment (principally stereognosis and proprioception)	44–51%[2], >90% in those with hemiplegia[3]
Vision	40–75%[3], 9–19% severe[1, 4]
Hearing	2–11% severe impairment[4, 5]
Epilepsy	20–40%[2]
Communication	40–58%[5, 6]
Feeding	50% some difficulty[2]; 10% non-oral feeding[4]

[1](Himmelmann et al., 2006), [2](Odding et al., 2006), [3](Koman et al., 2004), [4](Shevell et al., 2009), [5](Kennes et al., 2002), [6] (Bax et al., 2006)

Table 2.2 Prevalence rates for the motor severity levels and main co-morbidities of CP

Estimated prevalence rates quoted in the literature for the levels of motor severity and for the related impairments are shown in table 2.2. There are wide ranges of prevalence published for many of the impairments because of differences in case ascertainment between studies, and so it is hard to know what more precise levels may be for our own population. A number of other medical problems stem directly or indirectly from CP and these are summarised in table 2.3.

Body structure or function	**Impairment**	**Examples of resulting health problems and other difficulties**
Muscle	Abnormal tone Weakness	Abnormal growth with muscle shortening; joint contractures; scoliosis; joint dislocation; abnormal gait; pain; fatigue; sleep disturbance
Muscle	Abnormal and repetitive movements	Cervical spondylomyelosis; joint degeneration; pain; fatigue
Vision	Cortical visual impairment Visual-perceptual, visual processing and eye movement problems	Reading difficulties; sleep disturbance
Hearing	Hearing impairment	Communication difficulties
Cerebral cortex	Epilepsy	Affects driving and careers; attitudinal barriers; anxiety about fits and sudden death (SUDEP); sleep disturbance; cognitive deficits
Bulbar function	Chewing and swallowing problems	May need nasogastric or gastrostomy feeds; poor growth and delayed puberty; aspiration pneumonia; increased risk of mortality
Oromotor function	Speech difficulties	Communication difficulties
Gastrointestinal tract	Abnormal smooth muscle	Constipation; gastro-oesophageal reflux; pain; sleep disturbance
Genitourinary system	Neuropathic bladder	Urinary incontinence; urinary tract infection; renal damage; hygiene and self-care difficulties compounded; self-esteem problems

Table 2.3 Medical problems associated with CP and their sequelae

It is increasingly recognized that CP should be considered not simply as a paediatric condition, but one which should be considered across the life-course (Hilberink et al., 2007). A number of changes may occur during adolescence as a result of CP, impacting on an individual and affecting their ability to Participate. Many problems presenting in adolescence and young adulthood relate to secondary musculoskeletal pathology, including increasing pain (Jahnsen et al., 2004; Sandstrom et al., 2004) acquired cervical spondylotic myelopathy and overuse syndromes (Gajdosik and Cicirello, 2001).

Changes may occur in motor function, as a result of pain and fatigue, but also due to problems with balance (Jahnsen et al., 2006).

Fatigue is a symptom reported by adults with CP (Jahnsen et al., 2003), which may develop in adolescence and have an adverse effect on quality of life and Participation (Gajdosik and Cicirello, 2001). This may also be a factor for adolescents deciding whether to take part in research, particularly if they are asked to undertake activities after a day at school or work.

Epilepsy may improve in adolescence (Odding et al., 2006) but for some it may start at this age, or become harder to control. It may also have an increased impact on some areas of life at this time due to affects on driving and occupational choice. Anxieties about having fits in public and about the risk of sudden death may come to the fore at this age.

Health services for all adolescents in the UK are recognised to be inadequate in many ways (Intercollegiate Working Party on Adolescent Health, 2003; Stevenson et al., 1997; Bowes et al., 1995). As young disabled people move to care by adult teams, the holistic approach of child health, education and social services may be lost and available resources may be less (Ko and McEnery, 2004). This may exacerbate a young person’s psychological vulnerability and their health may suffer. A number of factors, including poor physical access to services and communication difficulties, mean that young people may not receive appropriate management of their health needs (Thomas et al., 1985).

2.6.1 Cognitive and psychological problems

This area is of particular concern when carrying out research with adolescents with CP. Self-reporting of Participation may be affected by any cognitive or psychological impairment that affects the individual’s ability to understand the purpose of research, to understand the questions asked and to be able to provide the answers, and the ability to attend to tasks necessary for data collection.

Individuals with CP are at increased risk of a number of cognitive and psychological difficulties. These include problems in intellectual functioning, reading ability (despite normal IQ), memory, attention, executive functioning, social communication disorders, and emotional and behavioural problems. I briefly discuss these in turn, and consider how they may impact on the research process.

Around half of those with CP will have an intellectual impairment (Odding et al., 2006) with variations in prevalence between the different CP types. For those with severe spastic four limb CP, 95–100% have IQ<50 and 75% have IQ<25 (Strauss et al., 2005). Overall, dyskinetic CP is associated with severe learning disability in around 50%, with one European study showing the highest risk of low IQ for those with moderate motor impairment, whilst IQ was similar for those with mild and severe impairment (Himmelmann et al., 2009). For those with unilateral CP, studies have shown 40–64% have an IQ in the normal range (Parkes et al., 2009). So, at least 40–50% of adolescents with CP should be cognitively able to self-report but alternative methods need to be considered for the remainder, who may not be able to self-report, or who may need considerable support to do so.

For those with an IQ in the normal range, other impairments may impact on learning. Difficulties with saccades[1] seen in some people with CP (Katayama and Tamas, 1987), and other visual skill deficits (Kozeis et al 2006) such as impaired visual processing skills can also affect reading, and may lead to young people finding reading slow and tiring. Impairments in auditory processing (Dorman et al 1984) have also been shown to affect the acquisition of reading and other academic skills. These are important considerations when administering written questionnaires. Having someone read the questions to participants may be preferable in this situation, for both improved comprehension and to reduce the burden on respondents.

A number of small studies have looked at memory function in children with CP (Dahlgren Sandberg, 2006; White and Christ, 2005; Sabbadini et al., 2001), with deficits

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[1] Saccades are the rapid movement of both eyes in one direction, for example when scanning text.

in short and long-term memory identified. Another study (Vargha-Khadem et al., 1992) found that the presence of epilepsy treated with medication was associated with poorer verbal and non-verbal memory in children with hemiplegia, when compared to both those without seizures and normal controls. Memory deficits may impact on completion of questionnaires, where an instruction needs to be recalled for multiple questions and where questions rely on recall for past events. Long-term memory problems may make it harder for young people to accurately report areas of Participation with which they are infrequently involved.

Studies have suggested that between 3–10% of children with CP also have a diagnosis of autistic spectrum disorder (ASD) (Cans, 2009; Kilincaslan and Mukaddes, 2009), with 3–4% children with ASD found to have CP (Kielinen et al., 2004). Studies have shown that milder social difficulties are also present for some with CP. For example, a study by Yude et al (Yude et al., 1998) found that children aged 9–10 with hemiplegia had fewer friends, were less popular and more likely to be victimized than matched controls. It did not appear that these could be fully accounted for by behavioural difficulties or IQ. The importance of these difficulties for research is that the young person may misinterpret questions because they understand language very literally, they may be anxious about meeting researchers and so decline involvement or they may fail to understand the purpose of the research. In the context of Participation, they may also have a different pattern of Participation to young people who do not have such difficulties.

A small study of 33 children, including those with unilateral and bilateral CP, looked at attention and executive function (Bottcher et al., 2009). This sample had verbal cognitive functioning in the normal range, but significant impairments were seen in both sustained and divided attention, as well as with executive function in general. Slower performance compared to test norms was also noted and it was hypothesized that this might be due to information processing problems associated with white matter lesions. These difficulties, if generalisable to other CP populations, may impact on the completion of measures used in research. For example, the speed for completion of questionnaires may be slower and young people may be easily distracted, potentially reducing the accuracy of responses.

A range of other emotional and behavioural problems have also been noted in a number of studies. A population-based survey carried out in the 1980s in the US found parent-reported behavioural problems were 5 times more common in children with CP (present in 25.5%) compared to the non-disabled population (McDermott et al., 1996). The risk of behavioural problems was higher where a child also had learning disability. Studies of children with hemiplegic CP have also found difficulties in emotional and behavioural functioning greater than in the general population (Parkes et al., 2009; Goodman and Graham, 1996).

2.7 Conclusions

Cerebral palsy is a heterogeneous group of disorders with a wide spectrum of impairments and co-morbidities. These put young people at risk of reduced Participation in a number of areas, making it all the more important that there should be a way of measuring it in this group. In addition, some impairments will have a direct bearing on how a young person is able to report their Participation, for example because of effects on verbal comprehension, reading ability and expressive communication.

When undertaking this research, it was important at all stages to understand the clinical spectrum of CP and the prevalence of the various co-morbidities. This had a bearing, for example, on the purposive sampling undertaken in the qualitative work, and on the choice of data to be collected on impairments when looking for evidence of known-groups validity as part of the psychometric evaluation of the draft instrument.

Because CP encompasses a range of impairments of varying severity, it was important to identify suitable classification systems to use in this project. These were needed when defining the study population as well as when examining the psychometric properties of the proposed instrument.

Chapter 3. Adolescence

Before designing an instrument for measuring Participation in adolescents with disability, the following questions need to be answered:

1. Who do we mean by adolescents?
2. What development occurs in adolescence and how does development and Participation in adolescence affect later adult Participation?
3. What is the effect of disability on the experience of adolescence?

This chapter examines these three areas.

3.1 The definition of adolescence

The stage of life between childhood and adulthood is present across cultures and throughout history. As a life stage, adolescence has both biological and social dimensions. Spear described 3 universal features: an increase in novelty seeking; an increase in risk-taking behaviour; and a shift in the predominant interactions from family to peer group. He suggests that this has an evolutionary basis in promoting separation from the family in order to reduce inbreeding, and is a phenomenon also seen in non-human animals (Spear, 2000).

Although age ranges are often used to define adolescence, there is no universally agreed definition (Sawyer et al., 2007). Age ranges used are often ones of convenience, for example, with the start at the onset of puberty (around 8–9 years) and the upper limit coinciding with a legal milestone such as the age of majority at 18 years. The WHO defines adolescence as being between the ages of 10 and 19 years (World Health Organisation, 2008) whilst the UN defines “youth” as being between the ages of 15–24 years (United Nations, 1996). The confusion in the UK over the age at which a person reaches adulthood is well illustrated by the range of legal milestones for different areas denoting adult status. These range from the age of criminal responsibility at 10 years, through heterosexual age of consent and of marriage at 16 years, ability to vote and purchase alcohol at 18 years and full entitlement to housing benefit at 25 years.

Similar inconsistencies of approach are seen in other countries (Sawyer et al., 2007). Some sociologists have split the period into early, middle and late adolescence (Steinberg, 1999), but again the age ranges for these categories vary (Coleman and Hendry, 1999), potentially limiting their usefulness in providing a common language and definitions.

A study in the US sought the views of a group of adolescents and adults. They found that legal and chronological milestones such as reaching the ages of 16, 18 or 21 years are not seen by either adolescents or older adults as signifying the start of adulthood. Although biological markers (such as reproductive capability) and norm compliance (such as avoiding criminality) were seen by larger proportions of both groups as important markers, the majority view cognitive milestones of accepting responsibility for one's own actions and independently deciding on personal values and beliefs as fundamental for achieving adulthood (Arnett, 2001).

3.1.1 Biological markers

A biological view of adolescence is usually seen to start with the onset of puberty. Taking an entirely biological perspective, the most obvious endpoint would then be the capacity to reproduce, and in some cultures this is the case. However, emotional and cognitive development clearly continues well beyond this, with contemporary neuroscience suggesting that the completion of maturation of the frontal lobes occurs towards the middle of the third decade (Gogtay and Thompson, 2010). The completion of this stage of brain development could therefore be considered an alternative biological endpoint of adolescence.

In the industrialised world, the onset of menarche and other pubertal stages has become earlier by around 3 months each decade from the mid 19th century until relatively recently, although more recent work has failed to show that this trend is being maintained (Karapanou and Papadimitriou, 2010). Female puberty may begin as early as 8 years with male from around 9.5 years (Coleman and Hendry, 1999), although the range is wide. The biological start of adolescence for some may therefore be much earlier than the social and cultural stage would typically be recognised.

If the view is taken that adult status is achieved when certain cognitive milestones are reached, this presents problems for young people with intellectual impairments. These young people risk being denied access to adult rights and services. Although those with more severe impairments may not be able to enjoy many such rights, it is important that they are still seen as adults rather than children. For some the milestones may be achieved over a longer timeframe and it may be developmentally appropriate to see some young people with intellectual disability as experiencing a more prolonged adolescent phase. This is an important point to consider with young people with CP, a significant proportion of whom will have intellectual impairment.

3.1.2 Sociological markers

As with biological markers, social and cultural markers change over time and between cultures. Depending on the patterns of finishing school, starting work, leaving the family home and marriage, the age of transition from childhood to adulthood may vary (Modell and Goodman, 1993). Compared to a few decades ago, children are exposed at earlier ages, via the media and due to changes in society, to information and experiences previously reserved for late adolescence and so psychologically as well as physically (Coleman and Hendry, 1999), the onset of adolescence is now much earlier than a century ago.

In pre-industrialised societies, marriage is often seen as the start of adulthood, although this may be over-simplistic and even young married people may feel they are still treated like children by elders (Kroger, 2004). In the UK, three main transitions have been described as marking entry into adulthood. They are the school to work transition, the domestic transition (becoming independent of the family), and the housing transition (permanent move from parental home) (Coleman and Hendry, 1999). In the UK, secular trends such as changes in the job market, the prolongation of fulltime education for many, the increased cost of property and of higher education, have all extended the time that young people remain in the family home and financially dependent on parents (Hendry et al., 1993). From this perspective, adolescence may therefore be seen to extend into the twenties for many young people.

Many people in their mid to late twenties, and sometimes later, still do not regard themselves as having fully reached adulthood. In one US study, 4% of 20–29-year-olds questioned felt they had yet to reach adulthood whilst 50% of them said they were adults in some respects and not in others. The figures for the 30–55-year-olds were 2% and 12% respectively (Arnett, 2001). Arnett, a US author, has coined the phrase *emerging adulthood* to describe the period between adolescence and full adulthood. The age range for this varies between individuals but is described as between around 18–29 years (Arnett, 2001; Arnett, 2000). Because it is a time of experimentation in lifestyles, jobs, and romantic relationships, there is huge diversity in the demographics of this group. This is in contrast to more demographic homogeneity in adolescence and in later adulthood. Arnett's thesis is that the postponement of marriage and child bearing to the late twenties and early thirties allows young people to have this intermediate, experimental stage of life.

3.1.3 Definition of adolescence used in this study

Given that there is no universally agreed age range for adolescence, decisions had to be made about the definition used for this project. A definition based purely on behavioural or role acquisition markers would not be practical for the purposes of recruitment and similarly biological markers such as onset of puberty would be difficult practically. The only practical definition would have to be primarily based on age, and the most appropriate age range for the purpose of the instrument would be one which covers a reasonably homogenous pattern of Participation and for which currently available child and adult instruments are not suitable. An age range of 14–21 years was therefore settled on. However, more flexibility would be possible if using the instrument for individuals in a clinical setting. The guide then would be that the instrument would be suitable if a young person has yet make the domestic and housing transition, since relevant areas of Participation in that case would be better represented in an adult instrument.

Another consideration is the words used to describe this life stage. Studies have shown that the term "young people" is preferred by individuals themselves, over "adolescents" or "teenagers" (Turner and McNulty, 2000). In the US in particular, the term “youth” is often used, but in the UK this also has negative connotations. For the purposes of this study, the terms “adolescent” and “young person” are used interchangeably. In study documentation for participants and families, and when naming the instrument, the preferred term “young person” has been used.

3.2 Adolescent development

A common view of adolescence is a negative one; that it is a “deficit version of adulthood” (Wyn, 2007), and “a period of preparation, not fulfillment” (Modell and Goodman, 1993). Taking a more positive view, adolescence can be seen as being characterized by a number of crucial developmental achievements and transitions, but also being a unique life-stage with a meaning and culture of its own (Priestley, 2003). It is for these reasons that Participation should be considered separately for adolescents, and why measurement tools should be specifically designed.

Even between modern industrialised cultures, adolescence may be differently experienced. Much of the literature on adolescence comes from the US and care must be taken not to assume that young people in the UK necessarily experience what these authors describe. Depending on the stability of a society and the availability of work and other markers of adulthood, the transition period may be seen as more or less stressful by adolescents themselves and the adults around them (Arnett, 1999).

3.2.1 Theories of adolescence

Theories about adolescent development and the adolescent experience evolved during the 20th century. In the 1900s, G Stanley Hall wrote about adolescence as being a time of storm and stress and the idea that adolescence is inevitably difficult and stressful has been a persistent one up to the present day, with the mass media often portraying adolescence in this way (Arnett, 1999). Later in the 20th century this idea of crisis was elaborated on by practitioners such as Anna Freud and Erik Erikson (Kroger, 2004). Erikson described a number of psychosocial “tasks” of adolescence that need to be undertaken for healthy development. In adolescence this is the identity crisis, which must be resolved for a coherent adult identity to be reached (Van Naarden Braun et al., 2006b; Kroger, 2004). Inherent in this idea was the concept of needing to experience a crisis. Anna Freud went as far as to say that not experiencing a stressful and difficult adolescence is not normal and such individuals will have psychological difficulties later in life (Steinberg, 1993).

More recent research has highlighted the fact that the majority of adolescents do not have a particularly difficult time (Coleman and Hendry, 1999). Most maintain reasonable relationships with their parents, succeed at school and do not suffer depression, drug addiction and delinquency. However, it is true that adolescence is a time when people are more likely than at other times in their lives to experience difficulties. These include risk-taking behaviour, mood disruptions and conflict with family members, in particular with parents (Arnett, 1999). There are both biological and social reasons for this, which are discussed below.

Several theories have looked at adolescence in terms of multiple transitions or “turning points” (Coleman and Hendry, 1999; Graber and Brooks-Gunn, 1996). Coleman’s focal theory suggests that adolescents deal with the issues that confront them in adolescence in a paced fashion, dealing with one before moving onto the next. Issues might include school transitions, changes in relationships both with parents and with peers and adults outside the family and the onset of puberty. Some of those must be dealt with at times that are out of the control of the young person, for example moves between schools. Others, such as renegotiating relationships, can be dealt with at a time the adolescent has the resources to do so. The adolescent is therefore an agent in their own development and takes an active role in their progress to adulthood. The other concept in Coleman’s model, is that of “goodness of fit”. This means that what is available for the adolescent in terms of educational, work and leisure opportunities and relationship experiences needs to be appropriate for that young person. For example, an academically able young person may be affected adversely by being sent to a school where scholastic achievement is not the norm.

We know from empirical research that timing of certain transitions are important, because effects may be felt right through life. Early pregnancy, for example, may affect subsequent transitions and life opportunities in education, work and relationships, which produce cumulative disadvantage (Elder, 1998). It may be useful to use the focal model when considering the adolescent with chronic illness or disability. If health transitions are not timed in consultation with the young person it may be harder for them to deal with them. The "goodness of fit" principle may explain why Participation in adolescence may be either facilitated or restricted by certain contextual factors. A young person may not benefit from educational or leisure opportunities if these are not congruent with their needs.

Another useful way of thinking about adolescence and development is the model proposed initially by Hill and then modified by Steinberg (Steinberg, 1999) and shown diagrammatically in figure 3.1. This model includes 3 universal functions of adolescence, 4 contexts in which an adolescent lives their life and 5 areas of psychosocial development. These are not unique to adolescence but are of particular importance and have a more intense quality at this time.

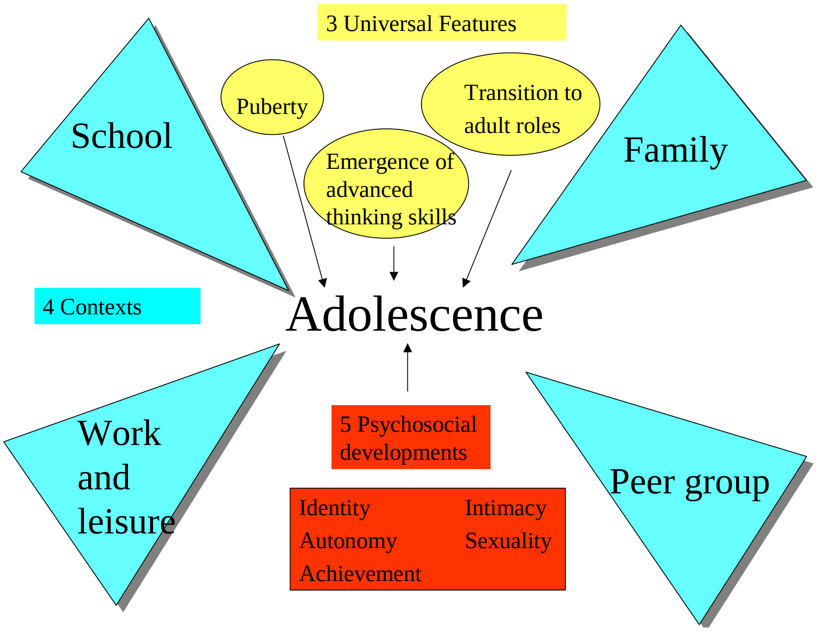

Figure 3.1 Model of adolescence based on Steinberg and Hill (Steinberg, 1999)

Participation can be seen as occurring within the four contexts, with opportunities for Participation affecting and being affected by both the universal features and the psychosocial developments. For those with disabilities, difficulties may arise in any of these areas. For example, research has shown that the timing of puberty affects self-perception and the perception of the young person by peers, leading to differences in peer relationships and potentially affecting identity development. For boys, delayed puberty can cause problems with self-esteem and social success whilst for girls, early puberty can be problematic, with evidence for an increase in mental health problems and reduced popularity with other girls (Coleman and Hendry, 1999). In CP, the neurological condition and its consequences may alter the timing of puberty, being either early precocious or delayed (Worley et al., 2002). This illustrates how the presence of a disabling condition may interact with adolescent development and potentially increase the challenges to the individual.

Although conditions like cerebral palsy are present from birth, adolescent development, with the increasing pre-occupation with self-image, means that young people may re-evaluate what their impairment means to them and to others. In addition, adolescence may itself bring changes in the manifestations of the CP (discussed in Chapter 2) which may also impact on identity development for these young people (Kelly and Field, 1996).

A number of different facets influence an individual’s identity. For those with impairments, these will be integrated into that developing identity in adolescence. Young people may be unsure whether to identify with disabled role models or with non-disabled. The disability rights movement has enabled many to see a “disability identity” positively. However, Priestley discusses the conflict which may occur because “disability identity” cuts across the age range, whereas “youth identity” is age specific (Priestley, 2003). Disabled adolescents, may find reconciling the two problematic.

Although empirical evidence is lacking, identity development may affect Participation choices. For example, whether or not a young person sees themselves as “a sporty person” may affect whether they decide to join certain clubs or other organizations.

Autonomy, as well as being identified as a key feature of adolescence, is also seen as important in Participation (Cardol et al., 2002). It has been suggested that development of autonomy in adolescence is of similar importance and significance as development of attachment in infancy. However, it has been studied to a much lesser extent. The term autonomy has also been used to mean a number of slightly different things when discussing adolescent development (Steinberg and Silverberg 1986). These include detachment from or resistance to parents and their control, a subjective sense of independence or the ability to make independent moral decisions (ibid). Individuation is the process by which adolescents come to see themselves as distinct individuals, separate from their parents. This does not however involve “detachment”, as parental attachment is essential to this process (Sartor and Youniss, 2002).

Development of autonomy may be affected by parental behaviour, by personal care needs and by intellectual functioning. It is important to make the distinction between autonomy and independence (or between what some call decisional and executional autonomy (Cardol et al., 2002)). Although some individuals will never be able to undertake some tasks without assistance, and are not therefore independent in this, they may well be able to make autonomous decisions, and so, for example, should be able to instruct someone providing personal care in how they wish that care to be provided. This may be hard for adolescents where parents are providing care.

During adolescence, patterns of friendship change and develop. In early adolescence, same-sex friendships and peer groups are common. Close relationships may develop with members of the same sex, and young people may identify with fewer “best friends”. As young people get older, they start to develop friendships with members of the opposite sex, which may not be viewed as romantic but may be a precursor to romantic or sexual relationships (Tuval-Mashiach et al., 2008). In mid and late adolescence, intimate and sexual relationships become commoner, in addition to non-sexual close friendships. These friendship experiments are possible because of the increasing amount of time adolescents spend with friends rather than family or other adults. They require the adolescents to be unsupervised by adults, with a degree of privacy. Needing the assistance of others for personal care may mean that this process does not happen to the same extent for adolescents with disabilities (Watson et al., 1999).

Parents may find it hard to appreciate that their disabled child is growing into a sexual adult and so may not provide the same support and information in this area that they would give a non-disabled sibling. Special schools also may not provide the same level of sex education to that provided in mainstream schools. As discussed above, for sexual relationships to develop, a young person needs to have the opportunity to establish intimate relationships through adolescence, and to be afforded appropriate privacy with peers. For those with personal care needs, it can be hard for young people to feel in control of their bodies and to have a sense of privacy enabling healthy sexuality to develop. Sadly, we know that a greater proportion of children and young people with disabilities are sexually abused (Sullivan and Knutson, 2000), further compounding difficulties with sexual health.

3.2.2 The neuroscience of adolescence

Steinberg has described the recent developments in neuroscience as the most significant advance in our understanding of adolescence for half a century (Steinberg, 2010). It has long been recognized that the key changes in cognitive function in adolescence are the development of abstract thought and executive functioning, which characterise adult humans (Crone, 2009). Recent studies using magnetic resonance technology have enabled structural and functional changes in the CNS to be examined in more detail, although the science is still at a relatively early stage (Steinberg, 2010; Johnson et al., 2009). What has become clear, as Steinberg comments, is "that the brain changes characteristic of adolescence are among the most dramatic and important to occur during the human life-span" (Steinberg, 2010).

In brief, significant remodelling in the prefrontal lobes in adolescence leads to a reduction in the gray matter and an increase in white matter. The final adult volume of the prefrontal cortex is not reached until the early 20s (Yurgelun-Todd, 2007). Less understood changes also occur in the temporal and parietal lobes and the cerebellum (Gogtay and Thompson, 2010). The increases in white matter reflect increases in myelination, and probably also axonal calibre (Paus, 2010). Changes in the gray matter are as a result of neuronal pruning and possibly an increase in intracortical myelination and other cellular changes (Gogtay and Thompson, 2010). This pruning leads to a more efficient and specialised level of functioning, with a reduction in more diffuse and irrelevant activity. Dopaminergic systems, known to be involved in motivation, also show marked changes (Forbes and Dahl, 2010).

Research has shown how some of these observed structural and functional changes are associated with the behavioural changes observed at this age. For example, maturation of the prefrontal cortex, seen on scans as cortical thinning, has been shown to correlate with both improved verbal memory and inhibition of behavioural responses. White matter increases seen in late adolescence are associated with an increase in impulse control (Yurgelun-Todd, 2007). How can this field contribute to our understanding of Participation?

One important finding of this research is a demonstration of the significant plasticity of the brain in early adolescence (Gogtay and Thompson, 2010). This has been suggested as a reason for the increased vulnerability of adolescents to various forms of psychopathology as well as to stress (Steinberg, 2010). It has also been shown in both animal and human studies, that myelination is affected by experience (Fields, 2008). One major implication for Participation is that interaction between changes in brain structure and functioning and the individual's experience may be of crucial importance at this time (Steinberg, 2010). This means that Participation patterns in certain areas could potentially have an effect not just on short-term psychological functioning, but on structural brain development, which may not be reversible. To date, we do not know to what extent this is the case.

Another area of research which may be helpful when interpreting research findings with adolescents is that of *hot* and *cold cognition*. This refers to cognitive processes in different states of emotional arousal. *Cold cognition* occurs in decontextualised experimental settings where adolescents may be quite good at decision-making, whereas in emotionally-charged real-life settings, where high risk behaviour takes place, they may find decision-making more challenging. It is thought that different neural networks are being used in the two types of situation, which mature at different times (Johnson et al., 2009). This may have implications for adolescents' self-reporting of behaviour and motivations.

3.3 Influence of Participation on adolescent development and later outcome and the impact of disability

Are there areas of Participation which are of particular importance to adolescent development and to adult Participation? If there are, how does disability impact? This body of literature needs to be considered when making decisions regarding the areas to be covered in a Participation instrument. I have only considered literature of relevance to UK and similar industrialized societies. For adolescents in the developing world, this is likely to be different.

Detailed discussion of the problems faced by young people with long-term health conditions and disabilities is notable for its absence in standard textbooks on adolescence. This is in stark contrast to the prominence of issues relating to other markers of disadvantage, such as poverty and minority ethnic background as well as gender differences (Coleman and Hendry, 1999; Steinberg, 1999; Feldman and Elliott, 1990). This is despite the fact that around 10% of adolescents have a long-term health condition (Suris et al., 2004). Depending on the severity of impairments, conditions such as CP can have a significant impact on the adolescent and their development. However, disruption to development is not inevitable, with studies showing that adolescent development is similar for many disabled and non-disabled youngsters and that with appropriate support, disabled young people can have a relatively trouble-free adolescence (Suris et al., 2004).

Looking broadly at adolescent development in those without disability, Roisman et al (Roisman et al., 2004) reported the results of a longitudinal study of 205 young people which confirmed their hypothesis that competencies established in early adolescence (friendships, academic achievement and conduct) were more important to later adult success than the emerging competencies of later adolescence (work and romantic relationships). There have been few longitudinal studies reported which investigate the links between Participation in adolescence and that in later adulthood, and so most of the evidence available is from cross-sectional or retrospective studies looking at specific areas of Participation. I now look at the individual areas of Participation where there is some suggestion in the literature for how Participation affects adolescent development and later Participation both for those with and without disabilities. These are ordered in the same way that Participation is described in the Chapters of the ICF, which are discussed more fully in Chapter 4.

3.3.1 Communication

The use of new technologies by adolescents has been extensively researched, often focusing on the possible harmful effects of on-line communication in particular (Gross et al., 2002). Evidence of positive benefit is harder to find, although reasons are given by some authors as to why it might be helpful. Subrahmanyam and colleagues, who published a review of the literature in 2001, suggest that as adolescents have a developmental need to communicate with a wide selection of people outside the family, the frequent use made of online communication by adolescents is developmentally appropriate (Subrahmanyam et al., 2001). However, they provide no empirical evidence for developmental benefit.

The observation has been made that young people not infrequently rush home from school where they have been all day to start communicating by phone or on-line with their school friends (Subrahmanyam et al., 2001). This suggests that it is something valued by the young people themselves.

Seymour and Lupton undertook qualitative research with disabled adults which found that online communication was viewed positively by the participants. They described how it enabled interactions with others which would otherwise not have been possible because of opportunity or distance. In some cases this involved relationships where only online communication occurred, but in others it was associated with later face-to-face communication as well (Seymour and Lupton, 2004). It may be therefore, that for adolescents with disabilities, online communication is also a facilitator for other Participation.

3.3.2 Self-care

An important aspect of self-care in adolescence is autonomy. In a study where young disabled adults were asked about what was important in helping them achieve independent living and employment, parental insistence on them learning self-care and other tasks was identified as facilitatory (Hendey and Pascall, 2001).

3.3.3 Domestic life

Although it has been reported that Participation in household chores in post-industrialised countries appears to have little generalisable benefit to development with, for example, no increase in responsibility seen in school, it has been shown to result in the learning of specific skills. This in itself may be helpful in later adolescence for domestic and housing transitions (Larson and Verma, 1999). However, I was unable to find empirical evidence for this.

White and Brinkerhoff asked parents in their study why they expected their children to carry out chores. The major reasons given were that it was for the benefit of the child developmentally, that the parent needed the help, or that it was the child’s duty to help the family. A small number said that it was important that the child learnt to perform the task (White and Brinkerhoff, 1981). Many parents in the study by Luther, who were asked to choose from a list of possible facilitators to successful transition to adulthood, agreed that “assigning appropriate household chores” is important (Luther, 2001).

Leaving home to live independently is a key transition. Researchers have looked at the effects of age at leaving home and White (White, 1994) published a review of the literature on this. She found that in the US and Western Europe, the majority of young people leave home between 18 and 21 years, with the majority expecting to live independently before marriage. For young people with disabilities, who tend to leave home later (Donkervoort et al., 2008), this may exacerbate feelings of difference. Studies have also shown that parents may have negative feelings about having adult children living with them (White, 1994), and this may have an effect on interpersonal relationships as well as the self-esteem of the young adult.

3.3.4 Interpersonal relationships

A key feature of adolescence is the gradual shift from a predominance of family-based interactions to those with peers. This is important for the development of autonomy although it is now recognised that connectedness to parents remains important (Coleman and Hendry, 1999). The evidence for how the quality of relationships in adolescence affects later relationships and other functioning relates mainly to parental relationships.

A longitudinal study of Swedish adolescents (with follow-up to age 37) found that good adolescent relationships with parents were associated with midlife partner satisfaction (Moller and Stattin, 2001). Studies of autonomy development suggest that some adolescents who show particularly early autonomy in their parental relationship (in other words, having a less dependent relationship) had more dependent relationships with peers (Steinberg and Silverberg, 1986). Hazan and Zeifman (cited in Moller and Stattin 2001) suggested that this premature shift from parental to peer dependence can result in earlier, and less secure romantic and sexual relationships.

Sartor and Youniss carried out a study in the US with over 1000 adolescents, looking at identity development and the extent of maternal support and both social and school monitoring. They found that there was a significantly positive correlation between identity achievement and maternal support and monitoring. This includes some factors which constitute areas of Participation. For example, maternal support included agreeing that “My mother enjoys doing things with me”, and monitoring included parents helping with homework, and watching them take part in school sports and other activities (Sartor and Youniss, 2002).

The study of young disabled adults by Pascall and Hendey (Hendey and Pascall, 2001) suggested that “over-protective” parents, or those who did not have high expectations of their disabled children, may be a barrier to some young people achieving independent living and employment. On the other side of the coin, parents who pushed their young people to achieve in different areas, and were able to provide resources of various kinds, were identified as very important facilitators.

Evidence for the value of peer relationships in adolescence comes from a study into resilience for young people with disabilities (King et al., 2003a). Resilience is the ability of people to cope well with adversity and many resilience factors are related to psychological features such as positive outlook and high self-esteem. However, other features described in this study included having a strong social network of peers and unrelated adults as well as having meaningful activities to take part in.

The peer group is also key to identity development (Tarrant et al., 2001). Interactions with peers enable adolescents to compare themselves with others, try out alternative identities and gain feedback on themselves and their identity. There are many practical reasons why young people with CP and other disabilities may have difficulties in spending time with their peer group. Those attending special schools may not go to a school in their locality, so friends may live some distance away and they may not know young people in their neighbourhood who attend local mainstream schools. Barriers to Participation including access and transport may affect how a young person can spend time with friends. As young people get older, it becomes less acceptable to them and their peers for parents to accompany them or provide support. If a group of friends all use equipment such as wheelchairs, meeting in public places such as restaurants or the cinema may need advanced organization, mitigating against the informal and spontaneous leisure time enjoyed by others of the same age. Social skills may also be affected by conditions such as CP (Nadeau and Tessier, 2006) and this may also impact on the development of more mature peer relationships and result in social isolation.

3.3.5 Employment

The literature on adolescents in paid employment was reviewed by Zimmer-Gembeck and Mortimer (Zimmer-Gembeck and Mortimer, 2006). They noted that concerns about employment whilst still at school affecting adolescents' school work were around for much of the 20th century. Those concerned with the negative effects point to the fact that work undertaken by adolescents whilst still at school is often low skilled, repetitive and boring and several studies have shown minimal benefit to the young person. However, at least one study (Shanahan and Flaherty, 2001) has shown that adolescents with part-time jobs did not spend less time on school work, but fitted work in along with other extracurricular activities. The review by Zimmer-Gembeck and Mortimer also looked at the evidence of the effects of work intensity and quality on other aspects of adolescents' functioning. Findings suggested that where work quality was high, adolescents showed greater degrees of motivation to do good work and have greater employment success in adulthood. High work quality has also been shown to moderate the negative effect on school performance of high work intensity (Zimmer-Gembeck and Mortimer, 2006).

Some studies have shown positive effects on punctuality, responsibility and increased independence from parents (Larson and Verma, 1999). Even if the work itself is not particularly stimulating or valuable in terms of skills learnt, it may give young people confidence that they are capable of holding down a job, and may also give future employers that confidence, which for those with disabilities may be especially valuable (Anderson and Vogel, 2000).

For those who have left education, youth unemployment is an issue in the UK and elsewhere. There is evidence that it is the worry about unemployment as much as its reality which may have a detrimental effect on mental health (Coleman and Hendry, 1999). A study in adults with juvenile idiopathic arthritis found that, despite similar educational attainment to controls, unemployment rates were 3 times higher (Foster et al., 2003). Those with disabilities may therefore have real worries about their employment prospects.

Decision-making about career choices and future work have been shown to be influenced by experiences of work in adolescence (Zimmer-Gembeck and Mortimer, 2006). Part-time informal jobs and work experience may both be helpful in this. Both may be more difficult for young people with disabilities to participate in (Anderson and Vogel 2000).

3.3.6 Education

It may seem self-evident that educational Participation is beneficial to adolescent development and future Participation and research evidence does support this.

Attendance at school is associated with benefit which increases with increasing time spent attending to school work, both to the individual and to society (Larson and Verma, 1999). A number of studies in different countries have shown that qualifications acquired in school are related to employment opportunities in the short and longer term (Coleman and Hendry, 1999).

A number of studies have suggested that for both children and adolescents, physical activity may be beneficial for academic achievement (Trudeau and Shephard, 2008). However, studies are mainly quasi-experimental and results have been conflicting. Whether the association is due to physical fitness improving cognitive function is not clear, but this does have implications for those with physical impairments where there may be barriers to physical activity within school, particularly in the mainstream setting. Extracurricular activities including sports have been shown to be predictors of academic success, and this may be due to improved motivation and commitment to the school rather than an effect of the activity in itself (Trudeau and Shephard, 2008).

For those with conditions such as CP, poorer school attendance and lower academic achievement may result from periods of illness, and attendance at medical and therapy appointments. Conversely, adolescents may prioritise school over attendance at appointments and participation in therapeutic regimes, which may have an adverse effect on their long-term health (Suris et al., 2004).

3.3.7 Community life

Duke and colleagues (Duke et al., 2009) looked at how adolescent family and community connectedness was related to what they termed civic engagement, in young adulthood. Connectedness included the subjective nature of relationships within the family, school and with other members of the community as well as the extent of shared activities with these groups. Civic engagement included voting, participation in political and other community groups and activities, voluntary work and blood donation. Using multivariate analysis, their study of 9130 individuals found that frequency of shared activities with family and school connection were unique predictors of young adult civic engagement. Egerton (Egerton, 2002) examined whether social and civic activity in adolescence was related to later engagement in higher education. Higher community involvement was associated with higher education, but parental socioeconomic status appeared to be a confounding factor.

Another study looking at the effects on young people with disabilities of taking part in voluntary work used both survey and case study methods. They found a positive effect on self-confidence, as well as increasing their social and practical skills (Roker et al., 1998).

3.3.8 Recreation and leisure

The major media used for leisure by European and US adolescents is TV (Larson and Verma, 1999). TV viewing, if excessive, may be detrimental as it displaces other activities such as sport, school work and reading. Exposure of children to media violence has been shown to be predictive of future aggression (Strasburger, 2009). However, strong evidence of a detrimental effect of moderate use is lacking. Subrahmanyam and colleagues published a review of the literature on media use in 2001, and report evidence of immediate improvement in skills in certain non-verbal domains following use of some computer games. However, they point to the lack of evidence that this translates into later academic or employment success (Subrahmanyam et al., 2001).

Non-structured leisure activities require a greater degree of initiative, and self-organisation than adult-defined activities such as schoolwork or household chores. It might therefore be expected that there are developmental benefits but evidence is lacking (Larson and Verma, 1999). Adolescent participation in non-sport structured activities such as music and arts has been found to predict positive changes in self-esteem and school achievement as well as greater adult career achievement and involvement in civic activities. Involvement in sports is associated with reduction in mental health problems, but large amounts of time spent in competitive team sports has been shown to be associated with alcohol use and delayed identity development (ibid).

Spending time alone and the importance of this in adolescence is discussed by a number of authors. In their review, Buchholz and Catton (Buchholz and Catton, 1999) draw attention to studies which have shown that more talented adolescents spend greater amounts of time alone and that this is associated with an increase in time spent undertaking cultural and artistic activities. They postulate that aloneness increases motivation for the development of such skills. Solitude has been noted by some adolescents as important for concentration on tasks and when mood was negative. Corsano and colleagues explored aloneness with a group of Italian adolescents and found that it was viewed most positively in older adolescents and they conclude that it may be important in facilitating identity development and in the process of individuation (Corsano et al., 2006). A young person with CP may have less time alone due to needing frequent personal assistance. Whether this will have a detrimental effect is not known.

3.4 Conclusions

Adolescence has both biological and social components, with both potentially affected by conditions such as CP. Although there is no universal definition of adolescence, an age range of 14–21 years was decided upon for the purposes of this study as being culturally appropriate, close to other definitions and encompassing the age range least well covered by existing instruments.

Theories of adolescence and adolescent development are helpful when considering how disability may impact on adolescent development. They highlight areas of Participation which are particularly important to consider for inclusion in an instrument for young people with disabilities. This discussion is considered in more depth in Chapter 6, where I examine the evidence for Participation patterns for adolescents and adults with disabilities.

The understanding of adolescent brain development is still in its early stages, and it is unclear how an individual’s Participation at this time may interact and potentially alter it. What we do know is that certain types of Participation are important for adolescent development and that certain patterns of Participation in adolescence are associated with positive outcomes in adulthood. Examples are strong parental relationships in adolescence being associated with higher satisfaction with spousal relationships in adulthood, and educational Participation and achievement being associated with better employment opportunities in adulthood. Adolescent Participation should therefore be valued both for its immediate effects on the individual, as well as for later outcomes. Again, this literature guided decision-making about areas of Participation to be included in the Participation measure.

Chapter 4. Participation

In this chapter, I discuss the evolution of Participation as a concept and the current areas of debate and I defend the position I have taken on the definition and operationalisation of Participation from which the instrument was developed.

The World Health Organisation (WHO) published the International Classification of Functioning Disability and Health (ICF) in 2001 (World Health Organisation, 2001), with a version for children and youth (ICF-CY) in 2007 (World Health Organisation, 2007). The ICF is one of the family of classifications produced by the WHO, which also includes the ICD coding system. It functions both as a method of classifying functioning and disability but also provides a discussion on how disability may be conceptualised.

The concept of Participation was introduced in the ICF and is included in the classification in nine chapters which combine Activities and Participation. Participation is defined as “involvement in life situations”, whilst Activities are “the execution of a task or action”. Since its inception, the ICF has been examined and used extensively in research, as witnessed by the now large and ever increasing literature concerning its use (Jelsma, 2009).

Although suggestions are made in the ICF, further definitive distinction between Participation and Activities is not made, and the ICF does not come to a clear conclusion about how Participation should be operationalised. This causes significant difficulties for users of the ICF, as I discuss below.

4.1 Background to the International Classification of Functioning Disability and Health

The ICF is the result of extensive revision of the 1980 International Classification of Impairment, Disability and Handicap (ICIDH) (World Health Organisation, 1980). The ICIDH was a classification of the consequences of disease and is based on a biomedical model. It was divided into Impairment (loss of normal structure or function), Disability (problem performing an activity) and Handicap. The latter was defined as the disadvantage experienced by an individual as a result of their impairment or ill health, which limits or prevents fulfillment of social roles which would normally be expected for that individual. Handicap is therefore the social deficit originating at the level of the individual. The role of the environment was not part of the model.

Members of the disabled community concerned with Disability Rights felt the ICIDH was unhelpful, and even harmful, for the emancipation of the disabled (Hurst, 2003; Pfeiffer, 2000). The term handicap is now used pejoratively in lay language, another reason that the concept has been rejected by the disabled community (Whiteneck and Dijkers, 2009).

The concepts defined in the ICIDH were refined by the Quebec Committee on the ICIDH (Noreau et al.). Informed by other models, including that of Nagi from the 1960s (Nagi, 1965 cited by Noreau et al.), they developed a model which they called the Disability Creation Process, a biosocial model. In this they defined *social participation*. The elements which make up social participation they termed *life habits*. These were defined as “regular activity or social role valued by the person or his/her socio-cultural context according to his/her characteristics”. Environmental factors were also included in the model (Fougeyrollas, 1995) and a measurement tool, the Assessment of Life Habits (Life-H) was developed, which is discussed in Chapter 5.

Also influenced by the earlier Nagi model, Verbrugge and Jette described *the Disablement Process* (Verbrugge and Jette, 1994). This model introduced the modifying social, psychological and environmental factors which interact on the pathway from pathology to disability. They described disability as the relationship between the person and the environment. They also rejected the frequent assumption that some life domains (such as self-care and paid employment) were more important than others (such as leisure).

These ideas were influential in the conceptualisation of disability presented in the ICF. In contrast to the ICIDH, the ICF is a classification of components of health rather than of consequences of disease, with the concept of Participation replacing that of handicap. It has universal application because it is couched in positive terms, and was developed with regard to the social model of disability. Its development was significantly influenced by the views of disabled experts (Hurst, 2003).

4.1.1 The structure of the ICF

The ICF has two parts. The first part has two components: Body Structures and Functions; and Activities and Participation. The second part concerns contextual factors which may impact on Activities or Participation and which can be environmental or personal. *Functioning* is used as an umbrella term, to include Body Functions, Activity and Participation, whilst *disability* encompasses impairments, Activity limitations and Participation restrictions.

The Activities and Participation component is divided into 9 domains. These are learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; and community, social and civic life. Domains are further subdivided into sub-domains with increasing levels of detail.

The ICF is a classification system that enables the concepts within it to be quantified. Each sub-domain has a unique code, and qualifiers of severity of impairment or degree of difficulty with Activities and Participation on a scale of 0 to 4 can be added. However, with a total of 1424 sub-domains, using the entire classification in a clinical or research setting is impractical (Jette et al., 2008). ICF core sets have been developed for specific conditions in adults in order to deal with this problem (Jette et al., 2008), but researchers wanting to quantify the concepts for specific purposes need to use other instruments developed from the ICF.

4.1.2 ICF-Children and Youth version

Although much of the ICF is applicable to children and young people, it was felt that some parts failed to include crucial aspects of the Activities and Participation in which they engage (Battaglia et al., 2004; Simeonsson et al., 2003). Therefore, a Children and Youth version (ICF-CY) was published in 2007 (World Health Organisation, 2007). This version seeks to take account of the changes occurring with development by the addition of a number of sub-domains (World Health Organisation, 2007). The ICF-CY is intended to apply from birth to 18 years. This age range was chosen to fit with other UN documents such as the UN Convention on the Rights of the Child (World Health Organisation, 2007).

In the main, the additions to the Activities and Participation chapters entail splitting some sub-domains into more detail to include early developmental tasks such as shuffling in the sub-domain Moving around (d445), breast feeding in Drinking (d560), and the different stages in Learning to read (d166).

Additional codes of relevance to adolescents are few. The Education domains (d810–d839) are given additional sub-domains of moving school programmes, maintaining participation in a programme, progressing within school and leaving school appropriately. The other changes of relevance are additional codes in the domestic life chapter. These are added to each first order sub-domain and are concerned with helping with tasks, defined as working with others to complete a task, with others in charge. These are not child or adolescent specific and could be applicable to adults in some situations, reflecting normal interdependence.

It is proposed that the new codes developed for the ICF-CY will be incorporated into the updated ICF. This seems advisable, since some codes may be applicable to adults with impairments, particularly cognitive impairments, and labeling these as relating only to children is unfortunate.

4.2 The concept of Participation

In this next section, I discuss the concept of Participation in more detail; how it may be differentiated from Activities, how it has been conceptualized and researched since the publication of the ICF, and how it relates to other concepts.

The reason for wishing to differentiate the two is that the sheer number of Activities and Participation domains combined makes measurement of both concepts impractical in one instrument. As Participation is the ultimate aim and of greatest importance to individuals, this was what I wanted to be able to measure.

One difficulty with the literature on Activities and Participation is variation in how the words are used. This is not entirely surprising, given the general as well as technical usage. In fact, it is difficult not to use the word *activity,* when referring to some forms of Participation, for example *leisure activity.* The term *participation* is also in widespread use in the UK to mean the involvement of patients in health service design and policy, or in clinical decision-making.

Another difficulty can be the use in the literature of various synonyms for these concepts. Terms such as *extended* or *instrumental activities of daily living*, which relate to more complex care of self and household (Verbrugge and Jette, 1994); *social functions*; *lifestyle activities*(Dijkers et al., 2000); and *life habits* (Fougeyrollas et al., 1997) all describe aspects of what in the ICF might be termed Participation.

4.2.1 Differentiating between Activities and Participation

As I have explained in the introduction to this chapter, the ICF gives users choice as to how Activities and Participation may be differentiated (World Health Organisation, 2001). The possible options are:

a) designating some domains as Activities and some as Participation, with no overlap
b) as a) but with partial overlap
c) designating all detailed sub-domains as Activities and the broad domain headings as Participation[1]
d) to use all domains as both, depending on whether an individual or societal perspective is taken.

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[1] For example, in the Domestic Life chapter, the domain d340 Doing housework would be classified as Participation, whilst its sub-domains d6400 Washing and drying clothes, d6401 Cleaning cooking area and utensils, d6402 Cleaning living area, and so on would be classified as Activities.

The ICF also allows for qualifiers of *performance* and *capacity,* which can be applied to each area of functioning. Performance relates to what an individual does within a real world setting, whereas capacity refers to what a person can do in a standardised setting. The ICF suggests that performance therefore relates most closely to Participation and capacity to Activity, a stance criticised as over-simplistic by some authors. This idea does however, inform the thinking around the difference between the two concepts (Forsyth and Jarvis, 2002) and some authors have developed this idea further when looking at the interactions between the capacity to do something with environmental and personal factors which affect whether it is performed. For example, Morris discusses the use of the term *capability*, which he describes as a combination of capacity and environmental facilitators. This then leads to performance, if personal factors such as choice allow it. Although such conceptualisations may be helpful in looking at the interplay between factors determining Activities and Participation, it is not clear how they help in deciding which sub-domains should be regarded as one or the other.

The reason given in the ICF for not defining more precisely which functions may be Activities and which Participation is that the uses for the classification may vary due to international differences, differences in individual professional ethos and theoretical frameworks. Some authors have suggested rather that it reflects a failure of the ICF authors to reach agreement on the conceptualisation of this part of the classification (Whiteneck and Dijkers, 2009).

Whatever the reasons for the lack of an agreed delineation between the two concepts, it has been widely agreed as a problem for users (Jelsma, 2009; Whiteneck and Dijkers, 2009; Coster and Khetani, 2008; Jette et al., 2003). However, the lack of consensus is not always reflected in the discussions about the definitions of the two concepts, with many authors justifying their interpretation by stating that they are using the terms "as defined by the ICF" without further clarifying their position. Many measurement scales designed to measure Participation in fact measure a mixture of Activities and Participation (Perenboom and Chorus, 2003) and many authors seem to use the terms interchangeably or refer to them together as a combined entity (Morris et al., 2005).

Without a clear agreed definition, instruments designed to measure Activities or Participation may have unclear validity, as neither researchers nor readers can be sure what is being measured, and studies using different instruments cannot be compared (Coster and Khetani, 2008).

Attempts to come to some conclusions about how best the two terms should be used was taken further by the North American Collaborating Centre (Canadian Institute for Health Information, 2001). They took each of the options listed by the ICF and looked to see how evidence from the ICF field trials and from other research literature fitted the different models. The best fit appeared to be where different sub-domains were allocated to one or another category, rather than differentiation at the domain level. A number of "problem" areas were identified where there was poor agreement about which constituted Participation and which Activity. The main problem areas were in the domains of self-care, mobility and communication, where some research suggested they constituted Activities and some felt that certain sub-domains, for example, eating in a social context, conversation and mobility outside the home, constituted Participation.

In an attempt to determine whether Activities and Participation are distinct domains or not, Jette and colleagues (Jette et al., 2003) used exploratory factor analysis on data obtained from a cohort of older adults using the Late Life Function and Disability Instrument. Items in the instrument were said to be similar to those in the ICF chapters on Mobility, Self-care and Domestic Life. They found items loaded onto 3 factors which they named *Mobility Activity*, *Daily Activity* and *Social/Role Participation*. The latter domain mapped most closely to the Interpersonal Interaction chapter of the ICF. Some findings were unexpected. For example, the item "take part in active recreation" loaded on Mobility Activity rather than Social Participation as hypothesized. They point out that findings may have been different with different populations, raising the possibility that the exact borderline between the two concepts may differ for different groups. For example, the greater emphasis that adolescents put on the social aspects of life (Murray, 2002), might have produced a different result with a younger age group.

Since the publication of the ICF, a number of authors have sought to go further than the discussion in the ICF in distinguishing the two concepts. Examples of suggested characteristics for the constructs are shown in table 4.1.

Activities	**Participation**	**Authors proposing or supporting distinction**
Personal functioning	Societal functioning	Canadian Institute for Health Information, 2001
Undertaken alone	Undertaken with others	Whiteneck and Dijkers, 2009
	Fulfils a personal goal or societal norm	McConachie et al., 2006
Simple tasks	Complex combinations of individual Activities	Jette et al., 2003
A means to an end	An end in itself	Whiteneck and Dijkers, 2009
Acts (independent of context) and tasks (specific purpose and context)	Societal involvement (societally valued endeavours, defined by the social role and not the constituent acts or tasks)	Badley, 2008

Table 4.1 Suggested differentiation between Activities and Participation

There are problems, in my view, with some of these methods of differentiation. Distinguishing on the basis of functioning at the individual or societal level, does not necessarily help in delineating which ICF sub-domains fit into which category (Canadian Institute for Health Information, 2001). Many areas have relevance personally and societally on different levels and the differentiation may vary between groups and individuals.

Definitions involving the presence or not of others is problematic when considering children and those who need assistance with personal care as a result of impairments, for whom it would not be normal to carry out certain Activities alone. In addition, the qualitative data from the study by Hammel and colleagues (Hammel et al., 2008) found that some private activities such as religious worship were regarded by participants as Participation. The definition for Sport (d9201) is given as “Engaging in competitive and informal or formally organised games or athletic events, performed alone or in a group, such as bowling, gymnastics or soccer". It would seem illogical to define working out in a gym as Participation if others are present, but Activity if one were alone. Although some emphasise the social context of Participation, others define Participation as simply an activity which fulfils a personal goal or societal norm. This latter definition may include some activities which are carried out alone (McConachie et al., 2006). To these arguments is added the question of whether Participation includes areas essential to survival, given that these are often performed alone. McConachie and colleagues (McConachie et al., 2006) have argued that to omit self care from a measure of Participation is illogical, but others clearly regard these as Activities, rather than Participation and would not subscribe to this view (Van Naarden Braun et al., 2006b).

Another defining characteristic relates to complexity, where Activities are relatively simple in comparison to Participation which comprises complex combinations of different individual Activities. Empirical evidence for this idea was provided by the study by Jette and colleagues (Jette et al., 2003). Their factor analysis found that the items loaded on the Activity domains were relatively simple tasks whereas those loading on the Participation domain were more complex behaviours consisting of a number of contributing tasks. However, there are a number of layers of complexity in the various sub-domains and so using this definition leads to further questions about the complexity level cut-offs which differentiate Activity from Participation (Coster and Khetani, 2008). For example, maintaining a job may require an individual to drive a car, which in turn requires the performance of a range of tasks involving fine hand use and solving complex problems. The difficulty then, is in deciding whether driving a car is Participation, or whether this only applies to the employment.

A related idea is Activities being conceptualised as a means to an end, whereas Participation is an end in itself. Participation is accomplished by a number of Activities combined, but these Activities may vary between individuals achieving the same Participation goal (Whiteneck and Dijkers, 2009). An example might be playing football in a team, which may be achieved by running by some and by propelling oneself in a wheelchair by others. This idea is also evident in the hierarchical conceptualisation proposed by Badley (Badley, 2008). She suggested that items in the ICF's Activities and Participation chapters be divided into *acts* (things done independent of context, e.g. standing, running), *tasks* (things done with specific purpose and in specific contexts, e.g. dressing) and *societal involvement* (societally valued endeavours, defined by the social role and not the constituent acts or tasks).

4.2.2 Is Participation an objective or subjective phenomenon?

As described in the ICF, Participation is an objective phenomenon. That is to say it can be observed by a third person. Of course, it is experienced subjectively by the individual, and that experience is of great importance to that individual. One area which is difficult to reconcile with the objectivity concept, but which the ICF and others state is integral to the concept of Participation, is that of involvement (Schenker et al., 2005a; World Health Organisation, 2001). As well as including taking part, being included or engaged in an area of life, and having access to needed resources, the ICF suggests that the concept also includes being accepted. It is stated however, that the subjective "sense of belonging" is excluded from the definition of participation. However, it is difficult to see how being accepted can be a valid concept unless perceived subjectively by the person concerned.

Some authors have argued that only the subjective experience of Participation is really important (Ueda and Okawa, 2003). One can argue that this may be the case for adults, but for children and adolescents, where adults have some responsibility for their well-being and where normal development depends on a certain level of Participation, objective measures of Participation are also important. However, subjective experience is clearly still important to young people and would be important to measure alongside objective measures.

In defining Participation, it is important to be clear about what it is not. Because it is about being involved in life, it is not simply physical functioning or health status. As an objective concept, it should also not reflect a person's internal state, such as their happiness or satisfaction, which is measured as Quality of Life (Forsyth and Jarvis, 2002), or as a subjective aspect of the Participation.

4.2.3 Determinants of Participation

Construct validity is one aspect of the new instrument which needed to be assessed. Construct validity is discussed in more detail in Chapter 7, but briefly, it is the extent to which an instrument is measuring what is intended. One way of looking for evidence of this is looking at how scores on the new measure relate to scores on a measure looking at a concept which is thought to be related in some way. To design this part of the study, it was therefore necessary to look at the literature concerning how other concepts relate to Participation.

Participation is likely to be determined by a combination of factors including a person's body structures and functioning (or impairments), ability to take part in activities (or disability), as well as environmental factors, including aids and appliances, and personal factors (Forsyth and Jarvis, 2002). These latter factors will include personal choice, values and interests as well as personal attitudes. King and colleagues (2003b) proposed a model of discretionary Participation (all domains except self-care and school) for children with disabilities. They divided the determinants as being at the level of the environment (supportive relationships with the child or parents, the physical and institutional environment), the family (family Participation, home environment, family resources and demographics) and the child (physical, cognitive, emotional and social functioning, self-perception, personal preferences), with many of these factors interacting with each other.

Other authors have also noted that for children, Participation is often both dependent on and related to the Participation of their parents and other family members (McConachie et al., 2006; Kremarik, 2000). With the increasing autonomy of adolescence however, this relationship may change, although it is still likely to be more influenced by parents than in later adult life. However, the Participation of adolescents with severe impairments may remain more closely reliant on the family.

The environmental effect on Participation is well illustrated by two studies. A study from the North of England showed a strong association between deprivation as measured by postcode and lower levels of Participation (Hammal et al., 2004). The

SPARCLE study, which examined the Participation and Quality of Life of children with CP across Europe, found that country of residence had a greater effect on Participation than impairment (Fauconnier et al., 2009).

A number of studies, however, have shown impairment to be a major determinant of Participation in children and adolescents. Donkervoort and colleagues in the Netherlands (Donkervoort et al., 2007) found that motor and level of education reached (as a proxy for cognitive functioning) were determinants of Participation for young people aged 16–20 years. Beckung and Hagberg (Beckung and Hagberg, 2002) showed that amongst children with CP aged 5–8 years, Participation restrictions in mobility, education, and social relationships were strongly influenced by activity limitation as measured by the Gross Motor Function Classification and by intellectual impairment. The SPARCLE study of children aged 8–12 with CP in Europe found that lower Participation frequency was related to more severe impairment (Fauconnier et al., 2009). In the school setting, Mancini and colleagues in the US found impairment to be a significant predictor of Participation for children, as measured by the School Function Assessment (Mancini et al., 2000).

Of all these determinants, impairments are the most straightforward to measure as they are objectively determined, relatively stable and there are validated tools with which to measure them. The association between impairment level and Participation score was therefore chosen for the assessment of construct validity.

4.2.4 Participation and autonomy

It has been argued that the concept of autonomy is central to Participation and that wherever an element of choice or control over one’s life is included, this produces Participation (Perenboom and Chorus, 2003). Having choices and achieving a degree of autonomy are key life goals for all young people (McConachie et al., 2006) and would seem to be important to consider when looking at their Participation.

It is important to be clear what is meant by autonomy. Two aspects of autonomy have been described: executional autonomy and decisional autonomy. The former describes acting as one chooses, or physical independence; the latter, making independent decisions. Cardol et al (Cardol et al., 2002) argue that Western liberal thinking has led to an overemphasis on physical independence, and the ignoring of interdependence which is a normal part of life for all. This pathologises people with disabilities for whom physical independence may be impossible, although decisional autonomy may not. Saadah (Saadah, 2002) in a response to the paper by Cardol (Cardol et al., 2002), points out that autonomy is also culturally variable, and family interdependence may be perceived as much more important in other parts of the world.

Shakespeare (Shakespeare, 2006) also discusses interdependence, pointing out that the health and cohesion of communities is strengthened by interdependence. However, decisional autonomy should be promoted for all where this is possible and for this reason it seems reasonable to regard it as an important aspect of Participation.

The presence of decisional autonomy in some domains may be a key part of the Participation. For example, when measuring Participation in self-care, frequency of Participation is meaningless as all people, unless neglected, will have their hygiene and nutrition needs attended to if they are unable to do so themselves. However, where possible, making the decisions about how that care is delivered, when and by whom, is important for young people and adults and therefore autonomy in self-care can be viewed as the key element of this Participation to measure.

4.2.5 Previous qualitative studies of Participation

It is all very well discussing how academics and other professionals view Participation, but the views of individuals with disabilities are key, and may help in deciding which the most important elements are. A few qualitative studies have been published where conceptualisation and experiences of Participation have been explored with disabled children or adults. The grounded theory study reported by Hammel et al (Hammel et al., 2008) involved 63 adults with a range of neurodisabilities. Data was collected using focus groups. The study identified 6 themes characterising successful Participation. These were: active and meaningful engagement/being a part of; choice and control; access and opportunity; social connection, inclusion and membership;

having an impact and supporting others; and personal and societal responsibilities. It was felt that there was no universal definition or core list of areas for “full” or optimal Participation because of the variety of individual interests and lifestyle choices.

Two small studies have been carried out with disabled children. Sample sizes for both were limited by time and resources, resulting in data saturation not being reached. Heah et al (Heah et al., 2007) carried out 8 semi-structured interviews with children aged between 6 and 15 years and their parents. Themes which emerged as characterising successful Participation were: having fun; being successful; doing things with other people; and performing independently. A study by Harding et al (Harding et al., 2009) involved case studies with 6 children aged 8 to 13 years. They looked at the environment in which Participation occurs and using photos and interviews, explored children’s experiences of the spaces in which they Participate and supports and barriers to Participation. They found that the positive or negative feelings about the place of Participation had an impact on children’s views of that Participation, and the need for adequate physical access within an environment in order to Participate was highlighted. The effects of the environment on Participation were explored in a slightly bigger study of 13 parents of children with CP in the UK (Lawlor et al., 2006). They found that mobility, transport and attitudes of others and of institutions were important in facilitating and restricting Participation.

A project undertaken by the Joseph Rowntree Trust looked at the experience of inclusive leisure Participation for young people aged 12–19 years with learning disabilities (Murray, 2002). The project used interviews, photographs and other art-based methods to elicit the views of around 100 young people. A key theme to emerge was that young people valued being and doing things with others. In particular, young people with severe learning disabilities valued being with others, even when supervising adults felt that the young people were observers rather than true participants and hence they perceived that the experience was of little value to the young people. This highlights the importance of self-reporting of Participation where possible with adolescents, particularly where subjective experience is being measured, as proxy measures may not be valid.

What these studies demonstrate is that the experience of Participation is complex, and what matters to individuals is often the subjective experience as much as whether Participation occurs, although that too is important (e.g. doing things with other people). The outcome of the Participation (e.g. whether the individual is successful, the impact on others) and the setting of the Participation (e.g. whether with others) are also important.

4.3 The definition of Participation used in this study

The definition of Participation that I decided upon for the purpose of this project was informed by the discussions above, as well as by the literature on adolescent development (see Chapter 3).

I felt that the most appropriate stance from the options described in the ICF was where some domains are designated as Activities and some as Participation, with partial overlap in domains such as communication and mobility. The definition developed was that Participation should include the areas of life which are societally valued, but not necessarily done in the company of others. Activities are regarded as a means to an end, in contrast to Participation which is an end in itself. Activities include the relatively simple sub-domains whilst Participation consists of a number of different Activities combined. An example of this would be the combination of Activities such as "Comprehending literal and implied meanings of messages in spoken language" and "Changing basic body position" in order to Participate in a sub-domain such as "Taking part in team sports".

I decided that most individual self-care domains essential to survival, and which could be carried out for the young person if necessary, should be viewed as Activities and not Participation. However, where these constituted complex combinations of Activities and where autonomy would be important in normal adolescent development, these sub-domains were regarded as Participation. An example would be organizing the daily routine for hygiene, dressing, etc.

Because of the importance of developing autonomy for adolescents, I felt this concept should be included in most Participation domains. Final decisions about which specific sub-domains to include in the instrument were made following analysis of the qualitative data, described in Chapter 8.

4.4 Conclusions

Participation is an objective concept, different from subjective well-being. Although the ICF provides a basic definition, it is left to individual users to operationalise this, in particular when differentiating between Activities and Participation. This has been unhelpful in promoting communication between practitioners and researchers and no consensus has yet been reached, although a number of authors have tried to refine the definitions. Studies with disabled individuals can help in determining the areas individuals view as of particular importance, but few studies have been published, and several of these are with small numbers of participants.

After considering the views expressed in the literature concerning conceptualisation of Participation, in combination with the literature on adolescent development, I defined Participation in sufficient detail to enable the process of instrument development to begin.

Chapter 5. Measuring Participation

Having clarified in more detail how Participation could be defined and operationalised, the next step was to consider how it could be measured. The aim of this chapter is to discuss which aspects can be measured and some of the difficulties inherent in their measurement. I provide justification for developing a new measure by reviewing existing instruments and discussing their shortcomings when used with adolescents. I conclude by outlining the desirable properties for the proposed new instrument.

5.1 How is Participation measured?

A vast array of instruments have been described which can be said to measure one or more Participation domains. Some of these were developed before the ICF, but measure similar constructs, for example the London Handicap Scale (Harwood et al., 1994) or the Assessment of Life Habits (Life-H) (Fougeyrollas et al., 1997). However, because the ICF was published within the last decade, only a limited number of instruments have so far been developed which aim specifically to measure Participation (McConachie et al., 2006; Morris et al., 2005). Because of the differences in interpretation possible with the ICF (as I discussed in the last chapter) even those instruments developed since the ICF vary in many ways. Most instruments were initially developed with people with a specific condition. For example, the Life-H was initially developed for adults with spinal cord injury, although it has subsequently been used with other groups (Noreau et al.)

The variation in how Participation is measured led Coster and Khetani (Coster and Khetani, 2008) to list 3 questions which they felt should be answered by instrument developers and users when considering measures:

1. What conceptual distinction is made between Activities and Participation?
2. Is the measure looking at objective or subjective aspects, or both?
3. From whose perspective is Participation being viewed?

To these, I would add:

4. Will all domains be included or will the measure only apply to limited domains?
5. What data are required – a detailed examination or a broad-brush?

Whilst the differentiation between Activities and Participation has been discussed in Chapter 4, the next section in this chapter examines which objective and subjective aspects of Participation can be measured. I also discuss the importance of self-reporting for adolescents. Considerations 4 and 5 are then discussed in Section 5.3.

5.2 What aspects can be measured?

The instruments which have been developed to measure Participation in adults and in children use a wide variety of qualifiers[1], both objective and subjective (McConachie et al., 2006; Morris et al., 2005; Perenboom and Chorus, 2003). I now describe the types of qualifiers which have been used in more detail.

5.2.1 Objective indicators

The simplest objective indicator is whether or not a person participates in a given domain. Frequency of Participation, whether or not assistance is used, who Participation is with and the setting may also be elicited. These measures are relatively easy for respondents to answer and potentially to verify.

An assumption which is made when scoring objective measures is that "more is better". This leads to a greater frequency of Participation producing a higher score, implying "better" Participation. Some commentators who support this view, argue that frequency of Participation is crucial in measurement (McConachie et al., 2006). I would argue that more Participation may be better, but will depend on the subjective experience of the Participation. For example, more Participation in an activity which a person finds stressful or experiences negatively in some way is unlikely to be beneficial in most situations. Excess participation in one activity to the detriment of other activities may also be harmful. An example of this is the finding that adolescents who spend a large amount of their free time in paid employment, take part in less extra-

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[1] A *qualifier* is the term used to mean what it is about the Participation that is being measured by an item, e.g. frequency, satisfaction, difficulty, etc.

curricular activities and are more likely to engage in delinquent behaviours (Steinberg and Cauffman, 1995). This problem may be overcome by including subjective qualifiers such as asking if “enough” or “the right amount” of time is spent in that activity. An alternative is to administer both objective and subjective measures of Participation.

It can be argued that measuring the extent of Participation is particularly crucial in children and young people. Adults clearly have a right to make entirely autonomous judgements about what they wish to participate in, but the responsibility for young people’s Participation to some extent still rests with parents and other adults. There is an obligation on the part of adults responsible for their welfare to provide opportunities for a range of Participation, even if the young person ultimately decides they do not want to take part.

Qualifiers relating to assistance and adaptations are used in some measurement tools, for example the Life-H and the School Function Assessment (SFA) (Coster et al., 1999). It is an understandable wish to measure how much assistance a disabled person requires to carry out a certain activity and it may be useful for determining policy and funding for equipment or in measuring individual changes in function over time. However, this will not capture how much decisional autonomy the person has in determining when and where an activity is carried out, which may be more important than the degree of assistance required. In addition it could be argued that aids and assistance are simply one part of the environment which may impact on Activities and Participation and there is no good reason to single them out over and above other facilitators or barriers. By including this in the scoring system, as is done in the Life-H instrument, a value judgement is made that requirement of assistance reduces the value of Participation in some way, which does not reflect the social model of disability.

Objective measures are probably the most useful when an individual is unable to self-report, given the uncertainty over the validity of proxy reports for subjective experience which have been highlighted with health-related quality of life measurement (Havermans et al., 2006; Kramer et al., 2004; Waters et al., 2003). This is important to bear in mind when considering young people with CP, a significant proportion of whom have a learning disability.

5.2.2 Subjective experience

Satisfaction, enjoyment or importance of Participation can all be included in instruments. Importance may be a valuable qualifier, given that Participation in some areas may have different levels of importance to people with disabilities compared to those without. Ueda and Okawa (Ueda and Okawa, 2003) point out that the importance of a particular area to the individual will determine whether Participation restriction in that area is actually of any consequence to them as an individual.

Hammel's paper describing a qualitative study with disabled adults (Hammel et al., 2008) highlighted the importance of subjective aspects of Participation to disabled people themselves. Areas identified as important included choice and control over Participation and social inclusion. This study found that the disabled people themselves rated the subjective experience as more important than the frequency and type of Participation engaged in.

A variety of adult instruments capture the concept of choice. It may be argued that this can be elicited objectively, although there may also be a subjective element. Phrases used include asking whether the respondent can participate "as and when I want" in the Keele Assessment of Participation (KAP) (Wilkie et al., 2005), or as "necessary", "important" or "desirable to me" in the Reintegration into Normal Life Index (Wood-Dauphinee et al., 1988).

Ueda and Okawa (Ueda and Okawa, 2003) argue that the individual's experience of Participation is what really matters, and any measure which does not include this is meaningless. They, and others, feel that the ICF itself should include a subjective dimension within the classification (Ueda and Okawa, 2003).

5.3 Content coverage of Participation instruments

Participation instruments have been developed that aim to measure multiple domains of Participation or a single domain. Those which cover multiple domains can be divided broadly into two types. One type, which I refer to as “broad-brush”, is a brief questionnaire with one or two questions for each major domain, and with scores for each item summed to produce a single score. These instruments are likely to be most useful for epidemiological surveys. An example would be the KAP (Wilkie et al., 2005), an adult instrument with 11 items. An example of an item is: “During the past 4 weeks, have you taken part in paid or voluntary work, as and when you have wanted?”

Other instruments are more detailed with multiple questions for each Participation domain, and may be used for epidemiological studies or in clinical settings. Some of these instruments aim to measure all domains in depth (for example, Life-H) and others measure only certain domains. An example of the latter is the Children’s Assessment of Participation and Enjoyment (CAPE) (King et al., 2004) which aims to measure discretionary Participation, and therefore omits items related to school and self-care. Some of the instruments covering all domains are very long, with many items, and some require multiple responses for each item. For example, the full version of the Life-H has several hundred items.

There are also instruments which cover only one Participation domain. Examples are the SFA (Coster et al., 1999) and the Adolescent Leisure Profile (Henry, 1998). Some instruments measure other constructs in addition to Participation. The SFA is in 3 sections: Participation, Task Supports (assistance and adaptations) and Activities. The Child and Adolescent Scale of Participation (CASP) (Bedell, 2004) has sections covering Home and Community Participation, Problems Experienced in Daily Life, Child’s Current Services and Family Services.

The type of instrument required will depend on the intended purposes. The most versatile instruments include all domains, although clearly they are not ideal if only one domain is of interest. Those with only a few questions on broad domains may be less sensitive to change than more detailed instruments, but will be quicker to complete.

5.4 Problems with existing instruments

Although multiple scales have been developed, not all have adequate psychometric data available or have been widely used (Imms, 2008). A Delphi study (Vargus-Adams and Martin, 2009) involving professionals and families asked what outcomes should be measured in CP. Participation was one of 8 areas identified but there was no consensus around which instruments should be used. Participants suggested a range of Participation instruments as suitable for children and young people, including some (e.g. Activity Scale for Kids (Young et al., 2000)) which I would regard as measuring Activities rather than Participation.

There are a number of further reasons why existing measures are inadequate when measuring the Participation of adolescents. The first of these is that there are no instruments covering multiple domains, which have been specifically designed for adolescents. The Life-H appears to be the only instrument that has both child and adult versions. Some of the instruments designed for children aim to include those in the adolescent age range, although most do not include older adolescents, with quoted upper age limits of around 14 years old. They include questions applicable to younger children, for example about play, and therefore may not be acceptable to adolescents. Adult instruments could be used for adolescents, but items concerned with home management, caring for children and spousal relationships are frequently not relevant and other items of importance to adolescents are frequently missing.

The only instruments to my knowledge developed specifically for adolescents are the Adolescent Leisure Profile and the Rotterdam Transition Checklist (Donkervoort et al., 2008). The former measures only leisure Participation, has 83 items and includes a number of objective and subjective qualifiers for each item. Because it is such a detailed instrument looking at just one area of Participation, it was not particularly helpful in informing item development for the new instrument. The Rotterdam Transition Checklist is concerned with measuring the progression of specific

Participation milestones in three stages through adolescence into early adulthood. It covers 7 areas of Participation and 4 aspects of health care and scores an individual's degree of transition.

Most instruments were not designed with UK populations. Culture has an influence on Participation patterns, and so instruments developed elsewhere may need to be adapted and then validated with the new population. This has been done in the UK with the CAPE and LIFE-H-Child (Fauconnier et al., 2009; H McConachie, personal communication). Some instruments include health related questions which may have poor face validity for those without disability (Jessen, 2004), making it more difficult to collect comparative data from the normal population.

Adolescents with sufficient cognitive ability are best able to report their own Participation. Many scales are not self-report, and those that are do not have proxy-report versions for use where an adolescent does not have the cognitive ability to self-report. As well as who reports the Participation, the relevance of the items to the respondents is clearly important in the validity of resulting scores, and so the involvement of potential respondents in instrument development is now seen as important (Waters et al., 2009). Most Participation instruments for children have not involved them in any major way in the development.

A recognized pitfall with the wording of questionnaire items is *double-barrelling* (Oppenheim, 2000). This is where several questions are included in one. A number of published instruments include complex questions where this is an issue. In the SFA, the respondent is asked to rate on a single scale of 1 (Participation extremely limited) through to 6 (Full Participation) "the extent to which the student actively participates in all relevant activities in the setting … and should consider all aspects of the tasks and activities involved (physical, cognitive, social etc)". An example of an item is "Playground/Recess: Free time spent in the classroom, gym or on the playground … including both physical and social-emotional aspects of Participation. Includes playing games involving physical activity, using playground equipment, following rules, and playing cooperatively with peers." Apart from the complexity of the cognitive processes required in answering such a question, it may be particularly difficult to answer if, for some activities a young person fully participates, and for others requires a large amount of assistance. Items such as these are also less likely to be sensitive to change; if one or two aspects showed small improvements, this may not be reflected in the score.

Another example is the CASP, where the respondent is asked “Compared to other children your child’s age what is your child’s current level of Participation in the following activities?” Item 7 reads: “Social, play or leisure activities with friends in the neighbourhood and community (e.g. casual games, hanging out, going to public places such as a movie theatre, park or restaurant)”. An answer indicating a low level of Participation may be indicated if the child takes part in none of these areas. However, it may also be answered in this way if Participation in only one area is poor but others are good, if the child Participates with friends who live further afield than the immediate neighbourhood, or if the friends are from the neighbourhood, but the Participation takes place in another town.

For instrument developers wanting to measure multiple domains, the alternative is to include many more individual items but this may reduce the acceptability of the instrument to respondents.

5.5 Instruments used to inform item development

There are only a relatively small number of well-evaluated instruments which measure Participation in a way which is similar enough to my aim to make them useful in informing item development and these are summarised in table 5.1 at the end of this chapter. Although less well used than the others, I also looked at the Children Helping Out: Responsibilities, Expectations and Supports (CHORES) instrument (Dunn, 2004) because of the importance of domestic Participation in adolescence.

5.6 Conclusions

A number of instruments can be used to measure Participation, but so far, none has been developed for adolescents covering all major Participation domains. Existing measures could be used but present a number of problems, supporting the need to develop a new instrument for this group. However, a number of existing instruments, designed either for children or adults, were identified as a potential source of items or to check content coverage and these have been described.

Returning to the considerations described at the beginning of this chapter based on the discussion by Coster and Khetani (Coster and Khetani, 2008), the measure I set out to develop was underpinned by the definition of Participation described in Chapter 4. That is, that Activities are differentiated from Participation at the level of ICF sub-domains, that Activities are simpler elements of functioning while Participation is made up of multiple Activities that may differ between individuals and that Participation is an end in itself. Prior to the qualitative work, I kept an open mind as to which qualifiers I would include. I did however decide that scoring respondents based on whether assistance is required would not be used, as it is not compatible with the social model of disability. I wanted the instrument to reflect the perspective of adolescents and chose my methods accordingly. I aimed to develop an instrument that would be self-report where possible but had a proxy report version so that it could be used with those with cognitive impairment. I also wanted to have an instrument which would have face validity for those without disability so that comparative data from the general population could be obtained, and so I included adolescents without disability in the qualitative work.

As most epidemiological research and also evaluation of clinical interventions is likely to require a measure of all domains, I decided to develop an instrument which covered all domains relevant to adolescents in detail. I also aimed to ensure items were as simple and unambiguous as possible, and chose methods (qualitative work with young people, expert review and cognitive interviews) which would help achieve this.

Name of instrument	**Age range**	**Country of origin**	**Number of items**	**Type of instrument**	**Domains included**	**Qualifiers**
CAPE (King et al., 2004)	6–14 years	Canada	49	Self-report Normative data available	Discretionary Participation	Who with, enjoyment
CASP (Bedell 2004)	3–21 years	US	20 in Participation section	Postal questionnaire Proxy report	Home and community Participation	Compared to others the same age. Importance to care-giver
CHORES (Dunn 2004)	6–11 years	US	33	Proxy report	Household Tasks – self-care and family care	Frequency and assistance
LIFE-H (Fougeyrollas et al., 1997)	Adult	Canada	240 (detailed) 77 (shortened)	Self-report	All domains – Activities and Participation	Level of difficulty, assistance, level of satisfaction
LIFE-H-Child (Fougeyrollas et al., 1997)	5–13 years	Canada	195 (full) 62 (shortened)	Derived from adult instrument Proxy report	All domains – Activities and Participation	Level of difficulty, assistance, level of satisfaction
SFA (Coster et al., 1999)	5–14 years	US	6 in Participation section	Proxy report	Activity and Participation in school	Assistance required

CAPE – Children's Assessment of Participation and Enjoyment; CASP – Child and Adolescent Scale of Participation; CHORES – Children Helping Out: Responsibilities, Expectations and Supports; Life-H – Assessment of life habits for children; SFA – School Function Assessment

Table 5.1 Participation instruments currently available that were referred to for item development

Chapter 6. Participation for young people with cerebral palsy

So far I have discussed the effects of cerebral palsy on individual functioning, the development taking place in adolescence and how Participation affects this, as well as how Participation may be conceptualized and measured. This chapter brings all these elements together in examining the evidence for how the Participation of young people with CP compares to that of the general population. This is important in putting the development of the proposed instrument in context particularly as the instrument itself may be used to compare Participation patterns for those with and without disability. Data on the areas of Participation where differences have been observed, are important when considering which specific areas should be included in the instrument.

In order to see the Participation of disabled adolescents in context, some understanding is also necessary of childhood and adulthood Participation for this group, as adolescent Participation will be both influenced by past Participation and itself influences that in the future. In addition, a young person's perception of their likely future Participation may affect their current choices.

I therefore start by discussing Participation patterns in children and in adults with CP before moving on to discuss the literature comparing adolescent Participation in young people with CP and other disabling conditions, with the general population.

6.1 Participation for children with cerebral palsy

Adolescent Participation is clearly not isolated from that in childhood. Some social factors, for example living with parents and attending full-time education, are common to both life stages, so differences seen in Participation between disabled individuals and their peers in earlier childhood may persist. Attitudinal barriers experienced by children, even if not present later, may nonetheless continue to affect Participation choices.

The Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE) (Fauconnier et al., 2009) was a multicentre study of children aged 8–12 years. It included 818 children with CP and looked at the relationships between Participation and quality of life and the environment. Findings were compared with data from the general population. The UK sample for SPARCLE was recruited from the NECCPS, which I also used for my work. Childhood Participation as found in SPARCLE is therefore of particular importance for my research. It is also the largest study of its kind to date.

SPARCLE found that apart from participating in relaxing activities, and playing non-sporting games, children with CP had lower Participation in all areas, compared to the general population. For example, two thirds of the general population played sport at least twice a week, compared to one third of the children with CP. Half of all children in the general population helped with housework compared to a quarter of those with CP. Although SPARCLE, as with other studies, found lower Participation for the disabled children in many areas, they also found that in some areas children with CP participated more. For example, children with CP participated to the same degree or more with activities arranged by their school, and those with mild to moderate impairments used a computer, played non-sporting games and ate out more than children in the general population.

In another large study, (Law et al., 2006; Law et al., 2005) Participation in leisure activities for children with physical disabilities aged 6–14 years was measured using the Children’s Assessment of Participation and Enjoyment (CAPE) instrument. Around half of their 427 participants had CP. Compared to a group of 354 school children without disabilities, those with disabilities participated in fewer different activities and at a reduced intensity. This was particularly marked for physically active or skill-based activities. Similar findings with a sample of 114 Australian children with CP aged 10–12 years have been reported (Imms et al., 2008). The latter study also found that children with CP participated in more organized sport and cultural activities than able-bodied peers, although overall, they were more likely to participate at home and with family rather than with friends and in the community.

Children spend a significant amount of time in school, and so their Participation there is very important. A number of studies have addressed educational Participation both quantitatively and qualitatively (Imms, 2008). For example, Schenker and colleagues (Schenker et al., 2005b) compared 148 Israeli primary school children with CP and 100 able-bodied students. Using the School Function Assessment, which measures participation and activity performance in the school setting, they found significant differences between those with CP and those without. Higher levels of impairment were associated with poorer Participation and they also found an association between speech and language difficulties and lower Participation. Participating in the playground was the area where the difference in scores was greatest between children with CP and their able-bodied peers; snack and mealtimes showed the smallest difference in Participation scores.

Hemmingsson and colleagues (Hemmingsson et al., 2003) looked at the effects of school assistants on the Participation of a small number of children (n=7) aged between 7 and 15 years with physical disabilities. They used a combination of observations and interviews and found that assistants could both facilitate or hinder Participation, depending on the situation. They also noted that educational and social Participation could sometimes conflict, with facilitation of one leading to a reduction in the other. Reduced quality of Participation of children with disabilities in peer relationships in school has also been shown by Watson and colleagues (Watson et al., 1999). Their study highlighted the fact that the greatly increased level of adult surveillance which the disabled children receive prevents the normal peer interactions, gossip and messing around, with the ever-present supervising adult often resented by other children.

Some studies have found that Participation intensity in some areas tends to reduce as children get older. This was demonstrated by King and colleagues (King et al., 2009) who looked at the changes in discretionary Participation measured by the CAPE over three years in children and young people with CP and other physical disabilities aged 6–15 years. Cross-sectional studies have also suggested this (Law et al., 2006).

Studies looking specifically at environmental barriers and facilitators to Participation for children with CP in the UK and elsewhere have identified numerous factors. However, the overall contributions of different factors and the interactions between them are still poorly understood (King et al., 2009). Barriers identified include financial difficulties, inadequate public services, availability of equipment, and high levels of family stress (Lawlor et al., 2006; Hammal et al., 2004; Mihaylov et al., 2004). High family level of Participation, higher family income and school and family expectations have been found to be facilitators (Shikako-Thomas et al., 2008; Law et al., 2006; Hendey and Pascall, 2001). Area of residence has also been shown to affect Participation (Fauconnier et al., 2009; Hammal et al., 2004).

6.2 Participation in adults with cerebral palsy

As I have argued in Chapter 3, in addition to adolescent Participation being of value in itself, it is also important for future functioning. Furthermore, it can be hypothesised, that young people make choices about current Participation based on their perception of their likely Participation in adulthood. Some evidence for this can be found where young people come from communities with high unemployment, and do not take up educational opportunities because they perceive that they will also not find employment and therefore see no purpose in education (Spencer and Dornbusch, 1990). It is therefore important to consider how Participation in adulthood is experienced by disabled people when trying to understand that in adolescence.

Michelson et al (Michelsen et al., 2006) looked at the Participation of adults with CP in the major life areas of independent living, employment, sexual relationships and childbearing, which they regarded as markers of social integration. The participants were 416 individuals aged 29–35 years living in Denmark. They were compared with 2247 age-matched controls. Two-thirds of participants lived independently, fewer than in the comparison sample. Developmental quotient, epilepsy and severity of motor impairment significantly predicted not achieving independent living. Compared to 69% in the comparison group, 28% of the CP group were co-habiting, with proportions married being 26% and 13% respectively. Both these sets of figures show a significant difference ($p<0.001$). 61% of the comparison group had biological children compared to 19% of the CP group, again statistically significant ($p<0.001$). Overall 55% of the participant group were not cohabiting, had no competitive employment and had no biological children, compared to 4% in the comparison group. Amongst those with at least one of these markers of social integration, only a quarter of the participants (compared to half of the comparison group) had all three. Other studies from US, Japan and Denmark have also shown lower proportions of adults with CP in paid employment (Michelsen et al., 2005; Murphy et al., 2000; Tobimatsu and Nakamura, 2000), living independently (Murphy et al., 2000) and in relationships (Michelsen et al., 2006) compared to the general population.

Van Naarden Braun and colleagues (Van Naarden Braun et al., 2006a) compared the leisure activities of young adults aged 21–25 years with developmental disabilities to a non-disabled comparison sample. This was a follow-up study to the Metropolitan Atlanta Developmental Disabilities Study, a population-based longitudinal study of children who were aged 10 years in 1975–77 and had certain impairments. Overall, young adults without impairment participated in significantly more leisure activities than those with impairment. Those with isolated hearing impairment, epilepsy or CP showed no difference in leisure Participation compared to the comparative sample. The number with isolated CP was small (18 out of a total of 490 with impairments) and it is not possible to discern from the paper how many of those with more than one impairment had CP. In addition, the questionnaire used contained only twelve leisure items. This study also found that educational attainment and the acquisition of adult social roles (competitive employment, post-secondary education or care-giving) were stronger predictors of leisure Participation than socioeconomic and demographic factors.

In a qualitative study (Hendey and Pascall, 2001) researchers in the UK interviewed adults with severe motor impairments about the barriers and facilitators of independent living and employment. Barriers included the limited availability of accessible accommodation which was affordable, and the unhelpful rules of the benefits system which made both independent living and paid employment incompatible for some. In addition, the time and energy needed to organise and manage personal care and other facets of independent living left many with insufficient time and energy for paid employment.

6.3 Participation in adolescents with cerebral palsy

As one would predict from the discussion above, Participation in adolescents with CP is also found to be reduced compared to the general population in many areas. However, as with the findings in the SPARCLE study, the detail is important because within the trend for lower Participation, there may be important variations in certain domains.

A study from Australia of 120 adolescents aged between 11 and 17 years with CP (Maher et al., 2007), examined the extent of physical and sedentary activity compared to a non-disabled sample. They found that young people with CP reported a lower level of physical activity for every time period during the preceding 7 days than similarly aged young people without CP. Physical activity was measured by self-report and was asked about in relation to time at school and out of school. Some types of physical activity undertaken were similar in both groups, other areas were more commonly reported by those with CP including playing with animals and with younger children, using playground equipment and swimming. These findings may suggest that those with CP have fewer opportunities for social activities with peers.

The use of new technologies is an important area of adolescent Participation in the developed world. A study from the Netherlands (Lathouwers et al., 2009) looked at how the frequency and nature of internet use amongst a sample of 97 physically disabled adolescents aged 13–18 years compared to a non-disabled group of 1566 young people. The disabled sample all had an IQ>75. Just over a third of the sample had cerebral palsy. They also looked at the degree of guidance provided by care-givers. Whilst no differences were seen in access to the internet, there were some differences in type of activity. Fewer disabled adolescents used the internet for obtaining information or for downloading films. Why this may be the case is not discussed in the paper, but it may be that the difference in downloading of information reflects differences in educational expectations. Lathouwers also found that those with disabilities were more likely to be warned about the risks of the internet and had more rules imposed on them at home. This may be an example of increased parental protectiveness of disabled young people, which in some situations may produce a barrier to Participation, but could also be entirely appropriate.

I could find no studies looking specifically at part-time work and work experience for young people with CP. However, a study by Anderson and Vogel (2000) in the US comparing the work experiences of a small number of adolescents (n=28) aged 13–19 years with spinal cord injuries and 25 friend or sibling controls, found non-significant differences in participation in chores or voluntary work, but significantly fewer disabled young people had experience of paid employment. They suggest that this is due to reduced expectations from parents as well as resistance from employers to consider taking on disabled young people in part-time jobs. They also make the point that those with more severe impairments may have less spare time available to take on paid work, because of the demands of their condition.

The CP Transition study in south-west Netherlands is a prospective longitudinal study of adolescents with CP, who were aged 16–20 years at the outset (Donkervoort et al., 2008). Those with severe intellectual impairment were not included. They looked at a number of areas of Participation and their determinants, using the Life-H to assess Participation. They found that 25% of participants at 18–22 years old were living on their own, compared to 36% in the reference population ($p<0.05$), and 23% had a job, compared to 49% of their able-bodied peers ($p<0.05$). The latter figure may overestimate the difference between the groups, as the reference population in that case was aged 18–24 years.

Two year follow-up data from the Dutch study described above, was published looking specifically at romantic and sexual relationships (Wiegerink et al., 2010a) and reported data from 87 participants. These were predominantly white and from urban areas and so the findings may not be generalisable to other populations. A study of 1962 Dutch adolescents aged 18–22 years from the general population was used for comparative data. They found that the proportion reporting three or more close friends (67%) was similar to the comparative general population sample (64%). Although 77% said that they had experience with a romantic relationship, only 23% were involved in such a relationship at the time of interview, which was significantly lower than the comparative group (61%, $p<0.001$). Going out with friends and dating were associated with later development of romantic and sexual relationships. Those who went out regularly with friends were four times more likely to have romantic relationships and sexual experience, highlighting the interaction of different areas of Participation.

Relationships for disabled adolescents were also examined in a study from 1991 from the US (Blum et al., 1991). 102 young people with spina bifida and 60 with CP, aged 12–22 years, were interviewed about peer and family relationships. They did not have comparison data from the general population, but they did ask the young people how some of their Participation compared with peers. As with other studies, they noted a low level of sexual relationships and a tendency for activities with peers to be passive and home-based (for example, watching TV). They also commented on the high level of family accord, with 98% reporting close relationships with parents, which they note may represent a delay in the normal individuation process of adolescence. They also found that 28% of their sample of young people did not contribute to household chores and of those that did, most undertook very minimal chores or only those related to personal hygiene.

Reductions in social Participation were also suggested by the more recent study by Engel-Yeger et al (Engel-Yeger et al., 2009). Data obtained using the CAPE showed that those with CP participated more at home, and were more likely to do activities on their own, as opposed to the non-impaired who were more likely to participate with friends. This study however, used small, unmatched samples from one geographical area and all young people with CP attended special school. Findings therefore may not be generalisable.

Doubt and McColl (Doubt and McColl, 2003) looked at the barriers to social Participation for young people with disabilities. These young people identified the attitudes of non-disabled peers, treating them as though they were younger or less intelligent, as one barrier. They also identified their own worries about acceptance as a barrier. This latter observation is not a surprise, given the increased self-awareness and concern about others' perception of oneself which is a developmental feature of adolescence. Given the findings discussed in Chapter 2 (Nadeau and Tessier, 2006; Yude et al., 1998) that younger children with CP have fewer friends and are more likely to be victimized, the perceptions of the adolescents may also be based on prior experience.

Brodin and Fasth (Brodin and Fasth, 2001) looked specifically at the equipment needs of adolescents. Their survey included 477 young people between the ages of 16 and 24 years with motor disabilities in Sweden. Just over a third of the sample had cerebral palsy and a third of those had severe intellectual disability. Depending on the area of Participation and the young person's level of impairment, in 16–62% of cases appropriate aids were unavailable. Of those who needed the assistance of another person, only 26% had chosen the person themselves. This is an important issue when considering the autonomy development for these young people.

The CP Transition study discussed above also looked at possible determinants of Participation in their sample. They found that, although not accounting for all the variance, motor functioning (measured by the Gross Motor Function Classification System) and educational level achieved were the major determinants of Participation, along with age (Donkervoort et al., 2007).

6.4 Conclusions

In summary, individuals with CP of all ages tend to have lower Participation in many life areas compared to the general population. The adolescent with CP is likely to have already experienced reduced Participation as a child, which may have reduced their expectations, as well as having led to a narrower range of experiences affecting development. Although the research literature is limited, and mostly involves small populations, the evidence we have suggests that barriers to Participation continue in adolescence, and when they reach adulthood, problems persist. The likely realities of adult Participation may affect both their aspirations and those of others for them, thereby impacting on current choices.

Areas of key importance – both because adolescents value them and because of their developmental role – were discussed in Chapter 3. The evidence I have presented above shows that these same areas – peer relationships, employment and other transitions to adult roles, such as independent living – are all those showing reduced levels of Participation in the samples of disabled adolescents studied. Facilitators and barriers are numerous and not well understood. The ability to satisfactorily measure a wide range of Participation domains is therefore of key importance if the lives of disabled adolescents are to be improved.

Chapter 7. Exploring the methodological framework

This chapter sets out the theory underpinning the different parts of this research. I start by discussing theories of measurement and the assumptions made when developing instruments to measure a construct such as Participation. I then introduce the philosophical underpinnings of the qualitative research methodology and how they affect the analysis and conclusions which can be drawn. In the final section I discuss how the concepts of validity and reliability relate to both the qualitative work, as well as the evaluation of the Participation instrument.

7.1 Theoretical basis of scale development

One of the main concerns of science is the measuring of things. Different branches of science have developed their own specialist methods for quantifying the phenomena in which they are interested. Measurement in the social sciences is concerned with measuring theoretically derived concepts rather than directly observable physical properties. The science of measuring psychological, educational and other social phenomena is called *psychometrics.*

There is no physical piece of equipment which we can hold up against a person to determine their quality of life, or their intelligence. Instead a questionnaire is usually used, and this consists of a number of individual items which reflect different facets of the concept of interest, and which are combined to produce an overall score. The concept being measured is sometimes referred to as the *latent variable*. A key requirement when developing a scale is a clear understanding of the phenomenon of interest and how it relates to other relevant constructs (Streiner and Norman, 2008).

The unit of measurement is an important consideration in any instrument. In his paper of 1946, Stevens defined 4 types of unit of measurement which determine the statistical manipulation which will be possible with the resulting scores. These he called interval, ratio, ordinal and nominal. An interval scale consists of numerically ordered points, with a known distance between the points, an example being degrees of temperature. A ratio scale is similar but has the added criterion of having a defined zero, allowing for the ratio between units to be calculated. Unless a scale includes an absolute zero, one measurement cannot be said to be a multiple of another. An ordinal scale also consists of response categories which are ordered but where the difference between responses is not known and may not be equal. An example might be a Participation scale where respondents indicate frequency using a scale from "Very frequently to "very rarely". Finally, a nominal scale has categories which cannot be ordered, such as ethnic group or gender (Stevens, 1946).

The importance of understanding this is to ensure the selection of the appropriate statistical tests. Many scales for measuring concepts such as Participation are ordinal, and care must be taken to use statistical tests which are appropriate. There appears to be some disagreement between statisticians and instrument developers about the use of certain tests with non-interval data. For example, some statisticians have been critical of tests such as Cronbach's alpha being used with ordinal data (Svensson, 2001) although these tests are widely accepted for such use. One widely used manual on test development states that ordinal data may be treated as interval for most purposes (Streiner and Norman, 2008). Following this tradition, I used such tests for the psychometric analysis of my instrument.

7.1.1 Theories of measurement in the social sciences

There are different ways in which questionnaire items can relate to the latent variable. In classical measurement theory, items are caused by the latent variable, and these have been termed *effect indicators*. For example, items on a scale designed to measure depression will consist of symptoms caused by depression. Alternatively, items may have different causes but they all contribute to the concept being measured. In other words, they have a common outcome, rather than a common cause (DeVellis, 2003). These have been described as *causal* or *defining indicators* (Bollen and Lennox, 1991; Fayers and Hand, 2002). I will use the latter term from now on as the word *causal* is confusing in this context. (Further confusion is generated by some authors referring to effect indicators as *indicator variables* and defining indicators as *defining variables*). Examples of concepts measured by defining indicators which have been discussed in the literature include health-related quality of life and the Apgar score (Fayers and Hand, 2002; Bollen and Lennox, 1991). The difference between effect and defining indicators is illustrated in figure 7.1.

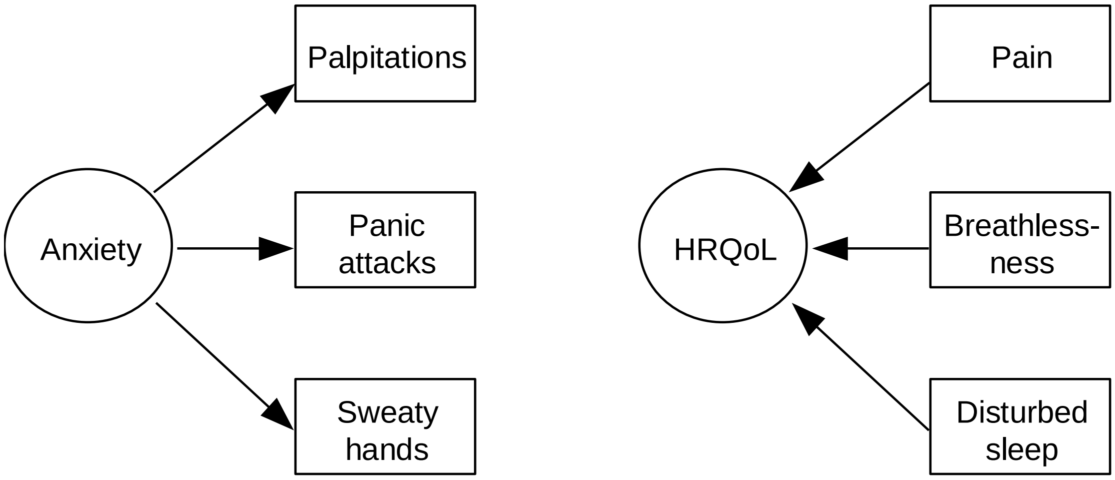

Figure 7.1 Models of concepts measured using effect (left hand diagram) and defining (right hand diagram) indicators

The science of psychometrics was developed by researchers devising instruments to measure intelligence and other psychological traits, where items tapping the underlying variable are facets of it. In this situation, each item taps the underlying construct to the same degree, and the items chosen for the scale are a random selection of those from the universe of all possible items. This has two results. Firstly, the items correlate with one another because of their relationship with the latent variable, and so internal consistency is useful in demonstrating that all the items are tapping the same latent variable. In contrast, when measuring HRQoL, not all patients will have the same symptoms which lead to a reduced quality of life, and the types of symptoms they experience will be determined by their specific disease, or its treatment. Therefore, one would not expect to find a correlation between all items in the same way (Fayers and Hand, 2002).

Secondly, as a result of the relationship between items and the latent variable, it doesn't matter which items are chosen from all possible items, because they all represent a facet of the construct in the same way. In other words, content coverage is less important. Using traditional methods, developers of some HRQoL instruments have found that in an attempt to improve internal consistency, they have removed many items from scales which patients say are important, thereby sacrificing content coverage and hence validity (Fayers and Hand, 2002). Separate versions of these scales have then been devised which maintain content validity, but lack internal consistency. Abandoning a requirement of internal consistency removes this conflict, as well as making better theoretical sense.

The study of measures using defining indicators has been termed *clinimetrics*, as it has been used for clinical measures. Whilst internal consistency is not relevant, other measures of reliability such as test-retest and the various aspects of content and construct validation are appropriate for either type of measure (Fayers and Hand, 2002).

Papers discussing the difference between these scenarios and the implications for appropriate evaluation of instruments have been published since the 1960s, but it is only relatively recently that researchers more widely have begun to appreciate the difference. Fayers and Hand (Fayers and Hand, 2002) published a very useful review of the issue, highlighting the difficulties that developers of HRQoL instruments have had in using psychometric methods to develop their instruments. Because instrument developers in the social sciences have been slow to appreciate the difference between these models and the implications for instrument evaluation, few papers report clinimetric rather than psychometric studies, where these would be more appropriate. Participation measures have not been developed in this way, and it is only recently that discussion has been published concerning this aspect of the measurement of Participation (Dijkers, 2010; Whiteneck and Dijkers, 2009).

All other Participation instruments to date have been evaluated using traditional psychometric principles, and it is unclear from previously published data whether Participation requires effect or defining indicators, or whether some domains may be one type of variable and some the other. I therefore kept an open mind at the outset about how the Participation measure should be evaluated, using both methods to examine the results.

Classical measurement theory (CMT), also known as classical test theory, was, as the name suggests, the original theory developed in the social sciences. It states that the observed score consists of the "true" score plus error (DeVellis, 2003). Scales developed according to the principles of CMT are made up of a number of items which all tap into the latent variable to a similar degree (DeVellis, 2003). Although this theory is the oldest, and newer theories have subsequently been developed, it is nevertheless still regarded as appropriate for many purposes (Streiner and Norman, 2008; DeVellis, 2003).

From CMT other theories have been developed which make different assumptions about the relationship between the items and the latent variable. Depending on the purpose of the instrument and the characteristics of the construct of interest, one or other theory may be more suitable. One theory originally derived from CMT is item response theory (IRT), an alternative that I rejected for use in this project. IRT has been used in the development of a number of types of instrument. Individual items and their characteristics are considered, rather than a more broad view of the scale overall. The characteristics of the respondent and the responses they give to the scale items are a major consideration. Three factors are considered for each item. The first is the difficulty, or the degree of the construct present for the participant to be able to answer the question. The second is the discriminatory power of the item, and the third takes account of the likelihood that a respondent has guessed the answer. Rasch analysis, a commonly used technique, is derived from IRT.

I chose to use CMT rather than IRT in designing my instrument, for several reasons. Firstly, IRT is most appropriate where there is an inherent hierarchy in the item pool and where the scale is unidimensional. I was not sure that either of these conditions applied to Participation across all ICF domains, and so felt CMT would be more appropriate. Secondly, the sample sizes necessary for testing scales designed using IRT are large and the recruitment of many hundreds of participants was not going to be possible given the time scales and resources available for this project. In addition, IRT has the same problems as CMT in evaluating scales consisting of defining indicators, as the assumptions are the same as CMT in terms of the direction of the relationship between items and the construct of interest. There would therefore be no advantage in using IRT over CMT if the Participation measure was found to be most appropriately defined as clinimetric.

7.1.2 Theoretical considerations for item sources

Because of the nature of the phenomena being measured in the social sciences, tools are often developed from theory and then tested empirically to determine whether the theory works in reality. The danger with relying entirely on theory is that, should the theory prove wrong, the scale will need completely rewriting following empirical testing. Using empirical data in addition to theory is therefore recommended. In some cases, empirical data may already exist, or research may need to be carried out for the purpose of developing the instrument (Streiner and Norman, 2008).

Data for items are often obtained from research participants from the population in which the instrument will be used, or from experts in the field (Streiner and Norman, 2008). I wanted to start with the views of adolescents as being the most important and likely to reflect the real world. Because of the societally-based power differential between young people and adult “experts”, I felt that starting with the views of experts would have made it more difficult to ensure the primacy of the young people's views and experiences.

7.2 Choosing a qualitative research paradigm

Underpinning all research is a set of assumptions about the nature of reality (ontology) and the nature of knowledge (epistemology). This determines the researcher's perspective on the research process, and so in turn will determine the methodology chosen and the way the data are interpreted. The philosophical perspective taken is known as the research *paradigm*. In quantitative research, this is not usually made explicit, but the assumptions exist nevertheless. The paradigm in which quantitative research is set is called *positivism.* The underlying assumption is that there is a single objective reality which can be known and measured and on which the researcher and the research process has no impact. The subjective meanings attached to phenomena by people are considered unknowable and therefore not able to be studied (Krauss, 2005).

In qualitative research however, the ontology and epistemology vary. Paradigms underpinning qualitative studies can be viewed as being on a spectrum, from realism at one end to constructionism at the other. Realism (similar to positivism) assumes that what people say, or how they are seen to behave, represents an objective and true version of events, and so there is no need to provide an interpretation of the data, or to "read between the lines". At the other end of the spectrum, constructionists believe that knowledge and reality are socially constructed and therefore there are multiple versions of reality experienced by the different individuals involved as participants and observers. The research process itself produces change in this reality.

7.2.1 Critical realism

Critical realism is the name given to a commonly used paradigm in health research. It is a position which can be viewed as being somewhere between positivism and constructionism (Krauss, 2005). It assumes that there is an objective reality which can be represented but that people will approach it from different perspectives and so interpretations of that reality will differ, but different accounts may be equally valid. Put another way, it has a realist ontology but a constructionist epistemology. I have taken this stance in analysing my data. In using qualitative data to construct items for a quantitative tool, it would make no sense without the concept of a single measurable reality. However, in interpreting the data, I reflected on the how the interview process might impact on how the experiences of the adolescents were relayed, and what might be affecting the way they reported their Participation and the meaning of it to them. I did not simply take their accounts at face value.

7.3 Choosing a qualitative research methodology

The research methodology is the overall process by which the research question is answered, and determines the methods used. Much qualitative research is conducted in order to provide an in-depth account of a phenomenon, often with a view to proposing models or theories for further exploration. Methodologies such as grounded theory or phenomenology are used for this purpose. The purpose of the this work however, was not to produce an overarching theory of Participation for adolescents with cerebral palsy, but to obtain the views and experiences of young people in order to develop items for a Participation measure. A methodology was therefore required which was appropriate to this applied use of qualitative data.

7.3.1 Thematic analysis

As the name suggests, thematic analysis simply means the identification and interpretation of themes, or patterns, in qualitative data. As such it is undertaken as part of the analysis in much qualitative work, including where the researcher is using one of the major methodologies such as grounded theory, or phenomenology. However, Braun and Clarke in their paper (Braun and Clarke, 2006) argue that thematic analysis should also stand on its own as a distinct methodology. Thematic analysis, as defined by Braun and Clarke, is not associated with any particular research paradigm, and can therefore be used by researchers with different theoretical standpoints, including a critical realist approach. Of course, the researcher's theoretical perspective must be made clear when reporting the work.

Thematic analysis was chosen for this research for the following reasons. It is suitable when simple themes are required from the data, rather than the development of more abstract, theoretical models of a phenomenon. It is suitable where the researcher already has a theoretical framework with which to code the data, referred to by Braun and Clarke as *theoretical* thematic analysis. As I was using the definition of Participation from the ICF, this was appropriate to my work. Thematic analysis also allows the researcher to analyse at varying levels of abstraction. Analysis at the *semantic* level is concerned with describing the data as it has been presented by the participant, and interpreting the patterns, their significance and meaning. It is not necessary to go to the *latent* level, where the underlying ideas, beliefs and assumptions are hypothesized (Braun and Clarke, 2006).

7.4 Using qualitative data in developing a quantitative tool

For some qualitative researchers, the idea of measuring a phenomenon using the fixed questions in a quantitative instrument would be incompatible with their epistemological beliefs (Krauss, 2005) and so they would reject this use of qualitative data. However, many do not find the two traditions incompatible, and it is now accepted practice to use both qualitative and quantitative methods in one piece of research, where this is appropriate to the research question. It is nevertheless important to ensure that the overall theoretical underpinnings of the different parts of the project are congruent (Morse, 1991).

The transformation of qualitative data into items for a quantitative instrument is acknowledged to be a challenging process (Sofaer, 2002; Fleury, 1993; Tilden et al., 1990). The difficulty is in ensuring that the meaning of the qualitative data is retained. It is important to keep as closely as possible to the qualitative data when writing items in order to take full advantage of this method of generating items. I wrote items for each theme identified from the data, repeatedly checking back to the data. The understandability of the language used in an instrument is likely to be maximised where qualitative data is used to derive items (Sofaer, 2002) especially the use of verbatim data chunks used within items (Fleury, 1993; Tilden et al., 1990). I used verbatim language wherever possible. In particular, the examples given to illustrate the items are, in the main, those given by the participants.

7.5 Concepts of validity

Validity is the state or quality of being sound, or true, and clearly this must apply to any scientific research. The first part of this research was qualitative and the second quantitative, and the concepts of validity used in the two have some differences. In this section I explain how validity has been demonstrated for each part.

7.5.1 Establishing trustworthiness of qualitative data

It is clearly important in all types of research that the reader or user of research findings can be confident that the results have meaning outside of the research context. In quantitative research, validity, reliability and generalisability are all looked for. In qualitative research, it is acknowledged that the process yields a different type of data, not amenable to the same evaluative criteria as quantitative but nevertheless it is important for there to be appropriate criteria to judge quality.

There has been much debate and discussion in the literature about how various aspects of the quality of qualitative research should be assessed. Initially this was a response to the critics from the dominant culture of quantitative researchers who claimed that qualitative research was non-scientific because it could not demonstrate validity as defined in the positivist paradigm. The most commonly cited set of evaluative criteria, those by Lincoln and Guba (Lincoln and Guba, 1985), were devised against this background and reflect the rather defensive atmosphere at the time. For each area of validity described in the quantitative literature, they mapped an equivalent one which was relevant to qualitative work. Whilst the Lincoln and Guba criteria of trustworthiness are seen as the gold standard by some, others have developed alternative checklists. There are also authors who reject the term validity completely, preferring to use terms such as “authenticity”, “fidelity” and “believability” (Sparkes, 2001).

Some qualitative research methodologies have been developed with a “recipe book” approach that includes instructions to researchers on how to demonstrate validity as part of the research process. An example is grounded theory. It can be more problematic where researchers use mixed methods, borrowing aspects from different methodologies. It has been argued that researchers using this pragmatic method must be even more careful that they are able to demonstrate the competence and good quality of their research (Miles and Huberman, 1994).

Whittemore and colleagues (Whittemore et al., 2001) published what they describe as a “synthesis of contemporary viewpoints” to come up with a list of elements which should be demonstrated as evidence of trustworthiness of qualitative data. These are in two parts: primary criteria, which are common to all, and secondary criteria, which are appropriate to some types of research but not others. Those evaluating research must be aware of the relevant epistemology, ontology and methodology as well as the research question, so that an appropriate weighting is given to the different criteria.

Another way of conceptualizing validity is described by Maxwell (Maxwell, 1992). He describes different types of validity by which any research can be assessed. *Descriptive* validity refers to that related to the method of collecting and processing the data (for example, the accuracy of transcripts). *Interpretative* validity is concerned with the way in which the analyst has performed their interpretation of the data. Both broad areas of validity are relevant to both qualitative and quantitative studies.

I have used a combination of different lists of criteria to ensure the standard of my work and to demonstrate this to the reader. Using Whittemore et al’s criteria

(Whittemore et al., 2001) as a starting point, I have summarised below the steps I have taken in this project to maximise the robustness and quality of my conclusions.

Credibility is whether the research results are believable and depends on the accurate representation of the accounts used and a clear demonstration that the explanations given fit the description of the data. Methods used in this project were the use of other people to both code the transcripts independently and to discuss the meaning of the data. Comparing my findings to evidence in the literature regarding adolescent Participation provided further evidence of credibility. *Authenticity* reflects the ability of the research to accurately reflect the feelings and experiences of the research participants. Using the participants' language in wording items and using the feelings of the young people about what was important to them, is evidence of this aspect.

Good qualitative research requires a high degree of *criticality* from the researcher to avoid unduly influencing the research results. I have tried to be reflexive in my consideration of the research process and analysis and have tried to identify possible biases, discussing these in the interpretation of my results. I asked my supervisors to examine and challenge my conclusions. A related criterion is *integrity*. Again, I have tried to look carefully and critically at my interpretations, iteratively examining the data and my interpretations of it. I have been transparent in my data management and analysis and tried to ensure what Maxwell describes as descriptive validity, by doing what I could to ensure the accuracy of transcripts.

Explicitness concerns the degree to which research methods and analysis are clearly described. The use of NVIVO software enabled me to make my analysis clear by the recording of copies of the node structure at various points in the coding and analysis process, memos, and records of the coded transcripts as well as the charts and other documents produced during analysis. *Vividness* relates to how accounts are presented and the degree of richness, imagination and clarity with which this is done. I tried to draw out the essence of the various themes, whilst at the same time not providing excessive detail. I used appropriate illustrative quotes to bring to life the participants' accounts. However, this criterion could be regarded as of less importance for my research question. *Thoroughness* applies to all areas of data collection and analysis. I recruited participants until I was satisfied that I had reached thematic saturation. I checked all transcripts repeatedly, immersing myself in the data. I used the constant comparative method and performed a detailed analysis of the data, to the degree necessary for the purpose of the research.

Congruence is ensured by choosing appropriate methods to answer the research question and the aims and objectives of the study. I have described the research methodology and the methods used and participants were sampled from an appropriate population. I have illustrated congruence between the data collection and the findings and between this and previous studies. The results fit into a context external to the study.

Sensitivity, Whittemore's final criterion, describes the ethical and sensitive treatment of participants. I was very careful to ensure that the young people themselves were consenting to take part, in addition to the parental consent needed for those less than 18 years. Although I was keen to interview young people alone, I was sensitive to their and their parents' wishes and therefore interviewed some with parents present. I included young people who are often excluded from research, such as those with severe communication difficulties, to ensure that their experience would be included.

7.5.2 Validity and reliability in scale development

In the context of psychometrics, validity refers to whether a scale actually measures what is intended, and reliability, whether it does so consistently. Both validity and reliability have several different components, and these are assessed in different ways. The facets of this study which contribute evidence of reliability and validity of the instrument are illustrated in figure 7.2.

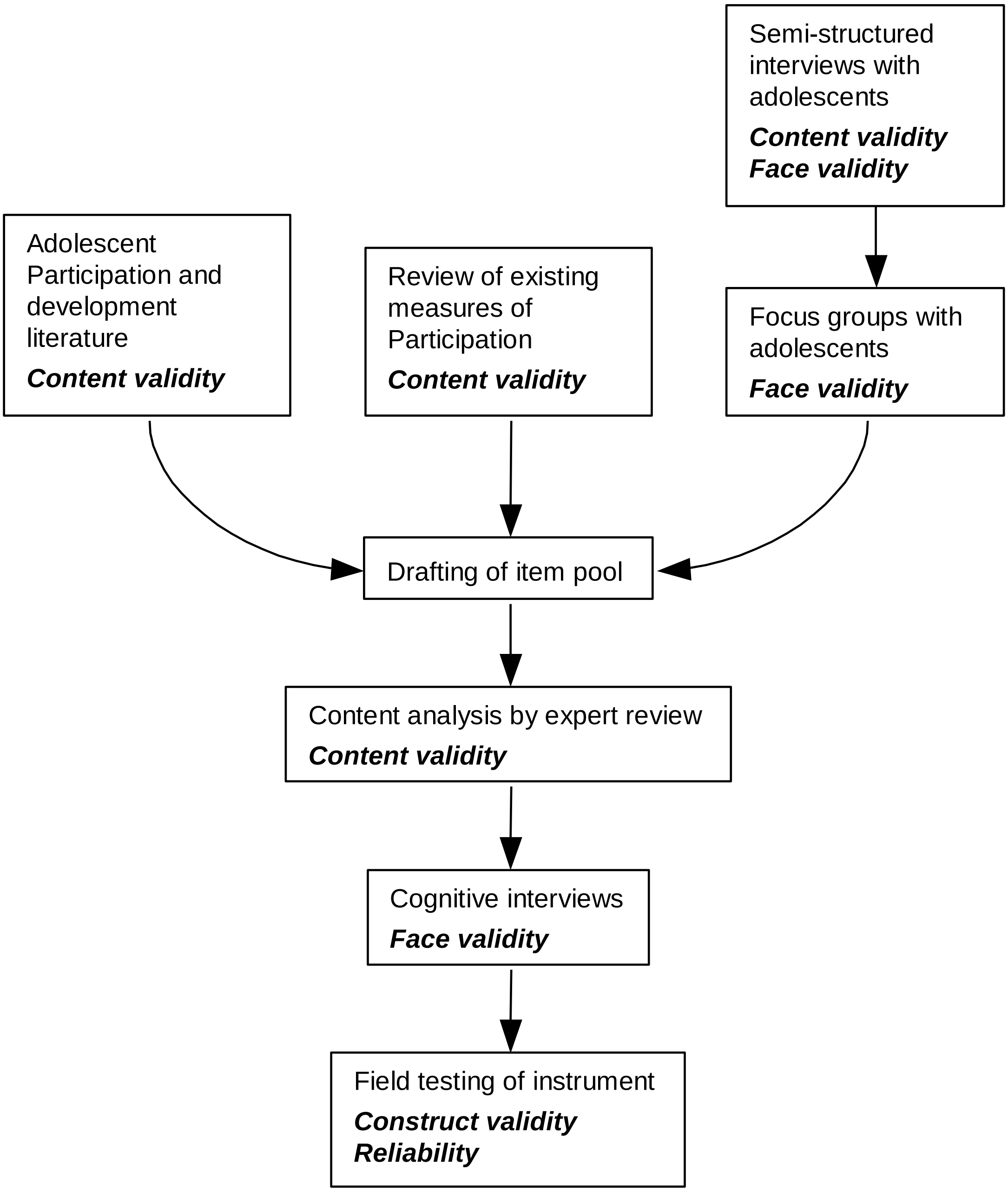

Figure 7.2 Contribution from different parts of the project to evidence of reliability and validity

7.5.2.1 Scale validity

Validity used to be considered as a property of the instrument. More recently, this view has shifted to consider the use to which an individual's score is put. Streiner and Norman describe it thus: "Validating a scale is really a process whereby we determine the degree of confidence we can place on inferences we make about people based on their scores from that scale" (Streiner and Norman, 2008). So it is the use of the scale, rather than the scale *per se*, which should be demonstrated as being valid. Although different "types" of validity are described, they are essentially just asking this question from different angles (Streiner and Norman, 2008).

Face validity refers to whether a scale looks valid to those completing it. In other words, do the questions make sense to respondents in the context in which they are being asked? Some have argued that this is just another name for acceptability, and it should not be defined as a type of validity, as some scales contain valid items which may not appear so to the layman. An example would be questions about appetite or sleep pattern in a depression scale, which non-experts may not know are important in clinical depression. Whether called face validity or acceptability, the views of potential respondents are important in scale design, as items not deemed relevant or asked in an acceptable way are less likely to be answered. In this study, I took two opportunities to gain feedback from respondents on the comprehensibility and acceptability of items in the instrument. The first was during the focus groups in the first part of the study, the second was during cognitive interviews at the start of the field-testing.

Content validity refers to whether the items in the scale are representative of different facets of the concept of interest. An essential pre-requisite of determining content validity is a clear definition of the concept and what it encompasses (DeVellis, 2003). Theoretically, items on a scale should be a random selection of the universe of possible items. In practice, we often do not have access to the complete universe of items and so content validity tends to be assessed by asking experts for their opinion on whether range of proposed items is sufficiently wide and appropriate. Content validity should be ensured by the manner in which an instrument is constructed (Tilden et al., 1990) and it is therefore imperative that the construction process is thorough and well considered. One element of this is the emphasis on ensuring that the qualitative data on which the instrument items are based is reflected faithfully in the items. Again the use of verbatim pieces of data as the basis of items helps ensure this (Fleury, 1993).

Content validity was assessed in this study by using experts to complete a content review questionnaire for draft items. The Content Validity Index was also calculated in order to quantify it.

Criterion validity refers to the degree to which scores will correlate with those from a "gold standard" measurement. In the case of adolescent Participation, there is no such standard and so I was not able to assess this. *Known-groups validity* relates to whether the scores on a new instrument are as predicted for certain groups of individuals, who are known to differ in the level of the construct they display. So from previously published research, we would predict that those with lower levels of impairment will participate less frequently and less diversely. I therefore concurrently administered measures of impairment when conducting the field-testing of the new instrument, in order to test this. This form of validity may need re-examination with time, as our understanding of constructs and their relationships develops and is refined (Streiner and Norman, 2008).

7.5.2.2 Reliability

The reliability of observed scores is the ratio of the true variance to the observed variance, where the observed variance is equal to the sum of the true and error variances. Therefore the reliability will increase as the proportion of error variance decreases. Reliability can be assessed in terms of how the items in the scale relate to one another (internal consistency) and also whether administrating the instrument on two occasions provides the same results. The latter is known as intra-rater or test-retest reliability. Inter-rater reliability is a measure of how reliable a scale is when completed by different respondents. As the respondents for this study were those felt to know the young person’s Participation the best (the young person where cognitively able, the main carer where not), inter-rater reliability was not applicable. I have analysed both the internal consistency of the instrument as well as test-retest reliability.

7.6 Ethical Considerations

An important ethical issue in research is the exclusion of groups seen as vulnerable, such as children and those with intellectual impairment. Although this is reasonable in circumstances where risks are significant and data can be obtained from other groups, it may create ethical problems if clinical management is then of lower quality for these groups because of a lack of research evidence. This was a key reason for developing a proxy report version of the instrument and including those with intellectual impairment in the field-testing. I also deliberately included in the qualitative work, young people with expressive communication impairments who not only may have different experiences of Participation from those without such impairments, but are more likely to be excluded from research.

Involving children and young people in research presents specific ethical issues. One of these is obtaining consent and involving those with intellectual impairment increases the complexity of this. In the qualitative work, as well as when field-testing the instrument, it was stressed to parents that the young people themselves needed to give consent, in addition to the parents. Although the risk was small, it was possible that asking participants to reflect on their Participation, and the restrictions might have been distressing. It was therefore important to ensure that the adolescents were fully informed and consented to take part.

There is no law relating to the age up to which parental consent is required for young people taking part in research. We erred on the side of caution and took written consent from all parents of young people less than 18. In the field-testing part of the project, for those with intellectual impairment unable to provide consent, carers were asked to involve the young person where feasible. An information sheet using pictures was supplied to help parents with this. Assent was obtained from the carer, consistent with the requirements of the Mental Capacity Act (UK Government, 2005).

7.7 Conclusions

An important first step in designing a research project is to clarify the theoretical underpinnings of what one is setting out to achieve. This will determine the methods chosen and the conclusions that can be drawn from the results. I decided to develop the instrument using classical measurement theory because that seemed the most appropriate method, given the uncertainty about the unidimensionality of Participation and whether or not it is an indicator or defining variable. The items would be informed using qualitative data obtained from young people. I chose to use thematic analysis interpreted from a critical realist standpoint. I tried to maximize the validity of this part of the study by using a number of evaluative criteria described in the literature.

I then planned to field-test the instrument I had developed to provide evidence of both reliability and validity. Intra-rater reliability and internal consistency would both be examined and content validity would be maximised by the methods used to develop items. Known-groups validity would be examined by comparing questionnaire scores with participant impairment levels.

This concludes the chapters describing the background to the research. The following three chapters will outline the methods used and results obtained in the three discrete stages of the project.

Chapter 8. Qualitative Study

The aim of this first part of the research was to obtain the views of adolescents with and without cerebral palsy about their Participation. This chapter describes the methods for this qualitative work and analysis. How this analysis then contributed to the development of instrument items is described in Chapter 9.

Ethics approval for this part of the project was obtained from the Research Ethics Committee for South London (06/Q0803/149).

8.1 Methods

As discussed in detail in Chapter 7, this part of the project involved a thematic analysis of the views of young people about their Participation, using a critical realist approach. The methods used were semi-structured interviews, from which information was obtained on what the young people participated in and their views of it. Focus groups were subsequently held for respondent validation as well as to obtain feedback from young people on the possible wording of items.

8.1.1 Semi-structured interviews

8.1.1.1 Rationale for use

A number of methods could have been chosen to obtain data from young people about their Participation. I discuss these options first before presenting the rationale behind the use of semi-structured interviews.

A quantitative survey would have had the advantage of being quick and relatively easy to undertake, but would not have allowed for probing of responses and respondents would have been constrained by the predetermined options presented. Diaries could also have been used to record Participation. This would have been time-consuming for participants, and would rely on a high level of commitment from them if accurate records were to be produced. Quite prolonged use of diaries would have been necessary to pick up on infrequent Participation, leading to potential problems with adherence. Observation of adolescents would have provided data on what they participate in but not their feelings about what they were doing and would again have been time-consuming and costly. For ethical and practical reasons, not all Participation would be observed and in particular, less frequent types of Participation such as holidays would be less likely to be captured.

Semi-structured interviews are commonly used to obtain data to inform the development of quantitative instruments (Streiner and Norman, 2008). I chose to use semi-structured interviews because they enable the research participants to tell the researcher in their own words about their lives. They were able to pick out what was most important to them and to explain why. The method allowed for probing participants on why they did or did not participate in certain areas and to ask them their views on their Participation and their aspirations for future Participation. Qualitative methods such as interviews enable the researcher to avoid making assumptions about the topic in advance, which may otherwise lead to missing key elements which are of importance to the study participants. Although I was using the ICF as a basis for the prompts, the interview structure ensured that areas not in the ICF could also be discussed.

Although the transcription of interview tapes, the manipulation of the data and the analysis are all very time-consuming and challenging to do well, it was decided for the reasons given above that this was the best method for obtaining data from young people.

8.1.1.2 Sampling and recruitment

A purposive sampling strategy was used to identify young people with CP likely to have a range of different experiences of Participation. Young people from across the age range, of both genders and with a range of types and severity of impairments were approached. I approached young people who attended both mainstream and special schools, and who lived in urban and rural areas and from a range of socio-economic backgrounds.

Recruitment was via the North of England Collaborative Cerebral Palsy Survey, local paediatricians and special schools. Those included on the survey were approached by their local paediatrician for permission to be contacted by the study team with further information. The inclusion criteria were a diagnosis of cerebral palsy and specific characteristics to fit the purposive sampling requirements. The young people also had to have an IQ in the normal range to enable them to adequately discuss their Participation and its meaning for them. Because of resource constraints, young people also had to be able to understand and communicate in English. Potential participants were sent information sheets about the study, before deciding whether or not they wanted to take part.

Young people without disabilities were recruited from a range of sources. As with those with CP, they were purposively sampled. Two were recruited as friends of those with CP who had been interviewed. Others were recruited through my personal contacts or those of my supervisors. For example, two were the children of people who worked with us and one was a friend of a neighbour. Information sheets were provided similar to those for the participants with CP.

Recruitment of participants continued until data saturation had been reached. This means that interim analysis performed between interviews was no longer yielding new themes.

8.1.1.3 Consent

Informed written consent was obtained from all participants following face-to-face discussion before interview. For those under the age of 18 years, parental consent was also obtained.

8.1.1.4 Setting

Young people were given the choice of interview venue. Most young people chose to be interviewed at home, whilst 3 chose school or college.

8.1.1.5 Process

The interviews followed a topic guide. The topic guide is included in Appendix B. Interim analysis was performed between groups of interviews and the minor alterations made to the topic guide. The preliminary analysis involved transcripts being read and initial coding and identifying possible themes undertaken.

The structure of the interviews was designed to focus the discussion on the areas of interest but to be flexible enough to enable the young person to discuss their own ideas and experiences. Participants were asked about their usual Participation at home, school and elsewhere as well as more occasional Participation. They were asked how they felt about the Participation they reported, what they enjoyed most and least and which areas were most important to them. They were asked to imagine the perfect day and asked to describe what they would choose to do. Those with CP were asked whether their disability affected their Participation in any areas and all the participants were asked whether there were things they would like to do but could not, and why they thought this was. The Participation of friends and siblings was also inquired about and whether this was similar or different to that of the interviewee. The ICF sub-domains were used as prompts for Participation not spontaneously mentioned by participants.

The interviews were audio-taped, and transcribed by a professional transcriber. The exception to this was for the two interviews where the participants had severe dysarthria. The professional transcriber was unable to understand these recordings and so I transcribed these recording.

Field notes were taken before and after the interviews to record my perceptions, feelings and thoughts about the interview as well as contextual details.

8.1.1.6 Effect of the researcher on the data collection

Reflexivity in the research process needs to take place on a number of levels. The researcher influences every step of the research process starting with defining the research question and the methods used for data collection. As a researcher, I have characteristics of which the participants were aware. I am older than them and am a doctor. Those with CP would have been very familiar with doctors, in particular paediatricians. How they felt about me would depend to some extent on their previous relationships with paediatricians. I had no way of knowing what the previous experiences of the young person had been in this regard and so this factor in the researcher-participant relationship is an unknown that is likely to be different for each interview. In addition, the way I asked questions and responded to the participant would have been affected by my own view of adolescence. This is shaped by my reading of the literature and by my personal experience of adolescence. This is discussed further in section 8.1.1.8.

The alternative, which would have removed the effects of an older, authority figure as interviewer, would have been to have peer interviewers. However, this would have involved training and recruitment of interviewers which would not have been possible within the time constraints of the study. Although some bias may have been removed by this, other biases may have been introduced as young people may have shaped their responses to a peer audience. This method would also not have been congruent with the aim of obtaining data to inform an instrument for administration by clinicians.

8.1.1.7 Data management and analysis

The analysis was managed using the NVIVO software programme *Version 9*. Thematic analysis was undertaken (Braun and Clarke, 2006) (described in more detail in Chapter 7) using the “Framework approach” to structure the analysis. The Framework

Approach is simply a method of organizing the analysis and breaks the process down into 5 stages (Ritchie and Spencer, 1994). I detail these below, and explain what I did at each stage.

1. *Familiarisation:* In this initial stage the analyst gains an overview of the data. When each transcript was completed, I listened to the tape whilst reading the manuscript to check for accuracy. When I was satisfied with the accuracy, I printed off a paper copy and read it through several times, making notes and identifying passages for coding. When the transcript was then entered into NVIVO, I read through it again before performing detailed coding. At this stage I also reread the notes made before and after the interview in my fieldwork diary.

2. *Identifying the thematic framework:* Here the thematic framework is laid out. I started with some *a priori* themes derived from the ICF. These included the nine domains of Participation as well as a few key sub domains. I did not use more detailed sub-domains at this stage as I did not want to be overly influenced by the ICF categorisation initially, preferring to let the themes emerge from the data. Later on I compared the emergent themes with the ICF sub-domains to see whether they were comparable. Some were but others did not easily map to the ICF. These were therefore kept as separate themes. Coding was also carried out independently by one of my supervisors and her coding and mine compared. Any differences were resolved by discussion. In addition two joint data sessions were held with two colleagues unconnected with the project (from medical and psychology backgrounds). They looked at selected passages from a number of the transcripts and discussed the themes they drew from the excerpts. This discussion confirmed some of my coding and introduced some new ideas. Barry and colleagues (Barry et al., 1999) describe the value of a team approach to analysis. They describe the benefits of having researchers from different backgrounds and disciplines who draw different

conclusions from the data and present different understandings of concepts. Researchers have to be more critical of their own thinking and are forced to be clearer and more explicit in their analysis when explaining it to others.

3. *Indexing:* The thematic framework is then systematically applied to all the data. Because I was using an iterative process, I went backwards and forwards between steps 2 and 3 during analysis. When all interviews were completed and coded, I went through the coding structure in detail, comparing with the ICF and other literature and refined the framework. Some themes were combined and others expanded. I then went through each transcript in detail on NVIVO and checked all coding against the revised framework.

4. *Charting*: At this stage, charts are constructed. Charts are tables in which the data on each theme are summarized to better visualise the data. I arranged charts by theme, mapping data to the participants.

5. *Mapping and interpretation:* In the final stage, the analyst goes back to the research question and the aims and objectives of the project. All charts, memos and notes are reviewed and patterns and structure are identified to form the final analysis. The aim of this project was to come up with possible items for the questionnaire from these themes and this is further described in Chapter 9.

Content analysis is a method of analysing qualitative data quantitatively by counting how many times a certain theme or element occurs within a source, or across sources. It is also known as “determining prevalence” (Braun and Clarke 2006). This quantification cannot be analysed statistically like quantitative research data. Nevertheless, it can add information to an analysis, by indicating the frequency with which an element or theme occurs within data. This may provide an indication of qualities such as importance, or common experience. I used it in key themes to give an indicator of how frequent an area of Participation was for the group studied.

8.1.1.8 Effect of the researcher on the analysis

The strength of qualitative methods is the ability to examine the data in a very detailed and flexible way, leading to an understanding of the deeper meanings of what participants say and the generation of theory from the data. However, the way meaning is extracted from the data and the development of theory will be strongly influenced by the researcher, their previous experiences, values, views and personality. There are ways to minimise this effect, and enhance the trustworthiness of the data. In this study the use of researchers other than me to check the coding and discuss areas of differing interpretation would have helped here.

Reflexivity is important in identifying the influences on the research from the researcher, even though these are not directly measurable. One reason for bias may be if researchers are part of the phenomenon under study (Barry et al., 1999). The relevance in this study is that all the researchers have been adolescents in the past. These experiences will be different and again the use of multiple analysts should help in minimising the effects.

I am very aware that reflection on my own adolescence has been an important aspect of this project. My views of what are “normal” and “healthy” patterns of Participation are partly influenced by my own experience. This in turn is influenced by my family and their Participation patterns. Although this cannot be removed from the research process, having an awareness of the potential bias helps to protect against it.

8.1.2 Focus groups

8.1.2.1 Rationale for use

As with semi-structured interviews, focus groups are also a commonly used method for obtaining data when developing questionnaires (O'Brien, 1997). I used focus groups after the interviews had been analysed for respondent validation, and to gain feedback on how young people understood certain items. The same young people who had taken part in the interviews were invited back for the focus groups. After interview, all but one participant said they would like to be invited to a group.

The advantage of focus groups used in this way is that they are less time consuming than conducting a second round of interviews with all the participants. The other advantage is that discussion is generated between group members, providing additional insights into the phenomenon under study. Areas of consensus and of differing views are highlighted. The disadvantages are that more vocal members may dominate a group and shyer participants may not feel able to dissent from an apparent group consensus. I was aware of this potential problem, and therefore tried to make sure that each participant had a chance to contribute to each area of discussion, as well as actively encouraging alternative views.

8.1.2.2 Setting and consent

The focus groups were held in a room at the hospital in the evening. I facilitated each group with another researcher taking handwritten notes. The meetings were also audiotaped. Participants gave written consent at the start of the groups.

8.1.2.3 Process

The groups lasted around 1.5–2 hours, with refreshments provided. Questions were asked regarding a number of domains of the draft questionnaire. The topic guide is included in Appendix C. Not all questions were asked of every group due to time constraints.

8.1.2.4 Analysis

The focus group data was added to that in the interviews and used to refine the draft questionnaire items but was not used to generate new themes. The data is presented together with the interview data in the results section below.

8.2 Results

8.2.1 Participants

Seventeen young people were interviewed. Twelve had CP and five had no disability. Table 8.1 shows the participants' individual characteristics, and table 8.2 summarises their demographic data.

For the focus groups, 8 young people took part in one of 3 groups. Those who took part are identified in table 8.1. Another 6 young people expressed the desire to attend a group but were unable to as they were unavailable on the dates arranged, which for 2 was because they had moved away to residential colleges. The other 3 young people declined to take part. Those taking part included 5 with CP and 3 without. There were an equal number of males and females.

Participant number and pseudonym	**Age**	**Gender**	**CP/AB**[1]	**Type of CP**	**Other difficulties**
1 Daisy*	15	F	AB	–	–
2 Mark	14	M	CP	Unilateral	Mild Learning Disability
3 James	14	M	CP	Unilateral	Mild Learning Disability
4 Rebecca*	15	F	CP	Unilateral	None
5 Shaun	18	M	AB	–	–
6 Peter*	21	M	CP	Unilateral	None
7 Alicia	15	F	CP	Bilateral, 2 limb, ambulant	None
8 Jerry	16	M	CP	Dyskinetic, ambulant	Severe dysarthria, previous epilepsy
9 Sara*	16	F	AB	–	–
10 Jade	15	F	AB	–	–
11 Duncan*	20	M	AB	–	–
12 Martin*	18	M	CP	Bilateral 4 limb, WC[2]	Mild dysarthria
13 Sam	16	M	CP	Unilateral	Moderate Learning Disability
14 Harry	19	M	CP	Bilateral 4 limb, WC	None
15 Eleanor	18	F	CP	Bilateral 4 limb, WC	Severe dysarthria
16 Zoe*	14	F	CP	Bilateral 3 limb, WC	None
17 Kate	19	F	CP	Bilateral, 2 limb, ambulant	None

* Participant who also took part in a focus group, [1] AB = able-bodied, [2]WC = wheelchair user

Table 8.1 Participant details

Demographic	**Number**
Gender:	
Male	9
Female	8
Age range 14–21y	
Median age 16y, mean 16y	
Distribution of CP:	
Unilateral	5
Bilateral	7
Associated difficulties:	
Dysarthria	3
Epilepsy	1
School history:	
Special	2
Mainstream	12
Both	4
Geographical location:	
Rural	2
Urban/suburban	15
Family structure:	
In one parent family	3
In two parent family	13
Siblings	16
Adopted	1
Living independently	1

Table 8.2 Summary of demographic data for sample

8.2.2 Participation domain themes

This section describes the major themes derived from the data which identify an area or group of areas of Participation. Some of these map clearly to the ICF, others less so. For some areas, there are links with more than one sub-domain of the ICF and these are described. Where themes are linked to sub-domains of the ICF, the domain codes are given ("d" followed by a 3 digit number). For clarity, I have referred to the ICF chapters by domain name rather than chapter number. The quotes are attributed to the participants using pseudonyms. Details of the participants and their pseudonyms are shown in table 8.1.

8.2.2.1 Communication

This theme featured frequently in the interviews. Young people described communicating in a functional manner to arrange social and other events, as well as chatting as a form of recreation. There was also discussion about the use of technology for communication. There are clear links here with the ICF domains of Recreation and Leisure (d920) and Interpersonal interactions and Relationships (d710–799).

The use of technology for communication, although it might seem more appropriately classified as Activity[1], appeared from the data to be not simply a means to an end for some adolescents. All the young people reported using telephones for speaking directly or texting. For some young people, significant time was spent on the phone or texting friends. One 16-year-old, Sara, saw phoning a friend as different to chatting face-to-face in school, where private conversation was more difficult. The following quote illustrates how chatting on the phone was a form of leisure for her and her friends:

> *" Yes, mmm. I mean um every night I phone B who is like one of my best friends and we just talk about everything, we just talk … we just talk about everything really, we're like on the phone for an hour and a half sometimes, well most nights in fact an hour and a half, just everything. It's just whatever you can think of, you just talk about."*

The particular experience some young people feel using technology is illustrated by Kate's description of texting:

> *"I like text because you know it's just like, texting is like an exciting way to see what they're going to say next, I know it sounds stupid but you know when you're like having a conversation and your phone goes and it's like 'Oh, what are they saying?' "*

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[1] As described in Chapter 4, Activity is "a task executed by an individual" in the ICF. In the conceptualisation of Activity and Participation developed for this study, I am including as Participation, areas regarded as an end in themselves. Areas which are only a means to an end I am categorising as Activities.

Online communication was a common communication modality for the young people interviewed. Eleven interviewees described its use. Some stated a preference for the use of social networking sites over email or phone because of the ability to talk to several friends at once. There was no apparent age or CP severity association with usage or non-usage. Of the 6 not using or who did not discuss it, 5 were boys.

8.2.2.2 Mobility

Much of this ICF chapter concerns Activities. However there were some areas that did seem to represent Participation. These included the use of transportation and walking and cycling undertaken for its own sake, rather than as a mode of transport.

The use of mechanized transportation was strongly linked to autonomy and independence and was viewed as very important by some participants. An example is described here, where Sara described owning a motor scooter:

> *"I absolutely love it, like just going when you want, you don't have to have a certain time to like oh I've got to leave now, I've got to, my mum's waiting outside, you can just be like oh, have a few drinks, down in the um at my gran's or something and then I can just go the next day or whatever, it's great, you can go whenever you want, I love it, absolutely love it."*

In contrast, Martin identified his lack of access to independent transportation as a barrier to romantic relationships. He also described his aspirations for independent mobility, and his description suggested that it was not simply the mobility which was important. Asked whether he would like to have his own car he replied:

> *"Oh I would love to do that, not a car, one of them bikes, the bikes they've got for wheelchair people. They've got special bikes, I'd love to drive one of them, it's like a scooter but … it fits your wheelchair in, it's lovely, they don't go that fast though which is the only trouble."*

Walking as a form of recreation was mentioned by 8 participants. This includes two participants who described going for a walk as a lone activity and the other 6 who described going for a walk with others. This data links with Recreation and Leisure. In addition, Duncan described walking as a method of relieving stress:

> *"If I'm really like, if me head's completely battered, I'll tend to take um a walk, and I'll walk down along the tracks and that."*

8.2.2.3 Self-care

Again, this chapter of the ICF contains a number of sub-domains which represent Activities. I would argue that the autonomous organisation of a person' self-care routine should be included in Participation, and young people in this study identified this as important. This has an overlap in the ICF with the sub-domain d230 Carrying out daily routine in the General Tasks and Demands domain.

Duncan identified autonomy in this area as being the thing he would least like to lose:

> *"Making me choices, well say if they didn't get us up in the morning and get us straight in the shower, that would be no good, they say you have one at night instead of then, I'd be annoyed about that, I would say there's loads of things there really, my whole routine. Someone telling us I was staying in the house today, cos they've decided, I wouldn't be happy with that either you know."*

Maintaining one's health could also be said to be Participation. This was not an area often mentioned by the young people, although the use of sport to keep fit was mentioned by some. Three participants mentioned active leisure pursuits (ball games, cycling and rollerblading) as providing fitness and one (Duncan) also mentioned his manual work as providing fitness. Martin mentioned his declining fitness which he attributed to attending a mainstream educational establishment which did not provide accessible sports activity, in contrast to his former placement in a special school:

> *"Every week without fail* [I played disability sport], *I was devastated they didn't do it here* [college] *cos I was really fit when I was there* [special school]*, fit in my body. I've still got it like but not as much as I had it."*

When prompted about Participation in healthcare and the degree of their autonomy with taking simple analgesia, for example, there was a wide variation in how independent young people were, with many still reliant on parental support. Peter explained that he might be happy to attend the doctors alone for simple problems but would take a parent if it were more complex. This was confirmed by others in the focus groups.

Although eating is an Activity, eating in a social context fulfils the criteria for Participation. Eight participants mentioned eating with immediate or extended family in the home. This was usually an evening meal with close family or Sunday lunch with extended family.

Eating out at restaurants was a popular activity with those who discussed it. It was part of several participants' "ideal day" and mentioned by a number as being something they did as part of birthday celebrations. When Daisy was asked whether she had done anything recently which gave her a real buzz, she described a meal at a restaurant with friends:

> *"Well, on Thursday, me and eleven other friends went to* [Street name] *to a Chinese Buffet. It was so much fun. It was the second time we'd done it. We got split into two tables of six, one upstairs and one down which wasn't so good. But I was with all my friends. I love being with all my friends."*

8.2.2.4 Domestic life

Areas within this domain which were discussed included d630 preparing meals, d640 doing housework, d620 acquisition of necessities which includes 6200 shopping, d6505 taking care of animals, d6501 maintaining dwelling and furniture, and d660 assisting others.

Very simple cooking involving reheating prepared food was described by a number of young people. This is illustrated by this quote from Shaun:

> *"Oh I'll cook for myself but I don't cook like a meal like what me mam does … Well me mam cooks chicken pasta or chicken or tuna bake, or stuff like that whereas I cook, well I cook whatever I can stick in the oven or the microwave."*

Peter described being prevented from cooking using the cooker hob by his parents:

> *"I mean well I don't cook through choice, um depending what my mum and dad want I'll either bung it in the oven or if they want microwave I'll bung it in the microwave cos they don't let me use the, the cooker, they don't like me making stuff so I just bung it into the oven or the microwave."*

Although many young people said they did not cook, a few did. For two it was linked to either a school course or career interest.

Participation in household chores was described frequently. It was not something which was generally described as enjoyable. However, some young people did describe it as worthwhile because it was practice for when they moved away from home and because it was a way they could help their parents. Whether this was indeed their view, or one which they thought socially desirable, is not clear. For example, James said:

> *"If you say rely on your mum and dad to clean your room, always wash dishes, to always make food for you, once you leave the house and you get your own job and you get your own flat, you won't know what to do. It'll be too hard for you so you learn younger, then you have the skills and the knowledge to know for when you're older."*

Tidying their room was the one task undertaken by those who said they undertook no other tasks. Most undertook a range of different chores, some outdoors as well as in, as described by James:

> *"I sometimes close the curtains, I sometimes hoover, might sometimes do the dishes, dust, set the table … wash the car occasionally, um hoover my room, tidy my room even though it's already tidy."*

Doing laundry and ironing were done mostly by older participants. Again, Peter said that he was discouraged from participating by parents:

> *"I mean my mum does the ironing and that, she doesn't trust me with the ironing or the washing in case I burn a hole or wash the wrong clothes, dye the washing, so she does that."*

"DIY" tasks were mentioned by two participants, both male. In both cases they were helping older family members. For most, shopping was for non-essential and luxury items but some young people did food shopping and other shopping for day-to-day items.

Helping parents by running errands such as going to the shops was an aspiration for Jerry:

> *"What I'm hoping to do is when I get a power chair, say if Mum needed some milk from the shop I would maybe say 'Can I go in my power chair and get it?'"*

Supporting family members emotionally as well as practically was described by Peter:

> *"I've um been down to see her* [grandmother] *cos um me mum's sister's died so I've went down just to see how she is and make sure she's all right and stuff and for a, just have a little chat if she wants, to have a little chat about anything."*

8.2.2.5 Interpersonal interactions and relationships

This area overlaps with that on communication, for example data coded under the heading of discussion and conversation where this was with friends could also relate to d750 informal social relationships, and where with family to d760 Family relationships. Specific sub-domains represented in this section are d7601 Child-parent relationships, d7603 Extended family relationships, d7500 Informal relationships with friends, d770 Intimate relationships and d730 Relating with strangers.

Most participants described participating in various ways with parents. This included watching TV, going shopping, going to the cinema, going on holiday or going out for a drink or meal. Others described spending time with members of the extended family. This time was described as highly valued by some. Here Daisy described what she did with grandparents:

> *"Daisy: I see* [grandparents] *every weekend … I love them to bits. Interviewer: And what do you do with them? Daisy: Play cards, play board games, watch TV, normal stuff."*

In the following excerpt, Sara was asked what she had done recently which she had particularly enjoyed. She described the family Christmas:

> *"Um, Christmas Day was amazing, it was really good … so everyone was happy and then we went down, we had a meal with all my, there was about 14 of us, no, 19 of us I think, to my Uncle George's and had a huge, like there was a huge, like 2 huge tables, like the young ones on one and then the older ones on the other and we all sat and had a good laugh and then we went, from that we went to my other aunt, to my other side of the family and just went and played like, well they had a game of poker going on and we had like the Who Wants to be a Millionaire questions, they had that on, so that was good, that was good fun. Boxing Day was a good day, we went and watched the rugby, like my dad's team playing rugby, um … it was just good crack, a good laugh, it was just a nice time cos um the family hardly ever get together and stuff so it was nice."*

As I discussed in Chapter 3, spending time in their peer group is important for adolescents' development. Friends were discussed frequently when discussing school Participation as well as recreation and leisure. The following comment from Sara highlighted the importance of time alone with friends without parents or other supervising adults present:

> *"Interviewer: And do you think if you take friends home to your house, is it important that you've got somewhere to chat to them without your parents being there, or does it not matter? Sara: Um, it depends what we're chatting about, like we do often quite just sit in my living room and have a bit laugh on with my mum and dad sometimes but then we'll go in my room, we never really talk seriously about like in front of them, kind of thing, like there are some things that I just wouldn't feel comfortable talking to my parents about. Um, so it just depends what you're talking about."*

The difficulties for young people with disabilities in finding the opportunity to spend time alone for the development of more intimate relationships was illustrated by Martin. He described the difficulties of his lack of independent transport because he was not able to use public transport independently and could not afford to pay for taxis. He felt that he was prevented from progressing to a sexual relationship with girlfriends by these barriers:

> *"Well* [I need] *to be able to have money to be able to take them out or go to theirs or for them to come to mine or something like that, it all comes down to money again which I haven't got none, so."*

Eight of the young people said they had had a romantic relationship at some stage, although only Rebecca said she currently had a boyfriend. Three of the young women said that they had no wish for a romantic relationship at the current time. Sara discussed how she viewed this as a positive thing, although how much this represented her true feelings and how much it was said to present a positive self-image is unclear:

> *"<u>Interviewer</u>: Do your friends have serious boyfriends do you think? <u>Sara</u>: Yes, yes. Um quite a lot of them do actually. I think, well, quite a lot of them have been seeing them for about like a year nearly now and stuff like that, so, intense relationships, but they always come with relationship problems and you just think 'Thank God I don't have a boyfriend' and it's just like 'Oh it's going to have to wait' but yes."*

Two of the older boys, Peter and Duncan were positive about past relationships, Peter saying that he missed the companionship of his ex-girlfriend. Use of wording to describe boy or girlfriends was discussed in the focus groups and lead to the definition ("someone with whom you are having a romantic relationship") used in the draft item.

Interactions with strangers were mentioned less frequently, as might be expected. Three participants talked about their interactions with strangers in the context of their part-time jobs or voluntary work. In discussing a possible item about relationships with neighbours in one of the focus groups, it became clear that the term “neighbour” was understood differently by different participants. This influenced the item wording.

8.2.2.6 Education

Educational Participation is included as part of the Major Life Areas domain. Thirteen participants were in School education (d820) and one in Higher education (d830). Three of the participants were no longer attending full-time education, one of whom was attending adult education sessions.

Overall, most participants disliked at least some aspect of school lessons. Reasons given were that subjects were hard, boring or they could not see the need to learn them. Sara described how she disliked one lesson because of its perceived irrelevance to her future:

> *“Um some things I suppose you’ve got to do if you don’t enjoy them but others, it’s like me and chemistry, I don’t really enjoy it and so I hardly learn anything and take it in, I just find it a waste of a lesson, well not a waste of a lesson cos I mean I learn things but some things I’ll just never use in later life like what if, if I wanted to do something with sport, what would I use chemical bonding and stuff, and it might come in somewhere but, I’m not really that bothered by it.”*

Harry appreciated the need to gain qualifications even if he did not enjoy the lessons:

> *“Interviewer: what’s the best bit of college? Harry: Not really nothing good about it especially. Just I’ve got to be here if I want to do something with me life … there’s nothing especially bad about it, nothing, not a reason why I want to be here really either apart from just getting a few qualifications so I can get on with stuff.”*

Daisy did enjoy the educational aspects of school, and these were linked to her long-term career aspirations. Before this however, she mentioned the social aspect of school:

> *"Interviewer: Tell me the best bits of school. Daisy: Being with my friends. And I do enjoy the learning too. Biology, I like that and chemistry sometimes. History is interesting as well. Science is most interesting. I want to be a physio."*

Focus group participants were asked for comments on wording for a question on school lessons. There were differences in understanding of the word "academic" and whether lessons such as drama would be included, suggesting that the word should not used in a questionnaire item. Participants also felt that there should be separate questions about learning outside school, for example, drama school attended in a young person's spare time. The word "vocational" was not familiar to participants, and they felt examples would be needed if that term were to be used in an item.

Homework is not specifically mentioned in the ICF, and this may be because it is not relevant to all education systems internationally. However, it is a common part of UK school-based education. Homework was done by almost all in full-time education and something which took up time in evenings, weekends and holidays. The exception was the one participant with more significant learning disability who denied having homework to do. When participants were doing exams imminently this was particularly noted, exemplified by Daisy:

> *"Interviewer: What will you be doing over half-term? Daisy: I'll be revising and doing coursework … About 2 hours per day revision, well that's what we're supposed to do. I don't know whether I'll actually do that. And then 1 to 1 and a half hours of coursework."*

One focus group participant felt that there was a difference between homework and revision. She felt that the former was for the teacher and the latter for the student's benefit. Group participants defined homework as school work done outside lessons and not necessarily at home. There were some concerns that the wording would need to ensure respondents did not feel they were being asked whether or not they completed all the homework set, rather than simply whether they did any.

Extra-curricular activities and social aspects of the school day are not included in the School Education sub-domain of the ICF. A number of areas of Participation which fit this description were described by the participants and I included them under the Education theme in my analysis. The sub-themes identified were school trips, extracurricular clubs and teams, informal social time within the school day and tasks associated with having a position of responsibility.

School trips were discussed with 5 of the participants. Three described trips within the UK and another, a planned trip abroad. Zoe said she would have liked to go but was unable to because of her personal care needs.

> *"Um I've, I would like to go on places abroad with school but I've never like been able to do that … Well it means someone to go with me and it would be, it would mean like my mam taking time off work and it would just kind of be like a big thing."*

Discussion in the focus groups found that young people would include trips that were either educational or mainly recreational in the same category.

Extracurricular clubs and teams were discussed by seven participants. Some of these were "revision clubs" which could be regarded as extra academic lessons. Others were sports clubs or performing arts such as school choir. Rebecca commented that she had taken part in such clubs in the past but no longer had time because of exam pressures.

A number of different positions of responsibility were identified by the young people as being possible within their school or that they themselves took. Three young people described roles associated with sport. Two undertook coaching of younger children, both of whom had CP. One participant was a sports team captain. The latter role was described as including public speaking, writing letters, and fundraising. Student councillor was mentioned as a role taken by one participant in the past and another mentioned that her friend was a student researcher. One participant took part in a library duty rota. Three participants denied taking any role. One knew of no such positions within his college and another felt that he was not the sort of student who would be chosen for such a role.

Benefits of these roles included the enjoyment of the activities associated with the role itself, such as teaching others, and greater confidence in skills such as public speaking. Jade expressed the view that having a position of responsibility within school could help provide a sense of purpose in attending school:

> *"I think some people with no role think 'What's the point of me going to school, I haven't really got anything to do today' or 'I don't feel like going to school today' but I suppose if you know you've got a job, like something to do, you think 'Well I'll have to go to school'."*

A range of informal activities were reported by the participants when they arrived at school, in break-times and lunchtimes. Twelve of the thirteen of the participants attending full time education at the time of interview discussed this. In order of frequency, these were spending time with friends (12 participants), eating and drinking (11 participants), and using computers (4 participants).

Spending time with friends included chatting, playing football or other games with friends and hanging out. One participant described watching other students. This suggests that although the predominant activity is chatting and being with friends, some students are on the periphery of such Participation. Comment was made by one participant that activities depended on the weather with more outdoor hanging out or playing ball games in the summer. There may also be gender differences for some types of informal Participation during the school day. When asked how she spent her free time, Jade remarked:

> *"Just chatting, oh you could play football and stuff but it's just, I can never be bothered, the lads normally play."*

Eating and drinking was described as occurring in different settings including packed lunches being eaten in classrooms, food being purchased in school or participants leaving the school premises to buy food. One participant spoke about being able to go home for lunch if he chose which he found more relaxing, giving him a chance to wind down and discuss the day's events with his father. In one of the focus groups it was reported that in some schools, young people can only leave the school premises over a certain age.

8.2.2.7 Work and economic life

The Major Life Areas domain of the ICF includes work and economic life sub-domains, which I combined into one theme.

Of the three young people who had left full-time education, one was unemployed and looking for work, one was in paid full-time employment and one was in part-time paid employment and part-time self-employed. Of the remaining 14, two of the young people described having a formal part-time job, one in a pub, and one at a youth club.

Five young people had informal jobs or had had one in the past. Two participants undertook babysitting for friends of the family or neighbours. Three young people helped their parents with elements of their job for which they were paid; one at her mother's hairdressing salon, one with door-to-door selling and one with using the internet to help her mother sort out finances related to her job. One participant had delivered newspapers in the past.

These jobs were mostly appreciated for the money they brought in but other perceived benefits were gaining an insight into full-time work, filling the time over summer holidays and a feeling of job satisfaction. A degree of independence resulting from a part-time job meant young people felt less of a burden on parents. This is illustrated in the following quotes first from Sara, and then from Kate:

> *"<u>Sara</u>: I just feel like if I pay for my own holiday I enjoy it more so it just gives us a better feeling and I don't feel guilty on my parents and stuff."*

> *"Kate: Um, I think that I feel more independent now cos I've got my job at the youth club. I get money that way, and you know I pay for most things myself like my clothes, you know I pay board. I feel like I'm more independent that way."*

One participant with CP, Eleanor, felt that having a job would detract from her studies. Harry was also concerned about how he would cope with a job as well as studying:

> *"If I'm going to do something, I want to do something that I can do well not barely struggle to do it so it's a case of come here* [to college] *to get the qualifications. I want to do a job that I know I can do to a decent standard rather than just getting a job for the sake of getting a job basically."*

What I could not tell from this data, was whether this was the primary reason they did not have jobs, or whether it represents a psychological defence to a lack of opportunity for these young people.

The sub-domain d840 Apprenticeship seemed to best fit the experience of two participants who were undertaking, or had undertaken in the recent past, courses outside formal education to enable them to take up a job. One had undertaken an informal apprenticeship as a plasterer and one was undertaking lifeguard training.

Apart from the contractual aspects of work, Participation in the workplace may also include social aspects. This is not specifically mentioned in the ICF. It has been noted by some authors that jobs typically performed by adolescents are less likely to involve these aspects of work (Steinberg, 1999). Those participants in jobs discussed some aspects of this and mainly related to chatting to other employees, as described by Duncan:

> *"When I'm in the kitchen I'm with the other lads, we're in a close area together and we always have a good laugh … it's a bit more sociable working in a kitchen."*

One of the topics of discussion in the focus groups was what areas might be included as "work". Most participants agreed that whilst formal paid employment and informal paid jobs such as paper rounds counted as work, helping in a family business without payment, or doing household chores for pocket money they did not regard as work. Along with work experience, these latter areas of Participation were felt to be better labelled as helping out, learning life skills or preparing for the future. There were some comments that some types of part-time job, particularly where informal, might be better regarded as work experience. One participant emphasised the qualitative difference between doing a job whilst still at school to "open your eyes" and learn to handle money, and working full-time to "survive".

Economic life is another major sub-domain within the Major Life Areas domain. This contains d860 Basic economic transactions and d865 Complex economic transactions. The former includes using money for buying goods and saving money.

Budgeting and how they choose to spend money was discussed with a number of participants because shopping was a major interest for many. Six of the young people discussed saving money, with only one stating that he did not save. Some discussed saving up for specific things. Sara described saving at specific times:

> *"Well, um, I never normally go shopping if I haven't got enough money cos normally if I haven't got enough money it must mean I'm saving so I never normally go unless I've got some spare."*

Some spending is seen by young people as important in order to facilitate Participation in social events, as Martin explained:

> *"<u>Interviewer</u>: What's the most important thing that you spend your money on do you think, from your point of view? <u>Martin</u>: It isn't the most important thing, well it is to me but um it won't sound right if I say to you drink, well not in that way but you know when you're with your friends, I don't have to have a drink but my mates always put one down."*

Focus group participants who discussed the wording of a question on spending money felt that to make the item relevant to the entire age range, both pocket money and wages should be included.

Complex economic transactions (d865) includes maintaining a bank account, as well as more complex areas such as buying properties and businesses. The degree of independence with managing the bank accounts varied. Some young people had an account that they administered but were aware that their parents managed one or more other accounts on their behalf. Peter described how it worked for him:

> *"When I was at Asda I got paid monthly and I um limited myself to £200 per month and I put the rest in a savings account I've got but now we get paid weekly so I um just limit myself to £100 per week and put and I'll … wait for the end of the month to put a bit of money in, so I've got a … bulk to put in … my mum set the, set my account up and what I do is at the end of the, no, I'll write a cheque out to my savings account and I'll get her when she goes for her lunch just to drop it in and get my book stamped and everything but bar that, I do everything."*

Eleanor, a young woman with severe dysarthria, held a joint account with her mother which she explained was because as she could not use the phone to contact the bank herself, although otherwise able to operate the account independently.

8.2.2.8 Community, political and civic life

The Community, Social and Civic life domain includes d910 Community life, d9300 Organised religion, d9100 Informal associations, d9102 Ceremonies, d950 Political life and citizenship. There is some overlap conceptually between this and d855 Non-remunerative employment in the work domain, as this includes voluntary and charity work which could also be seen as part of community life. I included voluntary and charity work within this latter theme.

Religion and Spirituality has its own sub-domain (d930) but I included it with Participation in groups in a young person's local community. One participant described regular church attendance and two others described occasional attendance, for example, at Christmas. Four young people said they were current or past members of Guides or Scouts groups. Four participants were current or past members of youth clubs. These tended to be the younger participants. Jade reported that some of her school peers attended army cadets.

Martin attended a community social club on a regular basis and Harry attended a disability sports club where he was a member of a team with other adults. This he had found beneficial, opening his eyes to what Participation might be possible:

> *"I play wheelchair rugby so it's with loads of people that have broke their necks and just seeing how most of them have got on with things, it's just a kick in the right direction to get on with things and start doing stuff rather than just taking the easy route all the time."*

Six young people had taken part in charity fundraising, for example, doing sponsored events. In addition two participants were or had been involved in working in charity shops. Five young people helped out with clubs or other activities for younger children such as Brownies, teaching younger children in schools or with sport or at a youth club. Duncan had done voluntary work with animals when younger and was contemplating restarting this.

This sub-domain (d9102) includes social ceremonies. The most frequently mentioned area which could fit here was birthday celebrations. For some this involved celebrating with family members, and some with friends. In this sample, there were differences in this pattern between those with severer impairments and those with mild or none. Those with severer impairments tended to celebrate their birthdays just with their family and were less likely to attend the birthday celebrations of their friends. This is illustrated by Eleanor's description of her 18th birthday and Jerry's description of his:

> *"Eleanor: For my eighteenth birthday, I had a party but not on my birthday because we went out to a restaurant. Interviewer: And how many of you went*

> *to the restaurant? <u>Eleanor</u>: Just the family. <u>Interviewer</u>: So did you do anything with your friends as well, or? <u>Eleanor</u>: No."*

> *"<u>Interviewer</u>: So what do you do for things like birthdays? <u>Jerry</u>: Usually what we do we have sausage rolls … <u>Interviewer</u>: Do you have friends round, or? <u>Jerry</u>:* [pause] *No … <u>Interviewer</u>: Do you go to other people's houses, friends' houses for birthdays? <u>Jerry</u>: I would be ready 'Would you like to come here and we'll have a birthday party', but usually no … if they say 'Oh it's my birthday today' I'd say 'Happy birthday' but I don't like go round to theirs."*

This contrasts with the experiences of Sara and Jade:

> *"<u>Interviewer</u>: What would you do for your birthday usually? <u>Sara</u>: Just have some friends over, um just have some friends over to mine, party normally, not like a big party, not like an organised party, just have some friends over and chill out and stuff."*

> *"<u>Jade:</u> I've got, there's some parties, birthdays parties, I'm going to one tonight. <u>Interviewer</u>: where else do you go out for birthdays …, what else have you done in the past? <u>Jade</u>: Um cinema, I went ice skating the other week, that was good, um people's houses, mostly the craze at the minute is to hire out a club. That's the new thing."*

None of the participants discussed participating in the activities of political parties. One participant commented that he was interested in environmental issues although not involved in any organisations. One participant described signing a petition relating to world poverty. In response to the question "What's good about being eighteen?" Eleanor said that it was being able to vote. Four young people said they had voted in elections of some sort and another three said they had had the opportunity but had not taken it.

8.2.2.9 Recreation and leisure

Recreation and Leisure (d920) is also a sub-domain of the Community, Social and Civic life domain, but because of its prominence in the lives of young people, I treated it as a separate theme. Within this section in the ICF there are 6 specific second order sub-domains: d9200 Play; d9201 Sports; d9202 Arts and Culture; d9203 Crafts; d9204

Hobbies; and d9205 Socialising. In addition sub-themes of time alone, outdoor pursuits, electronic media and tourism were identified in the data.

Despite the age of the participants, play was mentioned by some. Sara described this in free time at school:

> *"Messing around, just like you know what you do when you're little with the, like you spin each other round and stuff and just play little kids games even though we're meant to be 16 but we're just, I don't know, you just like do cartwheels and stuff and roly polys and just take the mick out of each other."*

Peter, the oldest participant in the group described it occurring in leisure time:

> *"Sitting on the swings and um, I know I'm quite big and that, but I quite like to go on the seesaw. Takes me back to how it was when I was younger and that when I used to play with my cousins and stuff so we just go on there and go on the swings and um get stuck halfway down the slide and just basically chat about what things have been going on and what have you, how work is and just what we've been getting up to."*

Not being able to "play" was one way in which Peter felt excluded because of his disability:

> *"*[My friends] *can well, they quite often, um I know it sounds a bit childish and that, but they quite often climb trees and climb over walls and stuff which I can't do which annoys me a little bit cos I've got to, I'll either have to walk around or I've got to, as I say, they're swinging from the trees like baboons and I've got to just um stand at the bottom watching which I get annoyed about and what have you but um I just think to myself there's nothing I can do about it so why get myself* [het] *up about it."*

Board and card games were mentioned as being played at home and with people outside the family. They were described by participants across the age range.

Informal socialising took many forms for the young people interviewed. These included parties, shopping with friends, meals or drinks out, and visiting friends' houses. A number of young people mentioned attending parties. These could be in a friend's house or in a public venue. Those who did attend parties described them positively. Parties were events where young people described dancing as well as chatting with friends and drinking alcohol. Informal socialising seemed to be less common for those with severer impairments. Martin and Eleanor explained some of the reasons why this might be the case:

> *"Martin: With them* [college friends]*, I've never been out with them because they're going upstairs and stuff … they've said 'Oh Martin, we're sorry, we're going upstairs because there's a party and we've been invited' and I said 'Don't worry mate, you can go.'"*

> *"Eleanor: I do go to parties but I don't go out very often … Because I need support. My Mum takes me and if my Mum wants to go out then there's nobody to look after my sister."*

Shopping was a common activity which young people used as a vehicle for socialising. All but three of the participants discussed shopping for leisure. This was undertaken both with friends and with family. It was a common area of participation across the age range. This could involve window shopping as well as actually purchasing goods, as Daisy described:

> *"Interviewer: What do you go shopping for? Daisy: Just to hang out. I don't have any money, so we don't buy things! We just talk and look wistfully* [laugh]*."*

Most participants with mild or no impairments spoke about going to others' houses. For those with more severe motor impairments, particularly combined with dysarthria or learning difficulties, this was less likely to occur. Hanging out at friends' houses was described across the age range. A description was provided by Jade:

> "[We chill out] *at each other's houses and stuff cos like my mum always says I'd rather you were in the house rather than on the streets obviously so we just have friends around and we sit and watch a film, we just sit and chat."*

This contrasts with those with more severe impairments, some of whom denied going to others' houses.

Visiting pubs and bars is clearly age-specific because of the laws regarding the consumption of alcohol. Younger people would be able to visit cafes instead, although there is no interview data on this. For the older participants, visiting pubs and bars with friends was something they did on a fairly regular basis.

Kate commented on how being able to go to pubs made her feel grown-up:

> *"You're 18 and you're allowed to go out drinking and things and sometimes I do go to the pub and things but like going out … and you know the pub, especially around here, there's always people you know and people you haven't seen for a while and you can always have a conversation with them about what they're doing and things … I think um going out to pubs and things it makes you feel kind of older, you know like old enough to go out you know, things like that."*

Commercial discos and clubs do not usually allow people below the age of 18 to attend. Schools and clubs however, do organise discos for younger people where alcohol is not available. This was not described by the participants, although night clubs were discussed with some of the older group and three said they went, although this tended to be occasionally.

All but two of the participants described eating out with other people. Sometimes this was with friends and sometimes with family. It was mentioned by a number of participants as part of an "ideal day" or a recent occasion that they had really enjoyed. An example of this was given by Shaun:

> *"Um, not normally but a couple of weeks ago, I think it was last week, me and my friends decided to go out to a restaurant and have a meal. Not normally we don't do that … not once in a lifetime but once like in a couple of months or so …* [to] *Pizza Hut or some Chinese restaurant."*

Visiting museums was an area of Participation described by three participants, undertaken during holidays for two young people and as part of school art projects for one other.

One participant described singing in the school choir and informally at home. Two participants described playing musical instruments when younger but they had stopped due to the pressure of school work. Twelve of the participants discussed listening to music. For some it was something they did very frequently, as described by Alicia:

> *"Interviewer: And you mentioned before that you've got your iPod, do you ever listen to music at home? Alicia: Yes all the time. Interviewer: So when would you do that? Alicia: When I get in from school and I come back and um if there's nothing on TV and um before I go to bed."*

The music they were listening to was mentioned by several participants as one of the topics of conversation when with friends.

Seven participants described reading books for pleasure. For four this was a regular pastime. Types of books enjoyed included fiction, and non-fiction including autobiography.

Five participants said they read newspapers, for two this was to read about sports results and one to look for jobs. Jade described reading a newspaper only if she happened to see something of interest:

> *"If it's in front of me I'll read it but I wouldn't say 'Ah where's the newspaper?' but if it's near I'll just have a flick through … Um, what, what the main headline is I suppose and then just, well I wouldn't really look for anything, it's just if something caught my attention and it's what's going on with that."*

Peter described the physical difficulty he experiences with manual skills when trying to read a newspaper:

> *"I detest them. My dad reads them but I'll just, I'll read it if there's a story that interests me … but … it just annoys me cos nearly every time the paper will fall apart and stuff and it just annoys me that … I can hold* [with my left hand], *I can hold it but it's not as strong as my … right, so it tends to just sort of slip and all the pages come out which angers me a bit, so I think that's why I don't really like newspapers."*

Magazines were read by six participants. For two this was related to specific interests; games and cars for one participant and health and fitness for the other. Three read magazines primarily for celebrity gossip.

Thirteen of the young people mentioned going to the cinema. It was listed by a number as something they would do as part of their "ideal day" or as something they would do to celebrate someone's birthday. Frequency varied from weekly to an occasional visit.

Going to the theatre was mentioned by two participants. One described going to London with the family in order to attend a show and the other mentioned going to the pantomime in the past. Two participants described going to pop concerts. Both described them as very enjoyable and exciting, as Sara described here:

> *"Well I've only ever been to one concert but I'm, I went to Basement Jacks for my friend's birthday, just me and her, and I, I absolutely loved it, it was just amazing."*

Hobbies or specific interests were only mentioned by Jerry, who described his interest in aeroplanes. He used the internet to look at types of planes and timetables as well as visiting airports with his father. Taking part in art and craft was mentioned by three participants. For one it was a major interest and for another it was her same age sibling who participated in this area.

Nine young people described participating in informal sport at an indoor venue. The most common sport was using a gym and swimming. Sometimes this was noted as something they did at particular times, for example on holiday and for some it was a regular area of participation. Martin described the barriers to him using a swimming pool:

> *"I haven't swam here since I was 8 … 'cos I need armbands and they don't provide armbands anymore. … plus the pools are freezing cold. I don't like cold pools, no way. … I just freeze up."*

James described his preference for going swimming informally with friends as opposed to formal lessons:

> *"It's boring though on Wednesdays, cos all you do is lengths, they don't really teach you anything, it's good when you go with your friends like on a Tuesday or Thursday cos then you can relax and have a time of freedom at the pool, cos you can jump about and stuff."*

Seven young people described an informal sporting or keep fit activity which takes place outside. This included playing games in the park, skateboarding, walking or cycling as exercise. Some of this was done alone and for others, with other people. Seasonal variation was noted by one participant, who cycled more frequently in the summer.

Formal sport was a major area of Participation for eight participants, including those with more severe CP. The latter played disability sports and some were very keen players who were members of teams, playing competitively in tournaments. For some it had influenced career choices. Often sports Participation was through school or college, but several described being part of teams outside school too. Rebecca spent a large amount of time riding her horse, but as with the informal sport, seasonal variation was evident here:

> *"Interviewer: And how often do you go and do things with the horses? Rebecca: About 4, 5 times a week. …* [events] *usually happen in the summer … I don't do much in the winter cos there's nothing much really to do. I just, but in the summer I enter loads … my bedroom is full of* [rosettes] *and trophies and everything."*

Martin was frustrated with the lack of availability of disability sports provision at the college he attended:

> *"It's just sport, it's got everything else that I like, but sport and that's the higher one but it annoys me, you see I do sport studies on a Monday and get involved with that as much as I can, but it's all able bodied which is boring for me. So I do a warm up, I do the practice but when it actually comes to like the game, I sit out. Interviewer: And how does that make you feel? Martin: Disappointed that I can't get stuck in there because not last week but the week before, I know my tutor very well … I accidentally ran into him because we were playing wheelchair hockey, and I was driving this and I don't like playing because I could hurt someone with this, really bad. … All of them are able bodied. I'm the only one in a wheelchair, which is gutting. Interviewer: And why would it be better to play disabled or wheelchair hockey, why would you be less likely to hurt people? Martin: Because if you were going to bash into, you would use your footplate and it would hit their footplate, you wouldn't really hit them, you would probably knack their chair leg but not them so it's all right."*

Three young people described attending live sporting events and one young man said he would like to go to football matches but had no-one to go with. For some it was a regular event and for others, an occasional one. Four young people said they watched sport on TV. For one this was a substitute for attendance at a live event which he had not been able to attend.

Some young people discussed the importance of privacy and Participation without parents and adults in positions of authority present. This is difficult to map to the ICF domains, but I placed it under the Recreation and Leisure theme, as, for the purposes of instrument development, that seemed most appropriate.

Thirteen young people discussed time spent alone doing certain activities. They described this time as an opportunity to relax, wind down, have "space" away from other people and time to think. Sara described the need for this:

> *"Um sometimes I get like too much, when I'm like, when the week is jam-packed and I don't have any free time, it just gets to my head and like I normally end up*

> *just going to sleep, just sleeping as much as I can in my bed, just, I don't know, spend time by myself, that's normally how I do it."*

For some young people, the amount of space at home was a barrier to spending time alone as described by Daisy:

> *"Generally I'm only on my own if I'm doing my homework. Because I share a room I don't get to just sit on my bed on my own. Every so often if I'm very stressed I might say 'Leave me alone for 5 minutes'. I don't like sharing my bedroom. We're always arguing, or it seems it. I like to sing a lot, my sister gets annoyed. Every other day I'm allowed to sing. So I can sing today but not tomorrow."*

Young people described playing on the computer, watching TV, listening to music, going for a walk or taking a bath as means of relaxing or de-stressing when alone.

Focus group participants who discussed this area felt that time alone in the house or outside would serve the same purpose.

Seven young people described what I categorised as outdoor pursuits. These included fishing, camping, riding quad bikes, bird watching and gardening at an allotment. Alicia was interviewed with her mother present. Her mother commented that the family's participation in outdoor activities was reduced because of her daughter's impairments:

> *"I think we found it quite difficult as a family we were quite into cycling because* [brother] *had a bike,* [sister] *had a bike. We did have Alicia on a trailer bike but we did damage your hands a few times going around walls and things and as she grew heavier we found we couldn't do it and we really missed out as a family."*

Watching TV, video or DVD was a common area participated in and was described by fourteen of the young people. It was something done alone, with friends and with family. For some it was a regular family activity. Seven young people described playing electronic games. These might be alone or with others. All those who described playing computer games were male. Some participants described playing games as a way of reducing stress as Martin described:

> *"Interviewer: And how do you handle stress? Martin: Sit down, sit on my Playstation, that's mainly it."*

As with playing computer games, using the internet for other leisure was described by males only. Jerry described using it as an information source:

> *"I maybe I just surf the internet … It depends what I'm like thinking of and so it might be the weather or might be flight times or might be who are* [name of football team] *playing on Saturday."*

Holidays were participated in by all participants. Some had not been recently but had been on holidays in the past. Sixteen young people described holidays with family. Some holidays were taken in the UK and many young people had been abroad. The importance of holidays was illustrated by the way Duncan illustrated his description by showing me a photo:

> *"Been down Cornwall and that with me mam and everything, that was a good place … We went and stayed in the caravans … Hired a minibus and drove all the way down. … We had um all of us, me mam, me mam's friend and her two sons, and two other of me mam's friends.* [goes and takes photo off sideboard] *That's us there at Land's End. There was a canny little crew of us … We had a good time down there.* [puts photo back]*"*

Similarly, Daisy described the importance of holidays for her:

> *"We go to Centre Parcs. We've been going for years. I really enjoy that. Interviewer: Why do you think you enjoy it? Daisy: Because I've got loads of memories. Does that sound funny? I'm so used to going. You're away from cars and roads and concrete buildings. It's relaxing."*

Frequency varied from occasional and not every year to several times per year. One participant described taking it in turns with her siblings to go away with family members on holiday. The reason for this may have been financial constraint although this was not discussed. Seven had been on holiday with friends, some of which were as organised trips with sports teams, or with Scouts or Guides.

Day trips were described by six young people with two denying participation in this area. Places visited were stately homes, the countryside, theme parks and the seaside.

8.2.2.10 Planning for the future

The areas discussed in this section are not explicitly mentioned in the ICF but could be included in the domain on human rights which includes “the right to control over one's destiny”.

Sleeping away from home is not included in the ICF, but is a common area of Participation for both children and adolescents. Sociologically it has been seen as an important area in many cultures for preparing for adulthood and independent living (Steinberg, 1999). Sleeping at others’ houses was mentioned by a number of participants. For some this was a frequent area participated in, for others less so. It was not dependent on age. A typical comment was that of Rebecca:

> *“Interviewer: Do you go and stay with other people? Rebecca: Yes … about once a week … We take in turns, like if I’ve been to their house and it’s their turn to come to me and stuff. Interviewer: OK and how many of you would be involved in that? Rebecca: It would be like one or two.”*

It was mentioned less by those with more severe impairments. Zoe described her experience and the access barrier which prevented her Participation:

> *“Um, I went to my friend’s party which was at Frankie and Benny’s, and um like well I kind of wish that I had been able to go to their sleepover but I didn’t … Um it would have been like, well the bathroom would have been upstairs and we would have been on the ground floor …”*

A focus group participant suggested “crash at a friend’s” might be more appropriate item wording for older respondents.

Some young people had very clear ideas and views about leaving home. Some were planning consciously for this, including Peter:

> *"Yes, um well, I've set my target, I would like to move out like by the age of 23, I can't say that, but I've started like two savings accounts up. Once one of them is full I'm putting money into the next one and that's really, that's what I'm saving for at the minute, for a deposit, for a house or flat … I just fancy getting a house on my own, just you know coming in, I mean I know this is my home but just saying, right this is my home, nobody else's and basically doing what I want to do um taking, um going to get my own shopping and um deciding what I want to eat and just what furniture I want and just little things like that I'm looking forward to doing on my own."*

Others such as Harry and Kate were more cautious:

> *"<u>Harry</u>: I'm not, I'm not in a hurry to do that but it's cos when I do move out, I want to move out and move into a decent place rather than just a, one of, that horrible council place, you know, I'd rather just wait, get some money, get a job sorted out and get a flat or a house in a decent area where I want to live and like … how I want the house or flat to be rather than just being dumped in somewhere where I don't really want to live there or it's not a very nice place to live basically."*
>
> *"<u>Kate</u>: Um, it is, I don't mind living at home, it's quite convenient with where I am, I never really, I never really felt like I wanted to move away but um cos I've got like friends and things, um I just think that moving somewhere, some people, cos I think like if you live away from home you have to have loads of confidence and things, like University and you know, living in your own house, you know paying bills and things, you have to have a lot of confidence to do that and I think living in a new area, I know like um getting the bus into University is quite new because like I had to work out the buses and getting into town and out of town, that was quite new because I didn't used to go into town quite a lot and so I am doing new things but um I feel quite comfortable coming back here because I know where I am and things but University is quite new but I think, I didn't feel like I could live away from home, I never really felt like moving away but some people I talk to are like desperate to move away from their parents' house and things."*

Work experience provided within the school was described by some young people. Jerry described his experience:

> *"I've done work experience for a week in year 10 helping the deputy head teacher at the primary school of* [the school he attends] *for a week and I enjoyed it … Tidying the room, making labels, um. But one thing that I really didn't enjoy was filing … I was supposed to photocopy all the pages from one file to another file and it took me nearly about two days to do, so it was boring, really boring* [emphasised]*."*

Work experience in organisations external to the school, although often arranged by school was mentioned by a number of young people. Some enjoyed it, others did not. For some, work experience gave ideas and insights into possible careers, as described by Martin:

> *"Because I did work experience at* [special school] *so from* [special school] *to* [name of company] *and we were working on the PCs all day and I thought this is my kind of job, I want to do this."*

Two of the focus groups discussed work experience. It was felt by participants that work experience done in school was qualitatively different to that in a workplace outside school. Participants commented that going to the unfamiliar environment of an external workplace would be a more challenging experience.

Most data regarding Participation in this area was concerned with work experience, although a number of comments were made about career aspirations. In one of the focus groups, it was felt that discussing future careers with an advisor could be helpful in clarifying a young person's thoughts.

8.2.3 Overarching themes

These themes were related to a number of different areas of Participation, with more importance for some than others.

8.2.3.1 Autonomy

Being able to make choices for themselves about Participation was highlighted in both the interviews and focus groups as important to the young people. The importance of autonomy in self-care routine was discussed in section 8.2.2.3.

Some young people with more severe impairments were reliant on parents for transport and lived some distance from friends. This makes being autonomous in making decisions about social life difficult, as described by Jerry, who described a reliance on parents to find him social activities:

> *"Interviewer: Was it your choice to go to the youth theatre, or? Jerry: My Mum and Dad heard about the youth theatre or something else and um usually they say 'Ah, we've found something which you can do' um … I usually, the only time I go out and about to see people or do stuff, I don't go out and see the boy next door and say 'Hey, do you want to go out somewhere'. I usually go out at night-time where we're seeing family or friends or going out with family."*

Martin highlighted how choosing the people you mixed with was important:

> *"Interviewer: So what sort of things is it important that you can choose for yourself? Martin: Like who you, like who you're seeing, girlfriend, boyfriend, whatever, your own set of friends."*

Having choices about how they spent their time was discussed with some other participants. Kate thought that the instrument being designed should ask young people about whether they make decisions about their activities:

> *"Interviewer: What do you think would be the important things to ask people about? Kate: Um I just think like what's important to them, like you know what they enjoy doing, like you know things like that, um I just think um you know, giving them a choice and not saying you have to do this and, you know, let them make decisions for themselves, I think that's quite important."*

The issue of autonomy was discussed with focus group participants. Participants noted that the amount of autonomy a young person had depended on the type of decision as well as competing factors. For example, when a young person was doing exams, parents would be less likely to allow them to exercise choices over how they spent spare time that they would have at other times. Participants were also asked whether they could answer a question asking them whether they had as much autonomy as others their age. They felt that it would be hard to know how much autonomy others really had “behind closed doors”.

8.2.3.2 Co-participants

I have already discussed above how there were differences between the young people in what areas of Participation were carried out alone, with friends and with family members. In general, those with severer impairments were more likely to participate with family members rather than friends. This was particularly noticeable for birthday celebrations and informal leisure.

In the focus groups, participants expressed the view that celebrating birthdays and other special events was important to do both with family and with friends but that the two were different experiences. The same applied to eating with either family or friends at home.

8.2.3.3 Participant views on instrument design and possible qualifiers

This topic was discussed to some extent in the interviews, but more so in the focus groups. In particular the understanding of different qualifiers was explored. Difficulties were highlighted with subjective responses to frequency, for example, “too often, about right, not often enough,” etc. It was felt by one group that it could be unclear from whose perspective this might be reported. If a parent wanted a young person to do something more than the young person themselves, this might be reflected in the answer. One participant commented that for something that was enjoyed, a respondent might wish to do more, but that might not be possible, e.g. attending a club which only meets weekly.

Describing difficulty in an area of Participation was also discussed. The participants queried how this might be evaluated. A respondent may make a comparison with others, or it may depend on a young person’s expectations and their self-esteem.

Similarly, focus group participants felt that the importance of an area could mean different things.

The qualifiers identified by the participants as most meaningful to them were choice and enjoyment. They felt that having choices and what was actually participated in should be separate questions.

8.3 Discussion

This qualitative work provided essential insights into the areas of Participation in the ICF which were of particular relevance to this group of young people. The reported frequency of different areas, and the level of importance ascribed to them for the young people, enabled me to gain a sense of what items it would be particularly important to include.

Some areas of Participation which might seem to some to be quite similar, were described by the young people as quite different, or were described differently by those with and without severe disability. Examples were who birthdays were celebrated with, and work experience performed within or outside school. These details were helpful when deciding which items to include in the questionnaire and how to describe them.

One finding that was somewhat surprising to me was the number of young people with CP in the sample who spent a large amount of time participating in sport. Some studies have shown in younger children that those with CP participate less in sporting activities than children in the general population (Law et al., 2006). However, the young people in this study for whom sport was a major interest attended a range of special and mainstream educational provision across the Northern region, suggesting that this was not a factor influenced by one or two schools where this was particularly encouraged. It may however be a cultural factor relating to the North of England. SPARCLE, a European multicentre study of the Participation of children with CP (see

6.2.1 for more details), found that Participation in sport was more frequent in the North of England and in Ireland than in the other European countries studied (Fauconnier et al., 2009).

Another area of Participation that seemed to be important for some, but might not have been expected, was “play”. Usually associated with younger children, a point highlighted by the participants, this was nonetheless described. Again, this led to the inclusion of an item to cover this that might otherwise have been omitted.

The focus groups were helpful in examining how items should be worded to avoid ambiguity. For example, the understanding of “neighbourhood” and “informal” were both found to be variable between participants. This led to alternative words being chosen, or examples given to help comprehension. These findings are not exclusive to this group. Words such as “neighbourhood” have been noted by other authors as variably understood by adults (Oppenheim, 2000). The discussions in the focus groups also provided some insight into how qualifiers of Participation might be interpreted. Discussion in the focus groups was also useful in devising a domain structure which had face validity for the young people.

Chapter 9. Item development and content review

This chapter describes the process of content validation. Content validity is the extent to which the items in a scale adequately tap the latent construct. The process of ensuring content validity has been described as having two phases (Polit and Beck, 2006; Lynn, 1986). The first, the *development* stage, involves the care taken in defining the construct and developing suitable items which tap it. The second, the *judgment-quantification* stage, involves the use of a panel of experts to assess the items for relevance and coverage. This chapter then, describes how items were developed from the qualitative data described in Chapter 8 and the subsequent content review by a group of experts.

9.1 Methods

9.1.1 Selection of items

As previously discussed, the data from the qualitative work with young people was the primary source of items. Other Participation measures and the published literature on adolescent development and Participation also influenced the choice of items. A bank of items was written which covered all the key domains of Participation. No effort was made to eliminate redundancy at this stage as the processes of expert review and then field-testing enable the best items to be identified later (DeVellis, 2003).

The items were arranged in an *a priori* domain structure based on the themes developed from the qualitative work.

9.1.2 Recruitment of experts

The aim was to obtain the views of experts from a range of relevant backgrounds. There is no agreed ideal number of experts, but authors suggest a minimum of 5 and a maximum of between 10 and 20 (Slocumb and Cole, 1991; Lynn, 1986). With few individuals having expertise in all relevant areas, I chose to approach a high number of experts. Given the effort that would be required by reviewers, I was also unsure what the response rate would be and so I approached more experts than needed.

The majority of experts approached were known to me or members of the project steering committee. Some were chosen for their research expertise, others for their professional experience. As recommended (Davis, 1992), an expert in instrument design was included as well as individuals with expertise in the concept of Participation and its measurement.

9.1.3 Content review questionnaire

Formal ascertainment of expert opinion using a structured feedback form elicits the best results (Slocumb and Cole, 1991). Several authors have outlined methods for how to obtain feedback in this way, including the information needed by reviewers about the study and the underlying concepts (Davis, 1992; Slocumb and Cole, 1991; Lynn, 1986). I used a number of these ideas when designing my review.

Items for consideration were presented in the form of a questionnaire. For each item, the respondent was asked to rate the relevance on a scale of 1 (not relevant) to 4 (highly relevant) and to state whether the wording was clear or not. Free text comments were invited. Further questions were asked about the overall questionnaire and whether the items provided full coverage of the concept. The questionnaire was accompanied by a covering letter, and an information sheet containing definitions of the relevant concepts. The items included in the questionnaire are shown in Appendix D.

Analysis involved calculating the content validity index (CVI) for each item and for the scale as a whole. The CVI is the proportion of experts rating the item as relevant (Polit and Beck, 2006). The use of the CVI has been criticised by some as it does not allow chance agreement to be adjusted for (Polit et al., 2007; Wynd et al., 2003) leading some to argue that other tests of inter-rater agreement, such as a multirater kappa

(Wynd et al., 2003), are more suitable. However, as has been noted (Polit et al., 2007), the information required here is the degree of agreement that an item is relevant, rather than agreement *per se*. What is of interest is consensus on the content validity. It would also seem reasonable to assume that the experts gave their views based on considered opinion rather than by guessing. The number of free text comments they provided would support this. I therefore felt that the CVI was a reasonable measure to use in summarising the experts' views.

Taking the acceptable value of the item-level CVI as 0.78 (Polit et al., 2007), any item with a CVI of less than this was considered for removal. Qualitative comments from the experts were also used as a guide to altering or removing items. Where expert comment appeared at odds with the qualitative data from the young people, the item was retained for field-testing. The position of items within the domain structure was also reviewed in the light of the expert comment.

A scale-level CVI was calculated for the remaining items, once the decision had been made about which items should be removed. The statistic used here was the *average agreement* CVI, which is the mean of the item-level CVIs. Some instrument developers have used what Polit and Beck (Polit and Beck, 2006) call the *universal agreement* scale-level CVI – the proportion of items where 100% of experts rated the item as relevant. This can produce a very different result to the average agreement statistic and is likely to be lower where there are a relatively large number of reviewers (Polit et al., 2007). I thought this was a less useful figure, as total agreement amongst a large number of experts, particularly where they have expertise in different aspects, is not necessary and the average agreement figure is more informative.

9.1.4 Construction of the questionnaire for field testing

The ideal questionnaire item is understood by all respondents with the sense the developer intends. The respondent should find it straightforward to answer, such that they answer it the same way when asked on a different occasion. The respondent should also feel comfortable answering accurately and truthfully. Writing items that fulfill these criteria is easier said than done and a number of texts examine the pitfalls of item writing (Streiner and Norman, 2008; Oppenheim, 2000). Important considerations for the items themselves are avoiding double-barrelled items (where an item contains more than one question) and making the items as clear and easily understood as possible. A number of factors will aid clarity. One of these relates to the complexity of the vocabulary and grammatical structure used, known as *readability*. Several methods for assessing readability calculate the average number of syllables per word, or words per sentence an example being the Flesch Reading Ease test (Flesch, 1948), which can be calculated by *Microsoft Word* (2007). One criticism of using such methods for scales is that without the use of certain words, the scale meaning may be lost (Streiner and Norman, 2008). I nevertheless thought it would be of some help to look at the readability of items using this method.

The layout and appearance of a questionnaire is also important in ensuring that respondents answer the questions in the way the researcher intends (Oppenheim, 2000). Piloting can help in establishing whether layout is appropriate. I took these considerations into account when designing the instrument for field-testing. Piloting with cognitive interviews was carried out at the start of field-testing and is described in detail in Chapter 10.

9.2 Results

9.2.1 Draft items

88 items were written which were put into 7 domains. 6 domains mapped to the ICF. The domains and how they map to the ICF are shown in figure 9.1 overleaf. The draft items are contained in the content review questionnaire in Appendix D.

Items were written in the form of statements followed by response options regarding frequency of Participation. Versions designed for self-report and proxy-report were written. The items for the two versions were identical in content, but the self-report version had items written in the first person and those for the proxy-report in the third person. For example, item 1.9 in the self report version read "*I wash my own clothes*" and in the proxy version "*They wash their own clothes*".

Response options were chosen to reflect the most likely range of frequency for an item. Where possible, options were made as similar as possible for items in the same section for ease of completion. Research has suggested that the limits of short term memory means that respondents find more than seven responses difficult to remember (Streiner and Norman, 2008), and so no more than seven were used.

For ease of communication, a name was also proposed for the instrument at this point. The Questionnaire of Young People's Participation was decided upon, abbreviated to QYPP (and pronounced "quip").

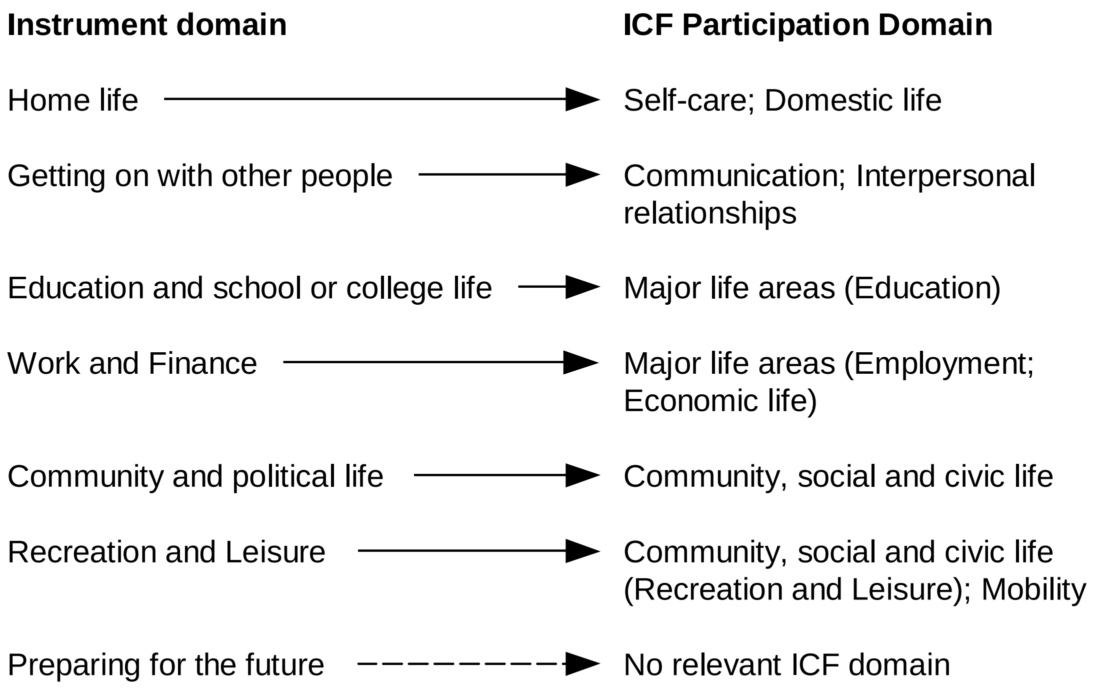

Figure 9.1 Proposed domains and their relationship to the ICF

9.2.2 Expert content review

Twenty-three individuals, listed in Appendix E, were approached and seventeen completed the content review questionnaire. They included experts with healthcare, education or academic backgrounds, with interests and expertise in adolescent health or education, paediatric or adult neurodisability, measurement of Participation or the development of measurement tools.

Item-level CVIs ranged from 41–100%. The results led to 11 items being removed, 7 split into two or more separate items and 6 new items being added, shown in tables 9.1, 9.2 and 9.3 respectively (see below). A number of free text comments were given regarding the wording clarity, many with suggested changes, and wording was subsequently changed in 52 items. Some experts made suggestions of additional items which could improve coverage of the concept and where these fitted with the described definition of Participation being used, they were added in.

Item	**Rationale for removal**
2. I improve or maintain my health and fitness	Felt to be too broad a question, covering a number of areas. Could be interpreted in a number of ways
12. I take part in looking after a pet	Only relevant if young person has a pet, therefore not relevant to all respondents
13. I do repairs on the house or furniture	CVI 44%
14. I help other family members with things they need	Repetition of other questions, too broad an item
28. I go to teaching or training that is not part of a regular school or college course	Unclear to experts exactly what was included, too difficult to clarify without being too long
36. I have a full-time job	Only relevant for those over 16y. Item which followed on part-time work retained as item on formal work with frequency options
44. I go to community events (e.g. fairs, carnivals, etc)	Unclear what might be included, unclear what “community” means in this context
53. I take part in local or national campaigns	CVI 64%
79. I use the computer for leisure activities such as surfing the internet or downloading music	Too much overlap with other questions
81. I do outdoor pursuits (e.g. fishing, hiking, camping, etc)	Scope too unclear, could overlap with other questions about sports
80. I spend time on my own relaxing or winding down	Already covered in other items

Table 9.1 Items removed following expert content review

Original item	Resulting items
10. I do other housework chores	1.10 I do chores in the home 1.11 I do chores outside at home
52. I take part in a political party or campaigning organisation	5.4 I take part in the activities of a political party 5.5 I take part in a campaigning organisation
39. I take part in work related activities such as taking meals with work colleagues, taking part in work related events and socialising with work colleagues	4.5 I spend breaks at work with colleagues 4.6 I chat informally with people I work with 4.7 I attend social events organised through work
66. I read books, newspapers or magazines for interest or pleasure	6.5 I read books for pleasure 6.6 I read newspapers or magazines
69. I go to shows or concerts	6.19 I go to live music events (e.g. concerts, gigs, festivals) 6.20 I go to the theatre
73. I go on holidays or day-trips with family or friends	6.31 I go on holiday with my family 6.32 I go on holiday with my friends 6.33 I go on day trips to tourist attractions
82. I travel in a car or use public transport (e.g. bus, train, tram, underground or Metro) for pleasure	6.34 I use public transport when I want to 6.35 I travel in a car when I want to

Table 9.2 Items split into two or more items following expert content review

The result of the content review was a prototype instrument of 92 items. The average scale-level CVI for retained items was 93%.

9.2.3 Readability score

The Flesch Reading Ease test (Flesch, 1948) was applied to the entire questionnaire including the instruction pages, but with the response options removed. This yielded a score of 70.8 for reading ease, with a Flesch-Kincaid Grade Level score of 6.6 (age equivalent around 11–12 years).

Item added
2.13 I spend time on my own with a boyfriend/girlfriend, without other people present
3. 2 I take tests or exams
3.3 The subjects I take are chosen by me
3.4 There are subjects I would like to take but cannot
4.8 I have applied for a job
7.6 I have written my c.v. or record of achievement

Table 9.3 Items added following expert content review

9.3 Discussion

Obtaining review from a range of experts from different backgrounds enabled valuable feedback to be obtained on item relevance, item coverage and wording clarity. The average scale-level CVI for the items retained in the draft instrument was high at 93%. Polit et al (Polit et al., 2007) suggest that a conservative cut-off of 90% for scale-level CVI should be aimed for.

Several of the experts commented on the excessive length of the instrument. Although this would clearly be true of a final version, it is important during development to have too many items so that the worst performing can be removed following both content review and subsequent field testing (Slocumb and Cole, 1991).

The expert review comments resulted in a large number of minor changes to item wording to improve clarity. The readability score was below the recommended 7–8th grade level (Flesch, 1948), providing additional evidence that the language used was not overly complex.

In conclusion, this part of the project represented the synthesis of the qualitative and other data into a draft instrument, which was further refined by expert content review.

This resulted in an instrument with sufficient content validity to be field-tested with a sample of young people with CP.

Chapter 10. Field-testing of the QYPP

This chapter describes the development of the instrument (from now on referred to as the QYPP) from the draft version constructed following expert review, through cognitive interviews with young people and carers, to field-testing. The purpose of the field-testing was to establish the psychometric properties of the instrument, including evidence for construct validity and for reliability. Item reduction was another key aim, as the final instrument needed to be shorter in order to make it acceptable for use clinically or in the research setting.

Research ethics approval for this part of the project was obtained from the Research Ethics Committee for Wales (08/MRE09/63). An assistant psychologist, Sarah Ludbrook, was employed for an 8-month period to assist with data collection, data entry and other administrative work for this part of the study. A data entry clerk, Alexis Burn, double-entered all data. I supervised both individuals in this work.

10.1 Methods

10.1.1 Recruitment

This part of the study was carried out with young people with cerebral palsy in the North of England. The aim was to recruit sufficient numbers of young people aged 14–20 years to be able to carry out construct validation and reliability testing with adequate power. For examining known-groups validity, a moderate correlation with impairment severity (between 0.5 and 0.65) would be looked for. With a sample size of 126 and a Type I error of 5%, we can with 80% power detect if correlation is 0.65 or larger given a null hypothesis value of 0.50 (Kraemer and Thiemann, 1987). For intra-rater reliability, I considered a correlation coefficient of above 0.8 to be acceptable. With a sample size of 52 and Type I error of 5%, we can with 80% power detect if the intra-rater reliability is 0.85 given a null hypothesis value of 0.80 (Kraemer and Thiemann, 1987). I therefore aimed to recruit 126 young people in total, with 52 completing a second questionnaire.

Recruitment of young people with cerebral palsy was carried out using the following sources:

- The North of England Collaborative Cerebral Palsy Survey[1] (NECCPS) (described further in Chapter 2)
- Paediatricians in the North East of England
- Physiotherapists in North Tyneside
- The regional adult rehabilitation team, Walkergate Park, Newcastle
- A school nurse in a special school for students with physical disabilities (Woodlawn School, Whitley Bay)
- A post-16 college for young people with CP and other disabilities (Northern Counties College, Newcastle)
- A patient support organization for people with CP (CP-Cumbria)

Clinicians contacted the young people and families by letter. Participants were asked to return a reply slip to the research team, indicating whether or not they were interested in taking part. Non-responders were sent a second letter. Those expressing an interest were telephoned to discuss the study further. At this stage, young people or their parents or carers were advised about the nature of the questionnaires and asked whether the young person would be able to self-report. Participants able to self-report were sent information sheets through the post, and 2 weeks later were telephoned again to arrange a visit. Those where a parent or carer felt self-report would not be appropriate were sent information sheets, consent form and questionnaires by post.

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[1] Some young people on NECCPS were already involved in another project, SPARCLE 2, a follow up study of a cohort of young people across Europe with CP. In order not to jeopardise recruitment for that study or to overburden families, these young people were only approached after they had completed data collection for SPARCLE 2. The approach was made by the research assistant at the end of her research visit to families. Interested families and young people were left with study information, and where permission was given, we contacted them by telephone a week later.

A £5 “thank you” voucher was given to participants on completion of the questionnaires, and this was mentioned in the information sheets. The amount was chosen as being appropriate to the level of involvement in the research. Informal discussions with young people concluded that this amount was large enough to be appreciated by them, but not so large as to be an inappropriate inducement.

When assessing test-retest reliability, the time interval between questionnaire completions needed to be planned such that sufficient time had elapsed to prevent recall of the answers given on the first occasion, but not so long that there has been real change in what is being measured. Around 2 weeks is regarded as reasonable for the avoidance of recall (Terwee et al., 2007), and so repeat questionnaires were sent 2 weeks after the initial completion.

10.1.2 Instruments

Participants were asked to complete two questionnaires; the draft QYPP (see Appendix F), and an impairment questionnaire (see Appendix A). The latter comprised the GMFCS (Palisano et al., 2007; Palisano et al., 1997) for gross motor function, the MACS (Eliasson et al., 2006) for fine motor function and questions based on those used for the NECCPS data collection covering vision, hearing, learning, epilepsy, feeding and communication.

10.1.3 Cognitive interviews

Cognitive interviewing is a technique used to improve question design by making sure items are understood and consistently interpreted (Sofaer, 2002). It uses techniques developed from cognitive psychology. The cognitive processes used to answer a question have been described as four stages (Jobe and Mingay 89): *comprehension*, *retrieval*, *estimation* or *judgement* and *response*. Each stage is assessed by asking participants questions about how they answered an item. Ascertaining comprehension ensures where possible that the meaning of questions is the same to participants as to those interested in the answers. Assessing retrieval involves, for example, asking the participant how they determined the frequency of an activity over the timescale asked. The ability of participants to do this has implications for the timescales used in the questionnaire. Estimation, or judgement, involves how the participant determines the relevance of what they retrieve from their long-term memory. They may feel confident that they can answer the question or may use the information they have retrieved to estimate a response. The final stage involves other factors that may influence the response including social desirability and the sensitivity of the question.

There are different ways to carry out cognitive interviews, and a combination of methods is often used (Streiner and Norman, 2008). Willis described two main methods (Willis, 1994): *thinking aloud* and *using probes*. *Thinking aloud* is where the participant is asked simply to articulate their thought processes as they read and respond to each item. This requires the respondent to have good understanding of what the interviewer is trying to establish. In *using probes*, specific questions are asked regarding each item. This latter method is therefore more explicit regarding the information the interviewer is seeking. Streiner and Norman (Streiner and Norman, 2008) describe two further techniques: *rephrasing,* where the respondent is asked to described the item in their own words; and *double-interviewing* where the respondent first completes the questionnaire and is then asked about how they came to their answers. In this study, double-interviewing was used, followed by a combination of probes and rephrasing, depending on the item.

A number of rounds of interviews are usually conducted, with the instrument being adjusted after each round. Between 4 and 15 participants is thought reasonable for each round (Willis, 1994). Because some refinement of questions had already taken place during the focus groups, I planned two rounds of 6 interviews with both young people and with carers who had provided proxy reports.

10.1.4 Self-report data collection

Data collection where young people could self-report was carried out at face-to-face visits. There were a number of reasons for this. It was essential that the young person completed the questionnaire themselves. Postal contact, which will mostly be through parents, would mean we had no idea who had actually completed the questionnaire; and if it was the young person, with how much guidance. Informed consent from the young person was very important and could only be meaningfully obtained in a one-to-one setting. An instrument should be tested and developed in a setting similar to the one in which it will eventually be used. Whilst it may be used by postal survey (for which further validation would be needed), it is much more often going to be used in a face-to-face interview or consultation setting, whether in clinical care, intervention trials or epidemiological studies.

10.1.5 Proxy-report data collection

For the proxy instrument, questionnaires were sent by post to parents or carers. Visiting parents as well as young people would have been too time-consuming and the reasons for visiting the young people listed above do not apply to the same extent for parents and carers.

10.1.6 General population data

General population data were collected as part of another study taking place locally at the same time[1]. Selected items from the draft QYPP were used in this study, and data were collected from local schools. In two schools, students were asked to complete the entire QYPP. Gender, age and socioeconomic status, in the form of the Family Affluence Score (Currie 2008)[2], were also collected on these students. The home postcodes for the participants with CP were collected, from which the Index of

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[1] This was the follow-up to the SPARCLE study, discussed in Chapter 6, Section 6.1.

[2] The Family Affluence Score is arrived at by adding scores based on 4 markers of affluence relating to the family: family car ownership, computer ownership, family holidays, and whether child has their own bedroom.

Multiple Deprivation (IMD)[1] was derived. However, since affluence is not the same as absence of deprivation, the two types of information cannot usefully be used to compare socioeconomic status of the participants with CP and those from the general population. Although postcodes were not available for the general population sample, the postcodes of the feeder primary schools whose pupils would generally go on to the secondary schools involved were available, which gives a crude indication of the degree of deprivation experienced by the young people in this sample.

10.1.7 Statistical analysis

Advice on statistical analysis was provided by Dr Heather Dickinson, University of Newcastle upon Tyne, and Dr Sally Corbett, Northumbria Healthcare NHS Foundation Trust. The analysis was carried out using SPSS version 17 (SPSS Inc, 2008). Analysis was performed with the aims of item reduction, evaluation of reliability and construct validation.

10.1.7.1 Item reduction

The draft instrument had 92 items, and I aimed to reduce this to 50 items or less, to make the instrument length more acceptable. To this end, a number of characteristics were examined for each item, to determine which items performed the best and should therefore be retained. These characteristics are described below. It was also important to bear in mind the results of the content validation performed previously, to ensure that this was not lost in the subsequent analysis. Those items ultimately removed did not necessarily perform *very* badly, but appeared less good than those that were retained.

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[1] The Index of Multiple Deprivation 2007 is a composite score obtained by combining indicators of deprivation in seven domains including employment, income, health, education and training, barriers to housing and services, environment and crime. Scores are assigned to each *Lower layer Super Output Area* (LSOA), geographically defined areas into which the UK has been divided. The UK Office for National Statistics website enables the LSOA to be identified for a given postcode and from that the IMD for each LSOA can be obtained.

Evidence for difficulty in answering the items was looked for. This included high levels of missing values, multiple responses from individuals to one question, and low test-retest reliability for individual items.

Items were also examined to see whether there was a difference in response depending on gender. This is a form of what is called *differential item functioning* (DIF), which describes the situation where individuals who differ in some aspect that should not affect an instrument score, such as gender or race, do in fact exhibit different scores on testing. It has two possible explanations – item impact and item bias (Zumbo, 2007). The former describes the situation where there is a true difference because of a difference between the groups in terms of the degree of the latent variable. For example, males tend to perform better than females in some visuo-spatial skills, and so a test of intelligence which contains such items may produce higher scores for males than for females. Item bias on the other hand, is where the responses are different for reasons unrelated to the degree of latent variable present, but due to factors such as the way questions are asked or the test setting (Zumbo, 2007). An example would be the fact that women may be more prepared to admit to certain feelings than men in a scale measuring depression. Statistical tests can demonstrate whether DIF is present. However, the differentiation between item impact and item bias can only be made by looking at the content literature to see which is most likely. Whatever the reason, it is normally unhelpful to have such items in a scale and so they should be rewritten if appropriate, or removed. Because of the non-normal distribution of responses for most items, Mann-Whitney U tests were carried out with both the CP and general population samples to ascertain whether gender was associated with response. Multiple regression, using the forced entry method, was also used with the CP data in order to see whether gender remained as a significant variable when the impairment levels (gross motor, fine motor, learning), age and interaction variables for gender and impairment level were included in the models.

Items where responses showed no difference between those with differing levels of impairment and between the CP and general population samples were also identified. Items which do not discriminate between individuals in this way, are likely to have lower construct validity and will be less useful when the instrument is used, whether this is to explore the determinants of Participation for those with CP, in intervention trials or to look at the Participation of individuals with CP compared to those in the general population.

Mann-Whitney U tests were used to compare the CP and general populations, and to compare those with differing severity of impairments. In addition, multiple regression was used to identify whether impairments were independently predictive of Participation.

Another reason to drop an item was if there was very low variance, with either predominantly high or low levels of Participation. This is also known as high or low frequency of endorsement (*p*), where *p* is the proportion of respondents giving a particular response. If the vast majority of respondents give one answer, then the item is not going to discriminate between them. Suggested acceptable endorsement rates are between 0.20 and 0.80 (Streiner and Norman, 2008).

Finally, redundant items were identified by looking at inter-item correlations as well as Cronbach's alpha for domains. Where two items were felt to be too similar, the least well performing item was dropped.

10.1.7.2 Scoring

Before scale-level analysis could be performed, decisions had to be made about how the instrument should be scored. Because the instrument consists of a number of different scales measuring different Participation domains, scores needed to be calculated for each scale, rather than for the instrument as a whole. The key questions when deciding how to score a scale, is whether items should have equal weight. If so, scoring can be done by simply adding up scores for each item. If it is felt that the items differ in importance, then weighting would need to be applied appropriately before summing the scores (Rust and Golombok, 2009). I have assumed that the items have equal weight, and summed the scores for each domain. I did this because we do not have information on which to base item weightings. It is also suggested in the literature that weighting is usually not necessary given that studies with other instruments have shown that the addition of weightings to some items, does not change the overall performance of the instrument (Streiner and Norman, 2008). This however, applies to scales with effect and not defining indicators (Fayers and Hand, 2002).

The number of response options was not the same for all questions in each domain and so all scores were adjusted so that the minimum and maximum scores for each question within a domain were the same, and other responses were equally divided. So, for example, where most items in one domain had a score of 0 through to 5, those with response options 0 to 4 were allocated rescaled scores of 0, 1.25, 2.5, 3.75 and 5.

Optimal scaling was performed to look at whether the response options for any items could reasonably be reduced to a dichotomous response. This function is available within the categorical principle components analysis (CATPCA) package of SPSS (CATPCA Version 1.1. Data Theory Scaling System Group, Faculty of Social and Behavioural Sciences, Leiden University, The Netherlands). Non-linear optimal scaling can be used to transform ordinal data where the zero point and the mutual distances between categories are unknown. The results are presented visually, with the plot illustrating the relationship between the original variable and the optimally scaled quantification. The curve produced is referred to as a *spline*[1]. Quantification of the

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[1] The term *spline* originates from boat building, and referred to a flexible strip of wood used to map out the surface of the hull. The wood was fixed down with lead weights at appropriate points to form the desired curve. This term was then adopted in mathematics, where it is used to describe a smooth, stiff curve, along which are fixed points, known as knots.

response options are plotted on the y-axis with the categories on the x-axis. Where a number of responses are given similar quantification (because the PCA suggests that more than one response category predicts the measured outcome to a similar extent) this suggests that these categories could be collapsed into one (SPSS Inc, 2008). I used this method to identify items whose splines suggested that a dichotomous response would be appropriate.

10.1.7.3 Reliability

Intra-scale and test-retest intra-rater reliability were assessed. Intra-scale reliability, or internal consistency, is a measure of the degree to which all the items are measuring aspects of the same latent variable. There are a number of ways of doing this. One method is the split-half reliability, where the scale is randomly split in two and the two halves correlated. However, depending on how the scale is split, slightly different results will be obtained, and in addition, it is not possible to identify which items are reducing reliability. I used Cronbach's alpha, the most commonly used test in scale construction, which is a variant of this; it is equivalent to the average of all possible split-half reliabilities. If this is done repeatedly, each time omitting one item it is possible to identify the degree to which each item contributes to the reliability.

The difficulty with using Cronbach's alpha is in deciding what level of reliability is ideal. Higher values are found with higher total numbers of items, because alpha is a function of the total number of items. Whilst it is true that a greater number of items increases reliability (Streiner and Norman, 2008), this needs to be borne in mind when using alpha as an indicator of the degree of homogeneity, particularly where scales have large numbers of items and values are inevitably high for this reason. Higher values are also found where there is item redundancy. A scale consisting of a large number of items all asking the same thing but with slightly different wording will appear very homogeneous but would not constitute a valid scale. Streiner and Norman (Streiner and Norman, 2008) suggest a value between 0.70 and 0.90 to demonstrate reliability without redundancy. Boyle (Boyle, 1991) argues that even lower levels of correlation can be found with a valid scale, and that a good scale may not in fact have particularly high internal consistency, highlighting the tension which may exist between the two concepts. He argues that Cronbach's alpha is most useful as a means of identifying redundant items. It may be that he is alluding to the situation where the items are defining rather than effect indicators, in which case internal consistency is an inappropriate parameter to be examining.

I calculated Cronbach's alpha for each section of the QYPP, using the standardized items value. Items which when removed led to an improved alpha were identified. Where inter-item correlations suggested it, such items were moved to more appropriate domains. Other items were removed altogether, unless they needed to be retained for content coverage.

Factor analysis is another way of demonstrating the degree of homogeneity in a scale, and in helping decide how many scales are required in an instrument like the QYPP. The domain structure for the QYPP was established *a priori*; that is to say it was designed before gathering data on the items. It is possible to then establish whether this domain structure appears reasonable by performing a confirmatory factor analysis. One way of doing this is by an extension of the item-total correlation described above but comparing each item's correlation within its domain and with the rest of the scale. If the domain structure works, the correlation will be higher within the domain than with the rest of the scale.

Particularly where a domain structure has not previously been identified, it is usual to carry out a principal components analysis to investigate the underlying factors (Terwee et al., 2007). The sample size needed for such an analysis is debated in the literature, with a figure of 5–10 times the number of items in the scale commonly quoted (DeVellis, 2003). The larger the number of underlying factors, the large the sample size needed. Because the domains in the QYPP were developed from the ICF, and some commentators have questioned the unidimensionality of the domains, PCA would be a good way to establish whether the *a priori* domains were reasonable. It was unlikely that I would have sufficient numbers, but a PCA was performed in order to see how many factors were likely to emerge.

Intra-rater test-retest reliability was examined using intra-class correlations (ICCs)[1] for individual items as well as for each section and the Standard Error of Measurement (SEM) for each section. When interpreting ICCs, it needs to be remembered that the correlation is affected by the spread of scores within the sample. This means that even when there is little variability between the first and second measurements, a low ICC can result if the variability in scores is low, and conversely, a high ICC may in part be due to the high level of variability. A range for satisfactory correlations is given in the literature as between 0.70 and 0.90 depending on the use to which the instrument will be put (Portney and Watkins 2000). But it is important that values are put in the context of other factors, including variance in scores, and it has been suggested that ICCs should be compared with those of similar instruments which have been demonstrated to perform well (Streiner and Norman, 2008; Portney and Watkins, 2000)

Weir (Weir, 2005) recommended that the standard error of measurement (SEM) be calculated in addition to the ICC, in order to provide additional information about the size of the difference in scores between the repeat measures. I used the formula given in his paper[2].

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[1] The two-way mixed model was used, where people effects are random and item effects are fixed (Weir, 2005; Shrout and Fleiss, 1979).

[2] The formula used is $SEM = SD\sqrt{1-ICC}$. I calculated the SD using the SS_{TOTAL} derived from the ANOVA, where $SD = \sqrt{SS_{TOTAL}} / (n-1)$.

10.1.7.4 Construct validation

Known-groups validity was examined to provide evidence of construct validity. I looked at the correlation between QYPP section scores and impairment severity. As discussed in Chapter 4, impairment has been shown in a number of studies to be one determinant of Participation for children and young people with CP. We would expect to find moderate correlation between impairment and Participation scores, if the two constructs are related as anticipated. Because the data was not normally distributed, Spearman's ρ was used.

10.1.7.5 Responsiveness of instrument

It is important for a reasonable spread of scores to be obtained if a scale is to discriminate sufficiently between respondents. A scale with >15% of respondents scoring at either end of the scale, is said to exhibit floor or ceiling effects (Terwee et al., 2007).

10.1.7.6 Missing values

I have dealt with missing values in the analysis by excluding those data points. This is because I did not have sufficient information to be able to tell how imputation might affect the results. Because of the low internal consistency seen for some of the sections (discussed below) imputation using individuals' means for that section may not have been reliable because of the low correlation between items.

10.2 Results

10.2.1 Participants

107 young people with CP participated in the study. The denominator for all recruitment sources was not known, so overall response rates could not be calculated. However it was known that 290 young people were approached via NECCPS and some clinicians, of whom 88 (30.3%) responded positively. The completion rate for those showing initial interest in the study was 89%. Figure 10.1 overleaf shows the recruitment in more detail.

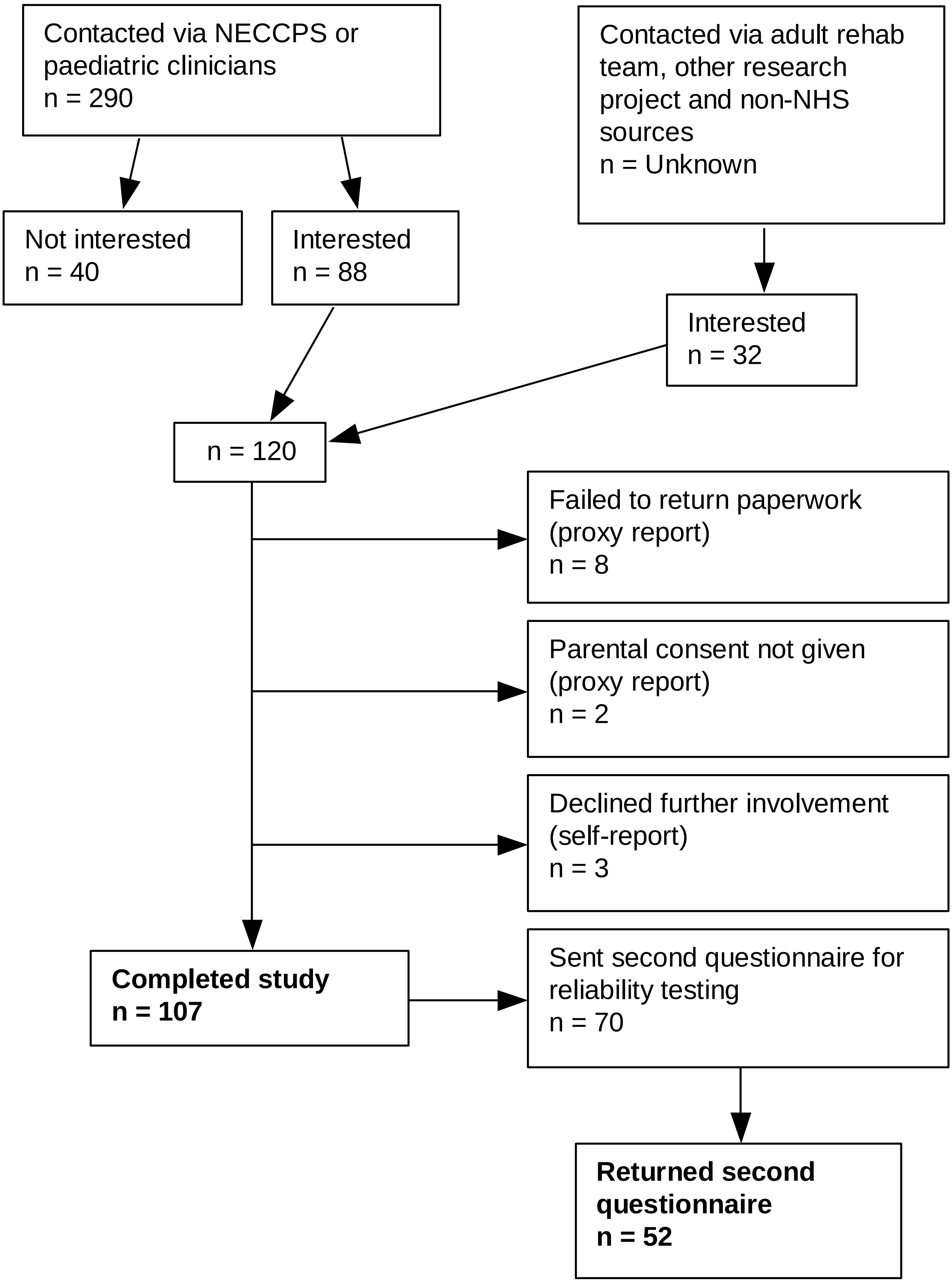

Figure 10.1 Flowchart showing recruitment and retention in study

For responders, age at time of data collection ranged from 13 years 2 months to 21 years 11 months (median 16 years 4 months, mean 16 years 7 months). Age at recruitment was slightly younger for those who participated (median 16 years 2 months) than non-responders (median 16 years 9 months), where details are available (Mann-Whitney U test, p=0.043). Northern Counties College contacted students aged over 16 years (and I have no details on the non-responders from this source), so the difference in age between responders and non-responders was likely to have been greater than this figure.

64 (60%) of the participants were male. This proportion was similar (59%) in the non-responders (X^2=0.010, p=0.92). Postcodes were available for all participants, and from some of the non-responders. From these, the quintile for the Index of Multiple Deprivation (IMD) was ascertained. 23% of responders lived in areas within the most deprived quintile for IMD, compared to 31% of non-responders (X^2=2.252, p=0.13).

10.2.2 Levels of impairment

All 107 participants completed the impairment questionnaire. Complete data was obtained for all questions apart from one missing data-point for hearing. On one questionnaire, mild to moderate as well as severe learning difficulty options were ticked. This participant was coded as having severe learning difficulty for the purposes of analysis, as this would lead to possible under- rather than over-estimate of known-groups validity.

Details of impairment are given in table 10.1. An overall measure of severity was also included, based on the SCPE classification[1].

38 (35.5%) had questionnaires answered for them by a proxy, the remainder self-reported. However, some of those whose parents said they could self-report, in fact needed support in doing so. In most of these cases, they needed the items read to them. This was either because of cognitive difficulties making reading difficult or slow, or because of visual difficulties including tracking problems. Some were able to report whether or not they participated in an area, but found working out frequency more difficult. Most of those requiring help with completion were described as having a severe learning difficulty.

Where a parent stated that they were happy to report on behalf of a young person who was capable of self-report but who did not want to, we explained that it was the young person's view that we were interested in. We asked parents to have further discussions with their child, which resulted in two agreeing to participate and one declining.

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[1] The Surveillance of Cerebral Palsy in Europe (SCPE) classification of severity is as follows: severe – unable to walk with or without aids *and* IQ<50; moderate – unable to walk with or without aids *or* IQ<50; mild – able to walk with or without aids and IQ>50 (A Colver, personal communication). I used the GMFCS I–III as equivalent to being able to walk with or without aids, and severe learning difficulty in place of IQ<50.

Area of functioning	Frequency of response (%)		
Gross motor	GMFCS	Level I	23 (21.5)
		Level II	37 (34.6)
		Level III	11 (10.3)
		Level IV	21 (19.6)
		Level V	15 (14)
Fine motor	MACS	Level I	26 (24.3)
		Level II	32 (29.9)
		Level III	26 (24.3)
		Level IV	14 (13.1)
		Level V	9 (8.4)
Learning	No difficulty		33 (30.8)
	Mild–moderate difficulty		35 (32.7)
	Severe difficulty		39 (36.4)
Vision	No problems		48 (44.9)
	Minor problems		52 (48.6)
	Blind		7 (6.5)
Hearing (n=106)	No problems		88 (83)
	Some hearing loss		7 (6.6)
	Aided		11 (10.4)
Epilepsy (n=106*)	Never had fits		60 (56.6)
	Ever had fits		46 (43.4)
	Still having fits		22 (20.6)
Feeding	No problems		81 (75.7)
	Oral feeding with problems		22 (20.6)
	Non-oral feeding, with or without oral feeding		4 (3.7)
Communication	No problems		54 (50.5)
	Communicate with speech, with difficulties		27 (25.2)
	Use alternative methods of communication		16 (15)
	No formal communication		10 (9.3)
Overall severity	Mild (GMFCS I–III and No–moderate learning difficulty)		57 (53.3)
	Moderate (GMFCS IV–V or Severe learning difficulty)		25 (23.4)
	Severe (GMFCS IV–V and Severe learning difficulty)		25 (23.4)

* 1 respondent answered “don’t know”

Table 10.1 Details of impairment severity for participants with CP

Of the 38 where a proxy report was completed, 10 were described as having mild to moderate learning difficulty and the other 28 as severe. Of those with mild or moderate learning difficulty, 5 were described as having a communication difficulty. Of the 69 who self-reported, 11 were said to have severe learning difficulties, 25 mild or moderate and the remaining 33 had none.

Although impairment data on non-responders were not available, data were available on the entire population aged 13–17 on NECCPS. These data were collected for each individual at age 4–5 years. The data are shown in Appendix G. When comparison was made between the two using X^2 tests, the differences for motor, visual, feeding and communication impairments were non-significant, but the difference for seizures, learning and hearing impairments was statistically significant, with the study sample having worse impairments. For example, 51% of the NECCPS population had no learning impairment recorded at age 4–5 years compared to 31% in our study sample (X^2=14.32 p=0.0008).

Although this was not formally recorded, most young people took around 20–30 minutes to complete the draft QYPP. Those with reading difficulties, cognitive difficulties or severe difficulties with hand function took longer. In the most extreme case, it took nearly 2 hours for a QYPP to be completed for a young woman who needed the items signed to her, her verbal non-speech responses to be interpreted to me by her mother, for me to then mark the questionnaire.

10.2.3 General population data

Data were collected from two schools in the northeast of England. One school used the first version of the QYPP (prior to the changes introduced following cognitive interviewing) and the other the final version. Data are not therefore available from all participants on all the final version questions.

540 young people took part, of whom 423 provided a date of birth, and 463 gave their gender. Some young people either omitted to provide demographic information at all, or gave erroneous information, such as the date of completion in place of their date of

birth. The age range where specified was 13 years to 17 years 11 months (mean 14 years 8 months, median 14 years 7 months). 225 (48.6%) were male.

Postcodes for the feeder primary schools were obtained. For the first school, where the number of respondents was 432, two out of the six feeder schools are located in a Lower layer Super Output Area with an Index of Multiple Deprivation in the lowest quintile. For the second school, from where there were 108 respondents, one out of seven feeder schools was in the lowest quintile.

10.2.4 Cognitive interviews

Twelve carers and twelve young people undertook cognitive interviews with two sets of item changes. Four of the young people did not have cerebral palsy, but were included in the initial rounds in order to speed up the process of data collection and reduce the number of participants with CP who completed earlier versions of the QYPP, and therefore for whom there was less complete data using the final version. This decision was made when it became clear that response rates were lower than expected. In addition, three of these young people were known to be in employment, which was not the case for most of those with CP and so feedback could be obtained on those items.

Comments led to changes in items where these were made by several individuals, or, if only made by one individual, where it was clear that changes were necessary for comprehension or ease of response. Where it was felt that a miscomprehension or comment about an item was not likely to be generally applicable, changes were not made, but extra probing on those items was used in subsequent interviews to test this conclusion.

There were no changes made to items in Section 1. In Section 2, it was identified that the word “leisure” was not understood by all young people and so the items referring to “leisure activities” with family members or friends were changed so that they asked about “spare time spent with …” or “activities in my spare time”. In Sections 3 and 5, there were changes to a response option in some items to make them easier to complete. The response options for the question on formal work in Section 4 were also changed. The original version had been similar in format to other items, with number of times per week or month, but it was pointed out that this was difficult to answer and so the responses were changed to hours per week. In Section 6, minor wording changes were made to the questions about transportation, including the additional phrase “*This may be alone or with other people*” to the item on public transport use, in response to queries from participants as to whether this was expected to be carried out completely independently. In Section 7, further detail was provided in the items on work experience, following concerns that the scope of these items was unclear. Section 8 was added for free text comments about any areas not covered. The complete list of changes is shown in Appendix H.

10.2.5 Scale level analysis

There was no pattern to the missing values for the data from the CP sample. The number of missing responses per item ranged from 0 to 10 (out of a total of 107 respondents), with 56 items out of a total of 92 having no missing data points. The proportion of missing data for the CP sample was 0.6%. This was in marked contrast to the missing values in the general population data, where there was an almost linear relationship (see figure 10.2) between the position of an item in the questionnaire and number of missing responses, with the number increasing from 4 missing data points for the first item to 82 for the last. The overall proportion of missing data in the general population sample was 7.1%.

As can be seen from figure 10.2 overleaf, there are a few questions where the number of missing values did not follow the trend, and these are discussed more fully later with the relevant section.

There was no clear pattern to items where participants gave more than one response. This occurred in two items in the CP sample, involving one individual in each (items 6.21 and 6.30). In the general population sample there were 69 instances involving 47 of the items, with between 1 and 4 individuals indicating more than one response.

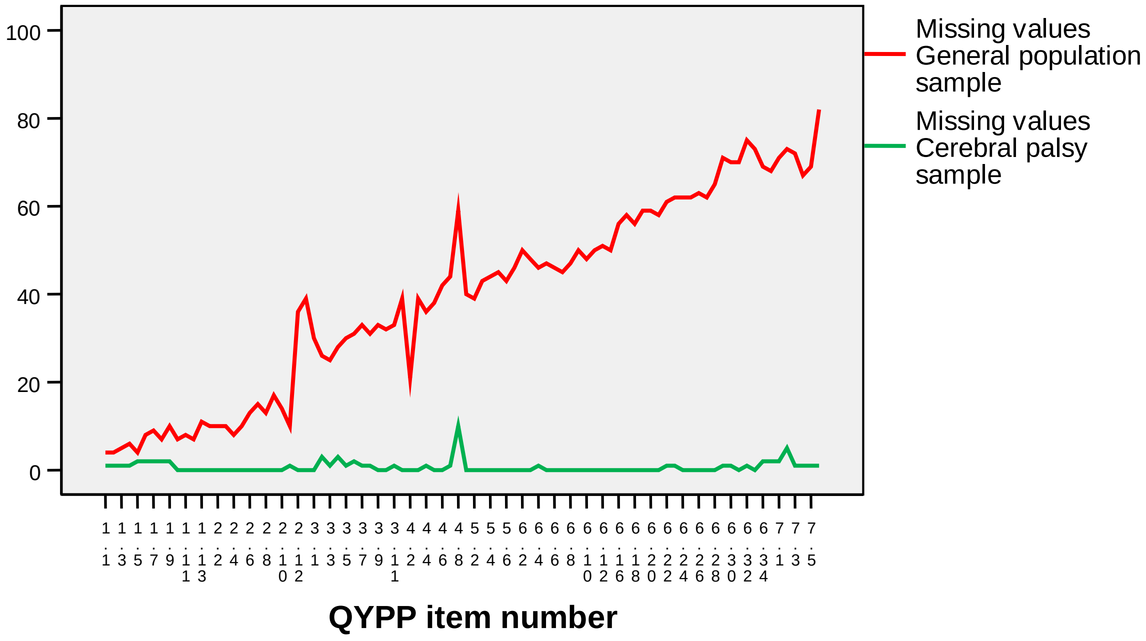


Figure 10.2 Number of missing responses by item number

10.2.5.1 Reliability

First I will discuss internal consistency. For each section of the draft QYPP, Cronbach's alpha was calculated and these values are shown in table 10.2 overleaf.

As discussed in the Methods section, items which increased the value of alpha when removed were taken out of that domain, and where appropriate were removed from the instrument altogether. When item reduction was finalised, alpha was recalculated for the new domains proposed. The results of these are shown in section 10.2.9.

For test-retest reliability, a total of 52 participants completed a second copy of the QYPP, representing a 74% response rate. 16 were proxy reports and 36 self-reports. Two young people were not asked to complete a second questionnaire as it was felt to be too burdensome, either because of health problems in the young person or the carer who would be supporting the completion. Recruitment for this part of the study continued until 52 questionnaires had been returned.

Draft QYPP section	**Cronbach's alpha**[*]
Section 1	0.85
Section 2	0.83
Section 3	0.60
Section 4	0.82
Section 5	0.58
Section 6	0.80
Section 7	0.57

[*] based on standardized items

Table 10.2 Cronbach's alpha for each section of the draft QYPP

The second questionnaires were completed between 12 days and 11 weeks after the first. 37(71.2%) were returned within 4 weeks. Intra-class correlations (ICC) and standard errors of measurement (SEM) for each domain are shown in table 10.3 overleaf. To provide information on reliability for individual items, ICCs were also calculated for each item and these can be found in the table in Appendix I and are discussed further with the item-level analysis.

Section 3 (School and College Life) was the only section with an ICC<0.80, and it also had a lower number of responses than other sections, as 6 (11.5%) were not in school or college. 24 completed one or both questionnaires during a school holiday and the value of the ICC for this group was higher (ICC=0.87, 95% CI 0.50–0.97). Analysis of those completing the second QYPP in under 4 weeks also found a slightly higher ICC

(ICC=0.76, 95% CI 0.46–0.90). I also compared ICCs between proxy reports (ICC=0.92, 95% CI 0.69–0.98) and self-reports (ICC=0.58, 95% CI 0.07–0.81). SEMs were high for sections 3 and 6, suggesting that there was real variation between scores for these sections.

Section	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Intra-class correlation[*] (95% Confidence Interval)	0.98 (0.96–0.99)	0.93 (0.87–0.96)	0.75 (0.51–0.87)	0.75 (0.51–0.87)	0.83 (0.70–0.90)	0.84 (0.72–0.91)	0.94 (0.90–0.97)
SEM	0.47	1.85	2.27	0.40	0.84	4.60	0.99

[*] average measures

Table 10.3 Test-retest reliability for each draft QYPP domain

10.2.5.2 Construct validation

Known groups validity was calculated by correlating total Participation scores with severity of impairment. Because not all the data were distributed normally, Spearman's ρ was calculated, although using Pearson's ρ produced similar results. The results are shown in table 10.4.

Section	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Correlation Coefficient	-0.77[*]	-0.59[*]	-0.41[*]	-0.51[*]	-0.24[*]	-0.55[*]	-0.48[*]

[*] p<0.01 for one-tailed test

Table 10.4 Correlations between section score and severity of impairment

10.2.5.3 Section scores

The range and distribution of scores for each section of the draft QYPP are shown in table 10.5.

Section	Total possible score ranges	Score range for CP data	Score range for general population data
1	0–65	0–53	7.25–65
2	0–78	3–66.4	3.2–78
3	0–55	9.33–46.17	0–55
4	0–40	0–32.25	0–35.41
5	0–30	0–16.6	0–29.8
6	0–210	35.2–118.4	48.6–178
7	0–30	0–23	0–30

Table 10.5 Overall scores by draft QYPP section

Scores showed very low variance with a floor effect for level of Participation in Section 5 (Community Life), with 43.9% in the CP sample and 42% in the general population having minimum scores, denoting no Participation in that section. There was also a floor effect for the CP sample for Section 7 (Preparing for the Future), with 19% of the sample having the minimum score.

10.2.6 Item reduction

Having analysed the sections as a whole, I then looked at each item in detail, to determine which items could be removed to both shorten the instrument and improve its psychometric properties. A process of elimination was performed by working through item characteristics as described in the methods section 10.1.7. I now present the detailed analysis, section by section. Fuller details of the results of the item-level analyses are included in Appendix I. The resulting new sections are discussed in Section 10.2.9.

10.2.6.1 Section 1 – Home life

In the draft QYPP, this section included 13 questions. Table 10.6 shows the decisions made for each item based on the item-level and scale-level statistics. Two items were moved to another domain, and 5 items were retained in the revised domain. For all retained items where there was a significant difference between the CP and general population samples, higher Participation was seen in the general population sample.

Item	Item fate	Rationale for decision
1.1 daily routine	Move domain	Retained for content validity and coverage although gender difference in the general population sample
1.2 snacks	Retain	Well-performing item
1.3 using cooker hob	Retain	Well-performing item
1.4 heating drinks and food	Retain	Well-performing item
1.5 meals with family	Remove	Negative correlation with other items
1.6 meals with friends at home	Remove	Decreased internal consistency, higher correlation with 6.16, but removed because of redundancy; 6.16 performed better
1.7 family birthday celebrations	Remove	Decreased internal consistency; poor test-retest reliability; not as discriminatory within CP population or between CP and general populations as other items
1.8 tidy room	Remove	Poor comprehension, concept better covered by 1.10
1.9 clothes washing/ironing	Remove	Decreased internal consistency; low frequency of endorsement (*p*=0.87 for never participating); poor test-retest reliability
1.10 household chores	Retain	Well-performing item
1.11 chores outside	Remove	Less discriminatory between CP and general populations than other items
1.12 shopping for essentials	Retain	Well-performing item
1.13 helping others	Move section	Higher correlation with relationship items

Table 10.6 Item decisions for Section 1

Item 1.8 performed well statistically, but a number of comments were made during the research visits suggesting that there was variation in how this item was understood. This was particularly so for those with moderate or severe learning difficulties where parents and carers commented that the young person did not make a mess, and therefore had no need to tidy. Others queried whether this meant completely reorganizing the contents of the room, or simply clearing away dirty cups. As the concept was covered by item 1.10 on household chores, I removed this item.

10.2.6.2 Section 2 – Getting on with people

There were 13 items in this section, 7 of which were removed. The items are shown in table 10.7 overleaf. The inter-item correlation between items 2.12 and 2.13 had a correlation coefficient of 0.95 and so item 2.12 was removed as redundant. One item was moved to a different domain, and the remaining 5 items were retained in this domain. For all retained items, where there was a significant difference between the CP and general population samples, higher Participation was seen in the general population sample.

Gender differences were found in the CP sample for items 2.2 and 2.4, although for the latter, this was not shown in the general population sample. Due to the importance for content validity of 2.4 (on-line communication) this item was retained.

Items 2.12 and 2.13 had more missing values in the general population sample than was expected from the missing value trend. These items both relate to time spent with someone in a romantic relationship and it may be that some young people did not feel they had adequate privacy in the classroom setting to answer these questions. There was no such finding in the CP sample.

Item	Item fate	Rationale for decision
2.1 talking with friends	Remove	Non-discriminatory between CP and general population; poor test-retest reliability
2.2 talking with family	Remove	Gender differences; decreased internal consistency
2.3 phone	Move domain	Well-performing item; higher correlation with autonomy items
2.4 on-line communication	Retain	Gender difference only in CP sample; otherwise well-performing item
2.5 talking with neighbours	Remove	Less discriminatory than other items within CP sample
2.6 talking with strangers	Retain	Well-performing item
2.7 leisure with parents	Remove	Non-discriminatory within CP sample, poor test-retest reliability; decreased internal consistency; negative correlations with other items
2.8 leisure with extended family	Remove	Non-discriminatory between CP and general populations; poor test-retest reliability
2.9 time with friends	Remove	Redundancy – similar concept covered by 2.10 which performed better
2.10 time alone with friends	Retain	Well-performing item
2.11 friends' birthday celebrations	Retain	Well-performing item
2.12 time with boy/girlfriend	Remove	Redundancy: concept covered by 2.13
2.13 time alone with boy/girlfriend	Retain	Well-performing item

Table 10.7 Item decisions for Section 2

10.2.6.3 Section 3 – School or college life

Nine of the young people in the CP sample were no longer in education and so responses are from the remaining 98. Section 3 contained 11 items, of which 6 were removed and the details are shown in table 10.8. Making decisions about items to retain in this section was more difficult because most items performed poorly on one test or another. Content validity and coverage were therefore considered carefully when deciding which items to retain.

The response patterns for items 3.3 and 3.4 were confusing, when comparing CP and general population data. Young people with CP said they were less likely than the general population sample to have chosen the subjects they take (item 3.3), but they were also less likely to say there were subjects they would like to take but could not (item 3.4). Reasons for this could be that the young people with CP are less aware of what subjects they might take but are not able to, or are more accepting of what is available and less inclined to express dissatisfaction. Item 3.4 also showed significant differences by gender and so was removed.

There was a significant difference between the CP and general population samples for item 3.1 (attending lessons) with higher Participation reported by those with CP. For the remaining items, where there was a significant difference between the CP and general population samples, higher Participation was seen in the general population sample.

Item	**Item fate**	**Rationale for decision**
3.1 lessons	Retain	Retained for content validity and coverage although poor test-retest reliability
3.2 tests or exams	Retain	Well-performing item
3.3 chosen subjects	Retain	Retained for content validity and coverage although relatively poor test-retest reliability
3.4 subjects would like to take	Remove	Inconsistency of responses when looked at with 3.3; gender differences; poor test-retest reliability
3.5 homework	Remove	Gender differences
3.6 position of responsibility	Retain	Retained for content validity and coverage although poor test-retest reliability and poor discrimination within CP population
3.7 clubs/teams	Remove	Poor test-retest reliability; non-discriminatory within CP and between CP and general populations; decreases internal consistency
3.8 break times	Retain	Retained for content validity although very poor test-retest reliability and non-discriminatory between CP and general populations
3.9 teach or coach others	Remove	Low frequency of endorsement (*p*=0.81 for never participating); very poor test-retest reliability; non-discriminatory between CP and general populations
3.10 meals	Remove	Gender difference; non-discriminatory between CP and general populations
3.11 trips	Remove	Decreases internal consistency; poor test-retest reliability; non-discriminatory within CP sample

Table 10.8 Item decisions for Section 3

10.2.6.4 Section 4 – Work and financial life

This section contained 2 items relating to financial Participation, of which the best performing was retained, but moved to a new domain. For the other 6 items, frequency of endorsement was low in the CP group. Only 6 young people in the CP sample said they had an informal part-time job and 3, a formal job. Of those, 2 had both informal and formal employment, giving a total number having any sort of employment as 7.

The numbers in work in the general population sample were significantly higher with 179 (36%) having an informal part-time job and 99 (20%) reporting a formal job. Because the numbers answering items 4.5 through to 4.7, relating to Participation in the workplace, were too small to usefully analyse for the CP group, the general population data was used to decide which items should be removed. In both the CP and general population samples, a number of young people answered in the affirmative to items 4.5–4.7, even though they had said they did not have a job. Only the data from those young people who responded positively to having employment were included in the analysis of these subsequent items.

The frequency data from the general population sample showed that there was a spread of responses for each of the three items 4.5, 4.6 and 4.7, with items 4.5 (breaks at work with colleagues) and 4.7 (social events with work colleagues) showing a normal distribution. These two items were therefore retained.

Item 4.8 (applied for a job) showed a higher level of missing values compared to adjacent items in the both the CP and general population sample. All those who failed to answer this item said they did not have a formal job, and so may have thought that this item was not applicable to them. In addition, this item correlated negatively with others in the section, and for this latter reason was removed.

For all retained items, where there was a significant difference between the CP and general population samples, higher Participation was seen in the general population sample. The summary for items in this section is shown in table 10.9 overleaf.

Item	Item fate	Rationale for removal from section
4.1 managing money	Move domain	Well performing item; higher correlation with autonomy items
4.2 managing savings	Remove	Redundancy: similar concept to 4.1 which performed better
4.3 informal job	Retain	Retained for content validity and coverage although low frequency of endorsement in CP sample
4.4 formal job	Retain	Retained for content validity and coverage although low frequency of endorsement in CP sample
4.5 breaks with colleagues	Retain	Well-performing item (general population data)
4.6 chat with colleagues	Remove	Response distribution skewed (general population data)
4.7 socialise with colleagues	Retain	Well-performing item (general population data)
4.8 applied for job	Remove	Poor correlation with whether or not the young person has formal or informal job; low frequency of endorsement (p=0.84 for CP sample, 0.69 for general population for never participated)

Table 10.9 Item decisions for Section 4

10.2.6.5 Section 5 – Community and political life

The 6 items in this section showed very low levels of Participation in both the CP and general population samples. The only item retained was that on voluntary work. Section 5 as a distinct domain was removed, with item 5.3 moved to the recreation and leisure section. Table 10.10 shows the item summaries for this section.

Item	Item fate	Rationale for removal from section
5.1 community group for young people	Remove	Non-discriminatory within CP and between CP and general populations
5.2 community group all ages	Remove	Non-discriminatory within CP and between CP and general populations
5.3 voluntary work	Move domain	Well performing item
5.4 political activity	Remove	Low frequency of endorsement; non-discriminatory within CP population
5.5 campaigning	Remove	Low frequency of endorsement; non-discriminatory within CP population
5.6 voting	Remove	Low frequency of endorsement; non-discriminatory within CP and between CP and general populations

Table 10.10 Item decisions for Section 5

10.2.6.6 Section 6 – Recreation and leisure

This was the largest section in the instrument with 35 items. Performance on a number of the items was poor, particularly with test-retest reliability, and in terms of internal consistency. The decisions made about the items are shown in table 10.11: 16 were retained, of which 3 were moved to another domain. For all retained items, where there was a significant difference between the CP and general population samples, higher Participation was seen in the general population sample.

A number of items reduced internal consistency, but their removal would have reduced the content validity and coverage of the domain. For this section, content coverage was therefore carefully considered once item statistics were available, and those items which performed well in all but internal consistency and which were important for item coverage were retained.

Item	**Item fate**	**Rationale for decision**
6.1 private time	Retain	Retained for content validity and coverage although non-discriminatory between CP and general population data and poor test-retest reliability
6.2 chose who spend spare time with	Remove	Redundancy: similar to 6.3 which performed better
6.3 chose how spend spare time	Move domain	Higher correlation with autonomy items
6.4 chilling	Remove	Very poor test-retest reliability; non-discriminatory within CP population
6.5 reading books	Remove	Gender differences
6.6 reading newspapers/magazines	Retain	Well-performing item
6.7 listening to music	Retain	Retained for content validity and coverage although negative correlations with other items and poor test-retest reliability
6.8 watching TV	Remove	Non-discriminatory within CP and between CP and general populations
6.9 videos/DVDs	Remove	Non-discriminatory within CP and between CP and general populations
6.10 electronic games	Retain	Well-performing item
6.11 shopping for pleasure	Retain	Retained for content validity and coverage although non-discriminatory within CP population
6.12 parties	Remove	Redundancy: similar to 2.11
6.13 hang out friends' houses	Move domain	Higher correlation with relationship items
6.14 drinks with friends	Retain	Well performing item
6.15 discos/nightclubs	Remove	Poor test-retest reliability; low frequency of endorsement (p=0.82 for never Participating)
6.16 meals at friends' houses	Remove	Redundancy: similar to 6.13 which performed better
6.17 eating out	Retain	Retained for content validity although poor test-retest reliability
6.18 cinema	Retain	Well-performing item
6.19 live music	Retain	Well-performing item
6.20 theatre	Remove	Gender differences; non-discriminatory within CP and between CP and general populations; poor test-retest reliability

6.21 live sport	Remove	Very poor test-retest reliability; gender differences
6.22 museums	Remove	Non-discriminatory between CP and general populations; poor test-retest reliability
6.23 arts and crafts	Remove	Gender differences; non-discriminatory within CP and between CP and general populations; poor test-retest reliability
6.24 performing arts	Retain	Reasonably well-performing item; important for content validity and coverage
6.25 hobbies	Remove	Poor test-retest reliability; less discriminatory than other items within CP and between CP and general populations
6.26 board games	Remove	Poor test-retest reliability; non-discriminatory between CP and general populations
6.27 organised sport	Retain	Well performing item
6.28 informal sport indoors	Remove	Poor test-retest reliability; not as discriminatory within CP population as other items
6.29 informal sport outdoors	Retain	Retained for content validity and coverage although test-retest reliability poor
6.30 go for walks	Remove	Very poor test-retest reliability; not discriminatory within CP population
6.31 family holidays	Remove	Non-discriminatory within CP and less discriminatory between CP and general populations than other items
6.32 holiday with friends	Retain	Well performing item
6.33 day trips	Remove	Non-discriminatory within CP and between CP and general populations
6.34 public transport	Move domain	Well-performing item but face validity suggested it would be better placed in different domain
6.35 travel by car	Remove	Non-discriminatory within CP and between CP and general populations

Table 10.11 Item decisions for Section 6

10.2.6.7 Section 7 – Preparing for the future

There were 6 items in this section: item 7.5 was removed and item 7.1 was moved to the recreation and leisure domain. This section was unusual in that 2 items (7.4 and 7.6, concerning work experience) had significantly higher Participation in the CP sample than the general population. This was most likely to be due to the older age of the CP group. The summary is shown in table 10.12 below.

Item	**Item fate**	**Rationale for decision**
7.1 sleepovers	Move domain	Higher correlation with relationship items
7.2 discussing leaving home	Retain	Well-performing item
7.3 discussing future job	Retain	Well-performing item
7.4 work experience in workplace	Retain	Well-performing item
7.5 work experience in school	Remove	Non-discriminatory within CP and between CP and general populations; poor test-retest reliability
7.6 written cv	Retain	Well-performing item

Table 10.12 Item decisions for Section 7

10.2.6.8 Section 8 – Additional information

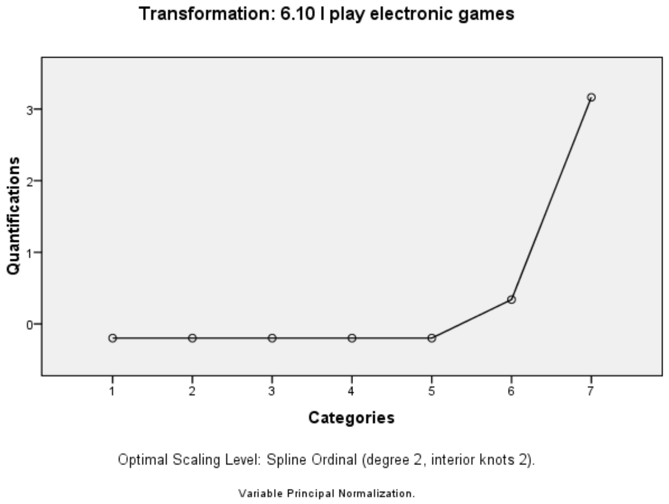
An additional question at the end of the QYPP asked if young people took part in any other area of life that had not been mentioned in the questionnaire. Eight participants responded to this question, four with more than one area of Participation. Their answers are shown in table 10.13. The two individuals who listed making DVDs or films were female; all the others were male.

Participation	**Frequency of response**	**How often**
Sport:		
Five-a-side cricket	1	About once a week
Horse-riding	2	About once a week
Off-road rally driving	1	Once every 2–3 months or less
Making DVDs/films	2	Once every 2–3 months or less
Discussions about how body works	1	Missing
Attending day centre	1	About 2–3 times/month
Visiting old ladies	1	About 2–3 times/month
Doing things at home	1	About once a week

Table 10.13 Responses to question on other Participation.

10.2.7 Optimal scaling

Optimal scaling was performed to look at whether the response options for any items could reasonably be reduced to a dichotomous response. When optimal scaling was plotted, 13 of those items retained in the shortened instrument were found to have splines suggesting that a dichotomous response would be appropriate. The same analysis was performed using the general population data, but only one of these items (6.10 playing electronic games) had a similarly shaped spline. Figure 10.3 shows the graphs generated for this item for each population. Analysis of the general population data identified a further 3 items where the data suggested a dichotomous response but the CP data did not. Figure 10.4 shows the graphs for an item where the splines differed between the two populations, in this case item 4.3 which had a very low frequency of endorsement in the CP population, suggesting that some of the differences seen between the two populations may be due to sample size. On the basis of this, no changes were made to item responses.



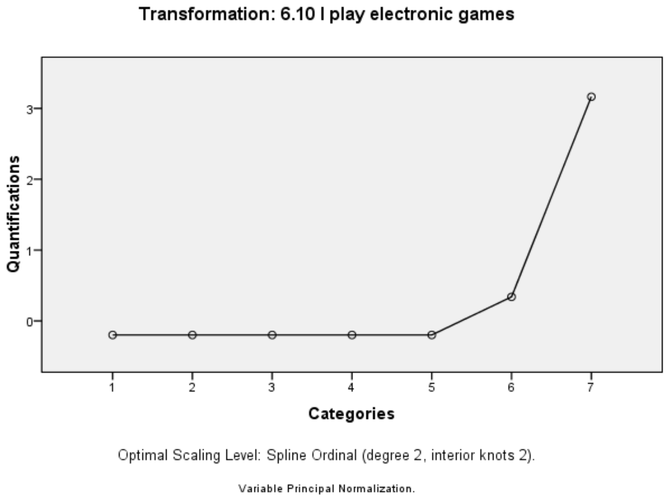


Figure 10.3 Optimal scaling graphs for item 6.10, suggesting a dichotomous response

Cerebral palsy data above, general population data below

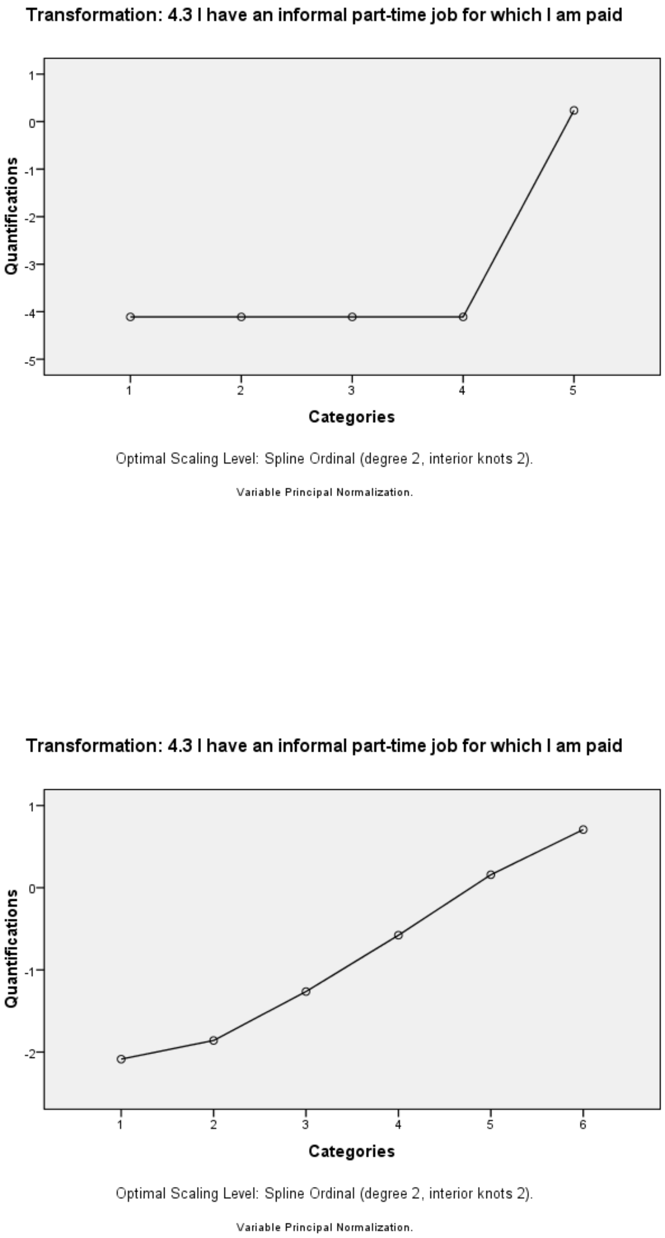


Figure 10.4 Optimal scaling graphs where splines differ

Cerebral palsy data above, general population below

10.2.8 Exploration of domain structure using PCA

As described in the methods, item-total and inter-item correlations were used to examine whether the original domain structure appeared to make sense. Some items were moved as a result of this and this has been described above under the section headings. A categorical principle components analysis was also carried out with the items it had been decided to retain. Using a two-factor model, the first factor accounted for 13.2% of the variance and the second 4.3%. This suggests that a very much greater sample size would be needed to do a formal factor analysis as there are clearly a great many factors underlying these variables.

10.2.9 Proposal for the final instrument

From the results for the item-level analysis, 47 items were removed as they performed less well than other items. This left 45 items which together make up the final version of the instrument (see Appendix J). It was divided into 7 domains which I have labeled Sections A through to G. I repeated the scale-level analyses of reliability and construct validation and table 10.14 shows the structure of the instrument and the results of these analyses. Referring back to the results from Chapter 9, I have also recalculated the scale-level Content Validity Index for each domain and these results are shown in table 10.15.

The final instrument retains the same domains as the original with the exception of Section 5 “Community and political life”. A new domain, which I have called “Autonomy”, contains items that correlated better with each other than the items in the sections in which they were originally placed.

Section	**Content covered**	**Internal consistency: Cronbach's Alpha**	**Test-retest reliability: ICC (95% Confidence Intervals)**	**Known-groups validity: Spearman's ρ**
Section A – Home Life	Making snacks Using cooker hob Heating food/drink Household chores Essential shopping	0.84	0.97 (0.95–0.99)	-0.79*
Section B – Getting on with people	Helping others Talking with strangers On-line communication Time alone with friends Friends' birthdays Alone with boy/girlfriend Sleepovers Hang out at friends' houses	0.75	0.96 (0.93–0.98)	-0.33**
Section C – Educational Life	Lessons/lectures Tests/exams Chose subjects Position of responsibility Breaktimes	0.49	0.83 (0.67–0.91)	-0.46*
Section D – Work life	Informal job Formal job Breaks with colleagues Socialise with colleagues	0.80	0.92 (0.87–0.96)	-0.17***
Section E – Recreation and leisure	Private time Newspapers Listening to music Electronic games Shopping for pleasure Drinks out in evenings Meals out Cinema Live music Informal sport outdoors Organised sport Performing arts Voluntary work Holidays with friends	0.63	0.91 (0.84–0.95)	-0.58*

Section F – Autonomy	Organising daily routine Deciding how to spend money Choosing how to spend time Use of phone	0.86	0.98 (0.97–0.99)	-0.66[*]
Section G – Preparing for the future	Leaving home discussed Careers discussed Work experience CV Public transport	0.61	0.90 (0.82–0.94)	-0.50[*]

[*] p<0.01 with a one tailed test; [**] p<0.05 with a one tailed test; [***] Non-significant

Table 10.14 Content, reliability and validity for the final instrument

Section	Scale-level Content Validity Index
Section A – Home life	95.5%
Section B – Getting on with people	95.7%
Section C – Educational life	88%
Section D – Work life	98%
Section E – Recreation and leisure	95.3%
Section F – Autonomy	95.5%
Section G – Preparing for the future	86%

Table 10.15 Content validity for the domains in the final instrument

Because the number of young people who participated in the work domain was so small, caution needs to be taken with the results for this section.

When the total scores were calculated, Mann-Whitney U tests demonstrated that there was a significant difference between the CP and general population samples ($p<0.01$ for all sections), showing that the final instrument differentiates between the two populations.

The score ranges are shown in table 10.16. Sections A and D in the CP population showed a floor effect, with 25% in A and 93% in D scoring zero. When the data for those with or without severe learning difficulties were analysed separately, only D retained the floor effect for those without severe learning difficulty. Floor effects were seen for Sections A, B, D and G for the group with severe learning difficulty. From the general population data, a floor effect was seen for D (57% scoring zero) and a ceiling effect for section F, where 21% had a maximum score.

Section	Possible range of scores	Range of scores in CP population data	Range of scores in general population data
A	0–25	0–22	0–25
B	0–48	9.6–42.4	11.4–48
C	0–25	2.08–21.08	0–25
D	0–16	0–9.8	0–16
E	0–84	5–49.5	15–81
F	0–16	5.67–16	8–16
G	0–25	0.83–22.5	0.83–25

Table 10.16 Score ranges for the final instrument

10.3 Discussion

10.3.1 Participants

The response rate for young people with CP was lower than expected, and a total of 107 young people were recruited within the project timescale. Other studies with young people of this age have had lower response rates than predicted, or than with younger children or adults (Richards et al., 2010; Middelkoop et al., 2008). A combination of factors is likely to have contributed to this. Firstly, we used an opt-in method of recruitment, so young people and families had to actively reply to the letter sent to them about the study. An opt-out might have produced a higher response rate, but obtaining telephone numbers would have been difficult, and the research ethics committee would have been unlikely to have permitted it.

Young people in general are less willing to take part research than older adults (Spigarelli, 2008), and this may be because they do not yet understand the need for people to participate in research in order to improve knowledge and hence services and treatments. Young people of this age with CP may not wish to dwell on their impairments, and taking part in research might add to their sense of difference. Lack of time has been identified as one reason why young people do not wish to take part in research (Wiegerink et al., 2010b) and this may be a reason for both failure to send back the reply slip or to want take part in the research. Involving young people in the design of research and providing incentives have both been identified as useful techniques for encouraging participation in this age group (McDonagh and Kelly, 2010). It was mentioned in the recruitment letter that young people had been key to the instrument development, which we had hoped would encourage participation. The £5 thank you voucher was only mentioned in the information sheets sent after the young person or parent had expressed an interest, and it might have improved response rates if this had been mentioned in the recruitment letter.

The lower than expected response rate meant that the target recruitment number, calculated at the outset to adequately power the study for assessing known-groups validity, was not reached. However, the results for this analysis were highly statistically significant. A larger sample size might have improved the decisions made for items where there was low frequency of Participation for those with CP, such as the work items.

Those who did participate were not significantly different from those who did not in terms of gender, age or level of socioeconomic deprivation. In terms of motor impairment, levels in the participants were not significantly different from those in other population-based studies (Morris et al., 2006a) or in the NECCPS adolescent population as a whole. However, our sample had a higher proportion of young people described as having a learning impairment than the NECCPS population over 13. However, the NECCPS impairment data were collected when the children were 4–5 years old, and it may be that between then and adolescence, mild impairment had become apparent in some young people. However, this is unlikely to account for all of the difference seen, and other possible reasons are that there is a greater likelihood that those with learning impairments could be persuaded by parents and others to take part in the research, or had more time available to do so. The proportion with learning difficulties does mean that differences observed between the CP and general population samples may have been greater than if the sample had had a lower prevalence of intellectual impairment.

The general population sample was not matched in any way to the CP sample. The average age was lower and the oldest participants in the general population group were 17, in contrast to the CP sample who included individuals up to and including 21 years. For some items, for example those concerning work and romantic relationships, the difference between responses might have been even greater with an age-matched comparator sample. In other areas where Participation appeared higher in the CP sample, for example work experience, the older age of the CP group may have been the explanation. This means that the comparison of data needs to be interpreted with care, but nonetheless it provided useful additional information when evaluating the items, suggesting which items were likely to be most discriminatory. In particular, the general population data on the work items enabled decisions to be made about which items could be considered for removal, when Participation rates in the CP sample were so low as to make this impossible. The general population data also provided confirmatory information on aspects such as differential item functioning for gender.

10.3.2 Acceptability

I argued at the outset that administering the self-report questionnaires at face-to-face visits would lead to more accurate data collection than administering it by post. Figure 10.2 (in section 10.2.5) confirms this in regard to missing data, where it can clearly be seen that relatively unsupervised completion in school led to many young people only answering earlier parts of the questionnaire. In contrast, questionnaire completion by the CP sample, where a researcher was present in the room, resulted in the proportion of missing data being only 0.6%. It also suggests that although the CP sample found the instrument acceptable to complete, instrument length is an issue in some settings.

One aim of the analysis was item reduction, and the shortened version proposed may have resulted in fewer items missed, although we cannot know this and if the instrument were to be used in a classroom setting in the future, piloting would need to be undertaken first to check this.

The decision on whether or not a young person could self-report was made by the parents. This was discussed over the telephone, and the parent was told that, in order to self-report, the young person would need to be able to tell us whether or not they participated in something and how often. It was felt that parents would be best placed to make this assessment. It is interesting then to see that not all those where parents said they would be unable to self-report, were said to have a severe learning difficulty or a communication difficulty. Not all impairments were asked about however, and it may be that some of these individuals had other impairments such as autism, which led the parents to make this decision. It may also be however, that some parents did not wish their young person to self-report for some reason other than their impairments, but did not communicate this to us.

10.3.3 Reliability

Test-retest reliability was at an acceptable level, above 0.70 for all sections. For Section 3, although the confidence limits were wide due to the small numbers, subgroup analysis showed higher values of ICC where questionnaires were completed in the holidays and when questionnaires were completed within 4 weeks of each other. One explanation is that the QYPP is detecting changes in this area of Participation over time. If this is the case, the higher test-retest reliability for proxy reports could be because parents are not always aware of these changes within the timescale of questionnaire completion, or that changes did not occur in this timescale for those with more severe intellectual impairment.

For some domains, reasonable internal consistency could be demonstrated whilst maintaining validity. For other areas, this was much more difficult to demonstrate. In particular, the section on recreation and leisure had low inter-item correlations including a number that were negatively correlated. It might be that with a larger sample size, a clear factor structure would have emerged within this large domain. I think it is more likely however, that some areas of Participation are defining variables, rather than causal (Fayers and Hand, 2002) and so inter-item correlations would be expected to be low, and clinimetric rather than psychometric analysis would be more appropriate. I will discuss this in more detail in the main discussion in Chapter 11.

The shortened version showed marked floor effects for those with severe learning difficulties in four of the seven sections. This means that the instrument has reduced ability to discriminate between these individuals, and will be less able to detect change. Although the aim of the project was to produce an instrument which would be appropriate for the whole adolescent CP population, this may not be possible. The needs of those with and without severe intellectual impairments may diverge so significantly at this age that different instruments are needed.

There was also a floor effect for Section D for those without severe learning disability and for the general population. In the latter, this may have been different, had this group included young people up to 21 years. There was a ceiling effect for the general population for Section F, but this was not present for the CP group, and in all other sections, the spread of scores was reasonable.

10.3.4 Validity

The scores correlated as expected with impairment. The only exception was Section 5 (Community life), which also performed poorly in other ways, notably in terms of variance. Evidence for known-groups validity was found for the shortened instrument, but similarly I was unable to demonstrate this correlation for the one section with very low frequency of endorsement (Section D Work life). Further evidence of construct validity is provided by the demonstration that the proposed shortened QYPP discriminates between the CP and general population groups.

Content validity appears reasonable for all the new domains, although there are now no items that specifically mention Participation with family members, since all these items performed poorly and were removed. Although Participation with friends is particularly important in adolescence, as was discussed in Chapter 3, that with family is also important. However, it may be that key areas of Participation with family members will be tapped by the items on discussing independent living and careers, and some of the leisure Participation items.

In addition to the expert review, item coverage was assessed by Section 8, where participants were asked whether any areas they participate in were not included in the questionnaire. Some of the responses would fit into existing items, such as the sport items. Horse-riding is a sport undertaken by many disabled young people and so should perhaps be included as an example in the questions about sport. Making DVDs could have been included in hobbies or interests, and “visiting old ladies” as voluntary work or in one of the communication items, such as talking to neighbours. The young man who specified the day centre had severe learning difficulties and it may be that that should be considered as an item to include in the work domain for groups where this area of Participation is important.

When completing the QYPP, young people commented on activities in the leisure domain which were organised via school. This was particularly the case where young people had learning disabilities. For example one young man went to the cinema on a regular basis which was organised by school. He and his parents saw this as leisure being facilitated by school. This conceptual overlap was illustrated by Murray (2002) in her study with young people with learning disabilities. She noted the definition of leisure perceived by the young people themselves: “Leisure was not seen in isolation from other aspects of their lives, forming as it did an integral part of their daily experience. The young people involved in this project overwhelmingly saw leisure as either ‘hanging out’ with other people or ‘doing things’ with people they enjoyed to be with. Leisure, therefore, was primarily defined as being about mutually enjoyable relationships.”

10.3.5 Optimal scaling

A dichotomous response for some items is likely to make the instrument quicker and simpler to complete. The statistical technique of optimal scaling provided information on whether items responses could be dichotomized. However, since the results differed between the CP and general population samples, I would be hesitant to change items without further data from larger samples. It might be appropriate to use the results to change items if the instrument is only to be used with a CP sample, but not with other populations where the results may be different.

10.4 Conclusions

Using the results of item and scale-level analyses, it has been possible to reduce the number of items in the instrument to around half the original. Construct validation in this population has been demonstrated as well as acceptable levels of test-retest reliability. Internal consistency was variable between the different sections and there was a tension between improving internal consistency and content validity. This is probably due to the nature of some domains of Participation, where items can more reasonably be viewed as defining rather than effect indicators. Clinimetric methods are best applied to these domain scales. I discuss this further in the next chapter.

Chapter 11. Discussion

11.1 Reasons why this work is important

The concept Participation evolved from earlier concepts such as handicap, and was an attempt to describe universal experiences, in which those with impairments may experience restrictions. Since the publication of the ICF in 2001, the nature and scope of the concept of Participation has been debated, including a widening of the concept to include a subjective component. A number of instruments have been designed to measure it, but none specifically for adolescents.

Adolescent Participation differs from that of both younger children and adults, and therefore tools designed for use in other age groups are not ideal, lacking face validity and omitting important areas. There is evidence that a number of areas of Participation in adolescence are predictive of later Participation in adulthood and there is also substantial evidence that the Participation of young people with disabilities such as cerebral palsy is both less frequent and less diverse than that of the general population. This makes Participation a crucial outcome to measure in this age group. These different factors point to a clear need to develop instruments to measure Participation in adolescence.

The content validity of an instrument is maximized if the perspectives of the likely respondents are central to the development of the instrument (Fleury, 1993; Imle and Atwood, 1988). In the development of previous Participation instruments for children their views of Participation have not been obtained or incorporated to the same degree. In this study, the views of adolescents were a key part of the instrument development. By starting with the view of young people, their views were given prime importance.

Involving those with severe expressive language impairments in qualitative research of this kind is a challenge. Because of the profound impact of such impairments on their relationships with others, their experiences of Participation may well be different from those without such difficulties. This group is often excluded from research because of these difficulties and their inclusion in this study is therefore an important strength.

Studies have shown that parents and adolescents may disagree when reporting certain aspects of the adolescent’s life and experiences. Peer relationships and leisure activities (Kramer et al., 2004), pain, health status and the impact of their health on family activities (Waters et al., 2003) have all been shown to be reported differently by young people and their parents. Where possible therefore, adolescents should self-report and the QYPP was designed as a self-report instrument. This is clearly not possible for those with significant cognitive impairments where proxy reporting will be necessary, and providing both versions enables the experiences of those with and without cognitive impairment to be measured. This means that the instrument can be used with the whole population for young people with CP, which is important for epidemiological studies. However, there proved to be a significant floor effect for those with severe cognitive impairment which means the instrument is less likely to be responsive to change, and may have lower face validity for this particular group.

11.2 Validity and reliability of the QYPP

The results show that in this population of young people with CP in the North of England, the QYPP is a valid measure of Participation. Content validity was maximised by the method of its development; items were derived from qualitative data from young people and the item pool was subsequently reviewed in a rigorous way by a group of experts. Construct validation, using the known-groups method, showed moderate negative correlations with impairment severity, consistent with previous research suggesting that Participation can be predicted in part by degree of impairment.

The QYPP also demonstrated test-retest reliability comparable with other Participation measures, with intraclass correlations greater than 0.75 for all sections. Test-retest studies using the School Function Assessment have found intraclass correlations of above 0.82 (Coster et al., 1998), whilst those for studies using the Life-H found that the correlations varied between sections, but all were above 0.60 (Noreau et al.). The educational Participation section of the QYPP had the lowest value, and this is most likely to be due to changes in Participation between QYPP completions.

Internal consistency was more variable. When the instrument was shortened, Cronbach's alpha values for the Home Life and Autonomy sections were above 0.80, demonstrating good internal consistency. However, the remaining sections have low values for Cronbach's alpha, and for some domains, such as the Recreation and Leisure, removing items to increase the value of alpha led to a loss of item coverage, thereby threatening the validity of the scale. Similarly low values of alpha have been found with other instruments. For example, values for the Children's Assessment of Participation and Enjoyment (CAPE), which measures discretionary participation much of which would be included in the Recreation and Leisure domain of the QYPP, ranged from 0.32 to 0.76 (Imms 2008).

In a special issue of Archives of Physical and Medical Rehabilitation in September 2010, Dijkers wrote an article about current issues in the measurement of Participation where he explored the problems inherent in the widespread use of psychometrics in the development of Participation measures (Dijkers, 2010). He proposed that Participation measurement be viewed as clinimetric rather than psychometric and called on instrument developers to use more appropriate techniques, in particular to abandon the use of item response theory. In my work I kept an open mind about which would ultimately be the most helpful way of conceptualising Participation, and I hope have therefore enabled the most appropriate conclusions to be reached. As I will now expand on below, this has enabled me to consider that some areas of Participation are measured using effect indicators and others defining indicators, which has not previously been discussed in the literature.

It may be that Participation is not one concept, or even the same type of concept, in all domains. So, for example, it is plausible to think of the domestic Participation domain (for which high internal consistency was demonstrated) as representing an underlying trait of involvement in domestic life which would involve participating in all items to do with household chores, cooking and shopping. Leisure Participation in contrast, can mean very different things to different people and “good Participation” involves a diversity of different types of Participation but not necessarily all. Thinking about it empirically, there is no good reason why there should be correlation between going to the cinema and playing ball games in the park, or between listening to music and playing computer games. Some people do some things and some others. Leisure Participation is also different to other areas in that it encompasses a wide number of areas and no-one has time to Participate in all of them at the maximum level. More Participation in one area may require less Participation in another, and this will differ between individuals. This would account for the negative inter-item correlations seen in this domain of the QYPP. Items for this domain would therefore be defining indicators, and internal consistency would not be expected.

So, going back to the diagram in Chapter 7 (figure 7.1) showing the difference between effect and defining indicators, the following figure (figure 11.1) illustrates the difference between domestic Participation (the Home Life section of the QYPP) and leisure Participation.

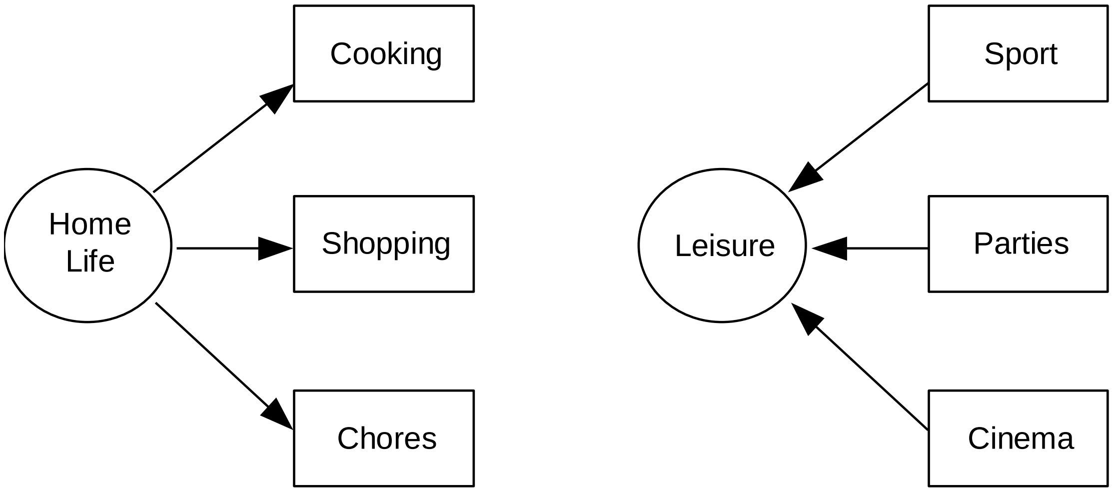


Figure 11.1 The difference between domestic Participation (effect indicators) and leisure Participation (defining indicators)

For clinimetric scales, it is appreciated that the causes for variance in scores may be external to the construct being measured (Fayers and Hand, 2002). So for health-related quality of life, different underlying diseases or their treatments will be the cause of the symptoms which result in the individual experiencing a poor quality of life. This is the reason that psychometric analysis with different disease groups yields different results. The corollaries for Participation, are factors such as physical environment and attitudes which play a causatory role, leading to different patterns of Participation between groups. This may be particularly true for adolescents where Participation patterns may be affected by the attitudes and culture within the family as well as in the wider society.

Participation in school or college was another section where internal consistency was low. Again it may be that educational Participation is not a trait possessed by an individual to a greater or lesser degree but more an outcome of the young person’s aptitudes and interests as well as the attitudes and culture of both school and family, and items are better conceptualised as defining indicators.

It is possible to combine both effect and defining indicators in one instrument. For example, using the HRQoL example again, Fayers and Hand suggest that the symptom lists used in HRQoL scales are defining indicators, whilst single questions such as “Do you think that your life is worth living?” or “How would you rate your overall Quality of Life” would be effect indicators (Fayers and Hand, 2002). In a Participation instrument like the QYPP, it would be similar, where different sections to be regarded as different types of measure.

11.3 Use of the instrument

The QYPP measures Participation frequency and is therefore an objective measure. As I have previously discussed, the subjective experience is also important, particularly to individuals themselves. Although some instruments combine both objective and subjective qualifiers, this has been criticised by some commentators as confusing, as the two concepts are likely to be different and the relationship between them is currently unclear (Whiteneck and Dijkers, 2009). It would however be appropriate, and in many situations advisable, to administer an instrument measuring subjective experience alongside the QYPP. This could either be a quality of life instrument, capturing overall subjective well-being, or a questionnaire asking specifically about the subjective experience relating to individual areas of Participation.

For those with severe or profound intellectual impairment, Participation scores in some sections of the QYPP were low. There were significant floor effects seen for this group with the shortened instrument, as some items removed because of negative correlation with other items in the draft version were those participated in by those with intellectual disability. Although my original aim was to produce an instrument that could be used with the entire population of young people with CP, it may be that for those with such impairments, this instrument is not appropriate. Alternatively, it may be that certain domains such as the Autonomy domain are not used, whilst others such as the School/college and Leisure sections are.

The qualitative data led us to believe that a generic instrument was appropriate. This was partly because the Participation undertaken and aspired to was similar between the young people with and without CP. It is also a reflection of the heterogeneity of impairments within the CP group, making a disability specific item unlikely to be relevant to all. Although instrument developers may choose for a number of reasons to develop either generic or condition specific measures, the evidence in general points to an advantage for generic measures as they appear to perform as well as disease-specific ones but with more flexibility and the ability to be used to compare groups (Streiner and Norman, 2008). Another advantage is that because they can be used more widely they are likely to be more widely evaluated, and data can be better compared. It is therefore advantageous that the QYPP is a generic instrument and it was helpful in the field-testing to have general population data for comparison.

From the data collected, it was not possible to determine the precise reasons why Participation differed in some areas between the different groups. It would be interesting to investigate further whether it is the specific impairments or disability per se that is more important in affecting Participation. This could be investigated further by using the QYPP with other groups of young people with long-term conditions. Examples would include young people with other congenital neuro-disabling conditions such as autistic spectrum disorders; with progressive conditions, such as muscular dystrophy; and with acquired disabilities such as acquired brain or spinal cord injury. It could also be used with young people with long-term conditions and disabilities which are not neurological in origin, such as asthma or rheumatological disorders. Using the QYPP to compare Participation in different ethnic groups or between those attending different types of school, would also be interesting.

Participation measures have been designed that can be used in a range of settings and for different purposes (Whiteneck, 2010). I have described them in chapter 5 as being either “broad-brush” or more detailed. The former are short with only one or two broad question per domain, whereas those which are detailed may contain 100 or more items tapping individual sub-domains. The QYPP is in the latter category, although in its final form considerably shorter than some instruments, such as the Life-H, or CAPE. As such it could be used in epidemiological research or in clinical practice. In the latter situation, clinicians could use either individual sections or the entire instrument to help a young person set goals or identify barriers to optimal Participation which need to be overcome. It might also be appropriate as an outcome measure in clinical settings or for interventional research, although as I discuss further below, responsiveness to change has yet to be demonstrated.

Another potential role for the QYPP is in service planning, where it could be used as part of a needs assessment for a specific group of young people. If frequency in a certain area of Participation is identified as lower for the group in question, services can then be targeted to facilitate improved Participation.

11.4 Limitations of this work

Data were gathered only in the northeast of England. Patterns of Participation are known to be influenced by the culture in which a person lives and there may be differences in Participation between this part of the country and other areas of the UK. Relying only on the views of adolescents in this area may lead to a picture that is not reflected in other parts of the country, although such differences are not likely to be large.

Those without a good use of English were excluded for practical reasons. It would have been costly, difficult and time-consuming to use interpreters to explain the project, obtain consent and carry out the interviews. There were also few young people on the NECCPS database without cognitive impairments from ethnic minorities and those that were approached were not interested in taking part in the research. This may have excluded a group whose experience of Participation was very different from that of the others interviewed.

The qualitative data on which the items for the questionnaire are based, were gathered only from adolescents and not from the parents or carers of young people with intellectual impairment. It might be advantageous to carry out qualitative work with parents and carers, as this might lead to additional questions or differences in question wording which would make it more applicable to these young people. However, it is important that the same information is obtained for all young people so that comparisons can be made, and questions of more relevance to those with significant intellectual disabilities may not be relevant to those who are self-reporting. This could reduce acceptability of the questionnaire to the latter group. The proxy questionnaires were also administered by post rather than visit because of resource restrictions. This may have led to us missing feedback about ease of completion and other factors, as we did not meet with the parent or carer. However, some feedback was obtained at cognitive interviews, which were carried out face to face.

The expert panel members were all adults, rather than adolescents although some other studies have used children and young people in expert panels (Schilling et al., 2007). However, the qualitative data gathered at the start of the research was the primary data source for developing items. In addition, the focus groups and cognitive interviews with young people could also be seen as analogous to some of the process of the expert panel. An attempt was also made to obtain the views of young people via the discussion forum on the Scope website, but this was unsuccessful, with only one response and this from a parent. The entire item list had to be put in the body of the forum post, and this may have overwhelmed readers. It may also be that few adolescents use such forums.

11.5 Proposal for future work

The aims and objectives of this research were met and an instrument has been developed to the point that it can be used in research and clinical settings to measure Participation. However, as with all such instruments, further refinements are possible and the use of the instrument in different settings and with different populations will lead to more data becoming available on its performance in those situations. There are some specific areas where further work with the instrument will be useful and I describe these below.

The scoring of clinimetric scales is more complicated than for psychometric ones (Fayers and Hand, 2002). Because effect indicators all tap the latent variable to a similar degree and represent a random sample of all possible items, it is logical to give them equal weight when calculating a score. However, this does not apply to defining variables, where the importance of individual items will vary in their impact on the concept being measured. Now that it is clear that some sections of the instrument would be better viewed as clinimetric rather than psychometric scales, further work will be needed to establish more sophisticated scoring. In clinimetric instruments, patients are usually involved in assigning weightings to items based on their relative importance (Dijkers, 2010) and this could be done with adolescents with and without disability.

It is important that an instrument designed for completion for those with impairment in hand function is made available in a form which is accessible to them. Although very few respondents were unable to mark the paper copy adequately and when this was difficult most said that completing an electronic form would not be any easier, it may also be that adolescents with milder or no impairment with hand function and who use computers routinely, would prefer this method of administration. In some situations it might increase completion rates. It would therefore be worth considering the piloting of an on-line version. However, there are some disadvantages with on-line questionnaires. One is that participants cannot easily see how many questions they have left to do, and this may affect motivation levels (Streiner and Norman, 2008). It is also less easy to go back and rethink answers to previous questions.

Further work involving the parents and carers of those with significant intellectual disability would be helpful. It is likely that further items need to be developed for this group, and some existing items may need removing although as has already been noted, this may make comparison with other groups more difficult.

This work was not designed to establish whether the instrument is responsive to change, an important property of any outcome measure. This is an area where research data are frequently lacking for already well-used instruments (Bedell and Coster 2008). Bedell and Coster, in their 2008 review of measures for use in children with traumatic brain injury, noted that instruments with broad items, such as the Child and Adolescent Scale of Participation and the School Function Assessment are least likely to be responsive, whereas more fine grained instruments were likely to perform better. As the QYPP is designed to be a detailed, rather than broad-brush measure, it may be responsive to change, but this will clearly need to be tested.

Another area of future study should be to establish whether the QYPP has predictive value. It would be very useful to know in detail whether Participation measured in young people using the QYPP predicted future Participation, and therefore whether intervention which changed Participation could be predicted to effect long term outcomes. An example might be whether scores in the "Preparing for the future" domain during adolescence (work experience, discussing careers etc) are predictive of competitive employment in adult life. At present, it is unclear from the literature whether or not this is likely to be the case.

It would be very helpful for future studies, if larger and more comparable general population data using the QYPP were to be obtained.

11.6 Conclusions

The Participation of those with disabilities remains significantly poorer compared to the general population, despite the development and wide acceptance of the social model of disability and the work of disability rights campaigners resulting in the enactment of anti-discrimination legislation. Health professionals must be able to measure Participation both in clinical and research setting, if they are to improve the lives of young people with such disabilities. The development of the Questionnaire of Young People's Participation enables the Participation of adolescents to be measured by an age-specific instrument for the first time.

Given that the precise definition and operationalisation of Participation are still debated, the use of QYPP will also contribute to the understanding of Participation and how it may be measured. Developers of outcome measures have tended to rely on psychometric techniques, which were developed for use with instruments measuring traits such as intelligence. Increasingly these techniques are being seen as inappropriate and clinimetrics is being promoted as more logical. My work has provided further evidence of the need to use clinimetrics when developing measures of Participation. My results also suggest that different areas of Participation may differ in the type of variable they represent.

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APPENDIX A – Impairment Questionnaire

Questions about the Young Person's Abilities

Please read the following and mark **only one** box **for each question** beside the answer that best describes the young person's abilities.

1. Moving about

☐ **They can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail** and walk wherever they want to go (including uneven surfaces, slopes or in crowds) and can run and jump although their speed, balance, and coordination may be slightly limited.

☐ **They can walk on their own without using walking aids, but need to hold the handrail when going up or down stairs** and often find it difficult to walk on uneven surfaces, slopes or in crowds.

☐ **They can stand on their own and only walk using a walking aid** (such as a Kaye walker, rollator, or any kind of crutches, walking sticks or canes etc) and find it difficult to climb stairs, or walk on uneven surfaces and may use a wheelchair when travelling for long distances or in crowds.

☐ **They can sit on their own but do not stand or walk without significant support** and therefore rely mostly on wheelchair at home, school and in the community and often need extra body/trunk support to improve arm and hand function and may achieve self-mobility using a powered wheelchair.

☐ **They have difficulty sitting on their own and controlling their head and body posture in most positions** and have difficulty achieving any voluntary control of movement and needs specially supportive chair to sit comfortably and have to be lifted or hoisted by another person to move.

2. Using their hands

☐ **They handle objects easily and successfully.** At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.

☐ **They handle most objects but with somewhat reduced quality and/or speed of achievement.** Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.

☐ **They handle objects with difficulty; need help to prepare and/or modify activities.** The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.

☐ **They handle a limited selection of easily managed objects in adapted situations.** Perform parts of activities with effort and with limited success. Require continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.

☐ **They do not handle objects and have severely limited ability to perform even simple actions.** Require total assistance.

3. Learning ability

☐ They have no problems with learning

☐ They need or needed extra help in school for their mild or moderate learning difficulty

☐ They need or needed extra help in school for their severe learning difficulty

4. Vision – Does the young person have a problem with their sight?

☐ No

☐ Yes, but has some vision (e.g. needs to wear glasses)

☐ Yes, they are blind or have no useful vision

☐ Do not know

5. Hearing – Does the young person have a problem with their hearing?

☐ No

☐ Yes, they have hearing loss, but don’t need hearing aids

☐ Yes, and they need hearing aids

☐ Do not know

6. Fits (seizures or epilepsy) – Has the young person ever had fits?

☐ No ☐ Do not know

☐ Yes

If yes, about how old were they when they last had fit?…………

How old were they when they last took medicine to stop fits?……………

7. Feeding difficulties – does the young person have problems chewing or swallowing?

☐ No

☐ Yes. They feed by mouth, but have difficulty chewing or swallowing

☐ Yes. They do not feed by mouth (e.g. they have a gastrostomy or nasogastric tube)

8. Communication – does the young person have problems communicating?

☐ No

☐ Yes. They have problems but they communicate with speech

☐ Yes. They use alternative communication methods

☐ Yes. They have no formal communication

You have now finished this set of questions.

Thank you very much!

APPENDIX B – Topic guide for interviews

Topic Guide and indicative questions for interviews

Introductory remarks

- Thank for agreeing to meet
- Recap purpose, timescale, tape recorder etc
- Check consent and gain consent to record interview
- Reiterate that participant can withdraw or not answer specific questions at any time
- Give details of support mechanisms which are available
- Opportunity for questions before starting.

Indicative interview questions.

I'd like to start by asking you about the sorts of things you do, so that I can build up a picture of your life.

1. Can you tell me what you did during the day yesterday? And for each activity I would like to know roughly how long you spent doing it.
If we could start with getting up…
Prompts: and then what did you do next? What about in the evening? etc

What was really good about yesterday?
What did you least enjoy about yesterday?

2. You've told me about quite a few things you do. What other activities have you done over the last week? And for each activity I would like to know roughly how long you spent doing it.
Prompts: Anything else you've done which was to do with [prompts depending on what types of activities have not yet been mentioned]
ICF domains/subdomains – see list below

What was really good about the last week?
What did you least enjoy about last week?

3. OK, so I've a fair idea about your last week. What other activities do you get involved with at other times?
Prompts: Anything else you've done which was to do with [prompts as with part 2]

Which of these activities were really good?
Which did you least enjoy?

4. If you could have your ideal day when you could do whatever you wanted, money no object, what would you do?
Prompts: tell me more about that….

What are the top three things you like doing best? Why is that?
What are the three things you least enjoy? Why is that?

5. Has anything excited you or given you a real buzz recently?

6. I have a list here of things that people do or get involved with. (Show list derived from ICF and other sources)
Are there things on here which you do and which we haven't yet discussed?
How important are these things to you?
Are there things that have been missed off the list?

7. Who lives at home with you? What do your Mum and Dad do for work?

8. Are there other activities that your siblings or friends do that you don't?

Concluding remarks

Thank you for taking part
Recap how information will be used
Any questions

APPENDIX C – Focus groups topic guide

Question 1

The following are statements which could be in the questionnaire concerning self-care. Do you think they make sense? Are there other things people do which should be included?

Autonomy with hygiene, washing and dressing

1. I decide on when and how I organise my self-care (e.g. washing, dressing, toileting etc)

Eating out

2. I eat meals with family members or others at home
3. I eat meals with others at their homes
4. I eat out in restaurants or public places where food is served

Looking after own health

5. I take care of simple health problems myself (e.g. taking painkillers like paracetamol, putting on a plaster)
6. I organise appointments with a nurse, doctor or therapist myself
7. I do activities to improve my health and fitness (e.g. choosing appropriate foods, carrying out exercises or therapy regimes)

Question 2

The following are statements which could be in the questionnaire concerning domestic life. Do you think they make sense? Are there other things people do which should be included?

Shopping

1. I go shopping for essential items (food for self and household, toiletries etc)

Preparing meals

2. I prepare snacks and drinks myself where cooking is not required (e.g. breakfast, a sandwich)

3. I prepare and cook meals myself

Household chores

4. I do clothes washing and ironing

5. I do other housework chores (e.g. vacuuming, washing and drying dishes) Please do not include clothes washing and ironing or tidying your own room.

Pets

6. I take care of a pet

Maintaining house and furniture

7. I do repairs on the house or furniture

Assisting others

8. I help other family members with things they need (e.g. housework, shopping, emotional support)

Question3

The following are statements which could be in the questionnaire concerning communication and relationships. Do you think they make sense? Are there other things people do which should be included?

Communication

1. I have conversations or discussions with friends

2. I have conversations or discussions with family members

3. I speak to adults outside my family

4. I speak to people from work or school who are not my friends

5. I speak to people in my neighbourhood

6. I telephone or text to contact people

7. I use on-line communication to contact people (e.g. email, MSN messaging or Facebook)

Social relationships

1. I do activities with my parents
2. I do activities with my sibling(s) (brothers and sisters)
3. I do activities with my extended family (grandparents, aunts, uncles or cousins)
4. I do activities with one or more friends
5. I do activities with adults outside my family
6. I have opportunities to see and do activities with a friend on my own without others present
7. I have or have had a girlfriend/boyfriend
8. I am involved, or have been involved in the past, in a sexual relationship/I take part in sexual activities with a girlfriend/boyfriend

Case

Claire is a 17 year old young woman. She has kissed 2 boys in the last 6 months. One she was going out with for 2 days and the other she kissed at a party and has not seen since.

How would she answer these questions?

1. I have or have had a girlfriend/boyfriend
2. I am involved, or have been involved in the past, in a sexual relationship
3 I take part, or have taken part in sexual activities with a girlfriend/boyfriend

Question 4

The following are statements which could be in the questionnaire concerning recreation and leisure. Do you think they make sense? Are there other things people do which should be included?

Informal leisure and socialising

(please include only time spent out of school or college)
1. I play or fool around, relax or chill out with other people
2. I play board or card games

3. I go to parties

4. I go shopping for pleasure

5. I go to other peoples' houses to hang out or socialise

Arts and culture

6. I visit museums or galleries

7. I draw, paint or do other art or craft activities

8. I play a musical instrument, sing or do drama for pleasure

9. I read books, newspapers or magazines for interest or pleasure

10. I listen to music

11. I go to the cinema or attend shows or concerts

12. I take part in other hobbies or interests (e.g. stamp collecting, trains)

13. I chose what to watch on TV

14. I watch DVDs or videos

Commercial leisure

15. I go to pubs, bars or night clubs

Holidays

16. I go on holidays or day-trips with family or friends

Sport

17. I watch live sport or follow sport on TV

18. I take part in sporting or fitness activities informally which take place in recreation facilities (e.g. swimming during public swimming sessions, going to the gym). Please do not include sport or fitness which is as part of an organised team or lesson.

19. I take part in informal sport outside (e.g. playing ballgames or skate-boarding in a park) Please do not include sport or fitness which is as part of an organised team or lesson.

20. I take part in formal sports activities (e.g. organised team sports, sporting competitions, sports lessons or coaching sessions)

Electronic leisure

21. I play computer or video games

22. I use the computer for leisure activities such as surfing the internet or downloading music (please do not include on-line communication such as email or MySpace)

Time alone

23. I spend time on my own relaxing or winding down

Outdoor pursuits

24. I take part in outdoor pursuits (e.g. fishing, hiking, camping)

Mobility

25. I travel in a car or use public transport (e.g. bus, train, tram, underground or Metro) for pleasure

26. I go for a walk (or move myself in a wheelchair) or cycle as an activity/for pleasure

Question 5

The following are statements which could be in the questionnaire concerning political life. Do you think they make sense? Are there other things people do which should be included?

1. I vote in local or national elections
2. I vote for members of school council or other local democratic bodies or take an active part in debates
3. I am a member of a political party or campaigning organisation (e.g. Friends of the Earth, Amnesty international, local campaigning organisation)
4. I have been involved in local or national political action (e.g. signing a petition, going on a protest march or rally)

APPENDIX D – Content review questionnaire

Home life

This domain includes items relating to looking after self, shopping for essential items, preparing and eating meals, household chores, caring for pets, maintaining house and furniture and assisting others.

Item no	Item and response wording	**Relevance – please ring the appropriate number for each item** **1 = the item is *not* relevant** **2 = the item needs major revisions to be relevant** **3 = the item needs minor revisions to be relevant** **4 = the item is relevant**	**Item has clarity**
1	I make the decisions about organising my daily routine (washing, dressing, toileting etc)	**1 2 3 4** **Comments**	**Yes** ☐ **No** ☐ **Comments**
2	I improve or maintain my health and fitness. (e.g. choosing healthy foods, doing physical exercises, following a therapy programme, making sure I take medicines I need, etc)	**1 2 3 4** **Comments**	**Yes** ☐ **No** ☐ **Comments**
3	I prepare snacks and cold drinks	**1 2 3 4** **Comments**	**Yes** ☐ **No** ☐ **Comments**

The remainder of the questionnaire was in the same format, the items being:

Home life contd

4 I prepare hot drinks and simple meals using the kettle, toaster or microwave

5 I prepare and cook hot meals using the cooker

6 I eat meals with members of my family at my home

7 I eat meals with friends at my home

8 I tidy my room

9 I do clothes washing and/or ironing

10 I do other housework chores (e.g. vacuuming, washing and drying dishes, cleaning rooms or furniture. etc) Please do not include clothes washing and ironing or tidying your own room

11 I go shopping for essential or day-to-day items (food for myself and household, toiletries etc) Please do not include shopping for pleasure or for buying “luxury” items like non-essential clothes, games, DVDs etc

12 I take part in looking after a pet

13 I do repairs on the house or furniture

14 I help other family members with things they need (e.g. housework, shopping etc)

15 I help friends and family by listening and supporting when they are upset

Getting on with other people

This domain includes items related to communication and social relationships

16 I have conversations or discussions with friends about things that matter to me

17 I have conversations or discussions with family members (parents, brothers or sisters, grandparents, extended family) about things that matter to me

18 I use the telephone or texting

19 I use on-line communication (e.g. email, MSN messaging or Facebook)

20 I do activities with one or both my parents (e.g. going out for leisure activities, doing activities at home)

21 I do activities with my extended family (grandparents, aunts, uncles or cousins)

22 I spend time with my friends outside school

23 I spend time with my friends on my own without my parents, carers or other adults present

24 I spend time with a boyfriend/girlfriend (someone with whom you are having a romantic relationship)

25 I speak to neighbours and other people who live near me

26 I speak to people I don’t know (e.g. asking for directions in the street, speaking to shop assistants)

Education and School or College life

This domain includes items relating to education and to school or college activities

27 I go to lessons or lectures (or other organised learning sessions such as tutorials or seminars)

28 I go to teaching or training that is not part of a regular school or college course (e.g. courses related to employment, adult education, National Vocational Qualifications (NVQ) etc). Please do not include sports or arts courses or lessons

29 I do homework or studying outside lessons or lectures

30 I take part in activities linked to a position of responsibility in school or college (e.g. prefect, sports team captain, member of school council)

31 I go to a school or college club or team outside lesson time (e.g. exam revision club, chess club, music group or choir, sports team etc)

32 I go on school trips (including field trips as part of an education course and holidays with the school)

33 I take part in informal activities of my choice in break and lunchtimes (such as chatting and relaxing with friends, using computers, playing sport informally etc)

34 I eat meals during school-time with my friends

35 I teach or coach others at school

Work and finances

This domain contains items relating to work and employment and to managing money

36 I have a full-time job

37 I have a formal part-time job (e.g. in shop, restaurant or other business where you receive wages)

38 I have an informal part-time job for which I am paid (e.g. babysitting, paper-round). Please do not include housework done to help parents for which you are given pocket money

39 I take part in work related activities such as taking meals with work colleagues, taking part in work related events and socialising with work colleagues

40 I decide when and how to spend my pocket money or wages

41 I manage my own savings account (this might be at a bank, building society or post office)

Community and political life

This domain includes items relating to community life, religion, human rights and political life

42 I take part in a community club or group for people of all ages (e.g. working men's or social club, community sports team, church or other religious group etc)

43 I take part in a community club or group for young people (e.g. youth club, Scouts or Guides etc)

44 I go to community events (e.g. fairs, carnivals etc)
45 I take part in voluntary or charity work (e.g. sponsored fundraising events, helping out in community groups, charity shops etc)
46 I celebrate birthdays and other special occasions with my family
47 I celebrate birthdays and other special occasions with my friends
48 I have private time by myself either at home or outside
49 I make choices about whom I spend my spare time with
50 I make choices about how I spend my spare time
51 I vote in elections. (Include local or national elections, or in elections for members of school council or other local democratic bodies)
52 I take part in a political party or campaigning organisation (e.g. Friends of the Earth, Amnesty International, local campaigning organisation)
53 I take part in local or national campaigns (e.g. signing a petition, going on a march or rally) Please do not include activity where this is part of being a member of a group or organisation

Recreation and leisure

This domain contains items relating to informal leisure and socialising, arts and culture, holidays, travel, sport, electronic leisure, time alone and outdoor pursuits. Respondents will be told that items relate to out-of-school activities

54 I play, fool around, relax or chill out with other people
55 I play board or card games
56 I go to parties
57 I go shopping for pleasure
58 I go to other peoples’ houses to hang out or socialise
59 I go to cafes, pubs, or bars with friends
60 I go to discos or night clubs
61 I eat meals with friends at their homes
62 I eat meals out in a cafe or restaurant
63 I visit museums or galleries
64 I draw, paint or do other art or craft activities
65 I play a musical instrument, sing or do drama
66 I read books, newspapers or magazines for interest or pleasure
67 I listen to music
68 I go to the cinema
69 I go to shows or concerts
70 I take part in other hobbies or interests (e.g. stamp collecting, trains etc)

71 I watch TV

72 I watch videos or DVDs

73 I go on holidays or day-trips with family or friends

74 I watch live sport or follow sport on TV

75 I take part in informal sporting or fitness at a recreation centre or other indoor venue (e.g. swimming during public swimming sessions, going to gym, etc). Please do not include sport or fitness as part of an organised team or lesson

76 I take part in sport outside (e.g. playing ball games in park, skateboarding, etc). Please do not include sport or fitness as part of an organised team or lesson

77 I take part in organised sport (e.g. organised team sports, sporting competitions, sports lessons or coaching sessions, etc)

78 I play computer or video games

79 I use the computer for leisure activities such as surfing the internet or downloading music. Please do not include on-line communication such as email or MySpace

80 I spend time on my own relaxing or winding down

81 I do outdoor pursuits (e.g. fishing, hiking, camping, etc)

Preparing for the future

I travel in a car or use public transport (e.g. bus, train, tram, underground or Metro) for pleasure

82 I go for a walk, cycle or move myself in a wheelchair as an activity for pleasure

83 I sleep at friend’s houses (e.g. at a “sleepover”)

84 I take part in discussions about when I might leave home

85 I do work experience in school

86 I do work experience outside school

87 I take part in discussions about careers

Please now consider the instrument as a whole.

To remind you, the instrument contains items in the following domains:

Home life, Getting on with other people, Education and school or college life, Work and financial life, Community and political life, Recreation and leisure, Preparing for the future

In your view, is the instrument comprehensive?

Yes ☐ **No** ☐

If no, what items do you feel should be added?

Do you think there are redundant items?

Yes ☐ **No** ☐

If yes, which items are they?

Do you have any other comments about the instrument as a whole?

Thank you very much for your time and effort. Your help with this project is very much appreciated

APPENDIX E – Details of content review experts

Name of Expert	**Professional Background**	**Area of Expertise**
Christine Jessen	Medical	Paediatric neurodisability, Participation
Chris Morris	Orthotics	Paediatric neurodisability, Participation
Rob Forsyth	Medical	Paediatric neurodisability, Participation
Steve Jarvis	Medical	Paediatric neurodisability, Participation
Kathryn Parkinson	Psychology	Paediatric neurodisability, Participation
Janet McDonagh	Medical	Adolescence, disability
Elaine McColl	Social science	Questionnaire design
Val Harpin	Medical	Paediatric neurodisability
Andy Jordan	Teaching	Post-16 Education
Lindsey Pennington	Speech and language therapy	Paediatric neurodisability, Participation
Anne Chamberlain	Medical	Young adult neurodisability
Gill Turner	Medical	Adolescence, disability
Anika Baddeley	Academic	Disability (Has CP)
Alison Pearce	Medical	Adolescence, disability
Jackie Parkes	Nursing	Paediatric neurodisability, Participation
Helen McConachie	Child Psychology	Paediatric neurodisability, Participation
Tom Herron	Teaching	Special Education

APPENDIX F – Draft QYPP Questions

1. Home life

This section asks questions about your life at home. Please tick the box which best matches your life.

1.1 I decide how I organise my daily routine (e.g. when to get washed, dressed, hair brushed) In general I do this:

All or almost all of the time; Most of the time; Some of the time; Very rarely; Never

1.2 I get myself food and drink that doesn't need cooking (e.g. snacks, cold drinks, breakfast cereals) In general I do this:

Every day; Most days but not every day; About once a week; About 2–3 times each month; About once a month or less; Never

1.3 I prepare and cook meals using the top of the cooker (cooker hob) In general I do this: Response options as 1.2

1.4 I make food and drink that I heat up (e.g. hot drinks or food heated in a toaster, microwave or oven) ***Please do not include food you cook on the cooker hob***

In general I do this: Response options as 1.2

1.5 I eat meals with members of my family at my home. In general I do this: Response options as 1.2

1.6 I eat meals with my friends at my home. In general I do this: Response options as 1.2

1.7 I attend birthday celebrations for members of my family (e.g. having a party, special meal, trip out) In general I do this: Response options as 1.2

1.8 I tidy my own room. In general I do this: Response options as 1.2

1.9 I wash my own clothes. In general I do this: Response options as 1.2

1.10 I do chores in the home (e.g. vacuuming, washing up, dusting) *Please do not include washing clothes or tidying your own room.* In general I do this:

Response options as 1.2

1.11 I do chores outside at home (e.g. gardening, cleaning car). In general I do this: Response options as 1.2

1.12 I shop for essential or day-to-day items (e.g. groceries for myself or the household, toiletries) *Please do not include shopping for pleasure or for buying "luxury" items such as non-essential clothes, games, DVDs etc.* In general I do this: Response options as 1.2

1.13 I help friends or family when they are upset (e.g. by listening to them and supporting them). In general I do this: Response options as 1.2

2. Getting on with other people

This section is about your relationships with other people

2.1 I talk about things that matter to me with friends. Please also include communicating in other ways e.g. sign language, using a communication aid. In general I do this:

Twice every day or more; About once every day; Most days but not every day; About once a week; About 2–3 times each month; About once each month or less; Never

2.2 I talk about things that matter to me with members of my family (e.g. with parents, brothers or sisters, grandparents, aunts, uncles). In general I do this:

Response options as 2.1

2.3 I use the phone to communicate (e.g. making calls, receiving calls, texting) *Please do not include using a mobile phone for taking pictures or for email.* In general I do this: Response options as 2.1

2.4 I use on-line communication (e.g. email, MSN messaging, Facebook). In general I do this: Response options as 2.1

2.5 I talk with neighbours and other people who live near me. In general I do this: Response options as 1.2

2.6 I talk to people I don't know when I need to (e.g. asking for directions in the street, talking to shop assistants) In general I do this: Response options as 1.2

2.7 I do activities in my spare time with my parent(s) or guardian(s) ***Please include things you may do together at home and when you go out.*** **In general I do this:**

Every day; Most days but not every day; About once a week; About 2–3 times each month; About once a month; About once every 2–3 months or less; Never

2.8 I do activities in my spare time with members of my extended family (e.g. grandparents, aunts, uncles or cousins) ***Please include things you may do together at home and when you go out*** **In general I do this:** Response options as 2.7

2.9 I spend spare time with my friends Please do not include time spent with friends in school, college or work. In general I do this: Response options as 2.7

2.10 I spend time with my friends on my own without my parents, carers or other adults present. In general I do this: Response options as 2.7

2.11 I attend birthday celebrations for my friends (e.g. having a party, special meal, trip out). In general I do this:

About once a week or more; About 2–3 times each month; About once a month; About once every 2–3 months; About once every 6 months or less; Never

2.12 I spend spare time with a boyfriend/girlfriend (someone with whom you are having a romantic relationship)

In general I do this: Response options as 1.2

2.13 I spend time on my own with a boyfriend/girlfriend, without other people present. In general I do this: Response options as 1.2

3. Education and School or College life

This section is about your education. Please answer these questions if you are at school, college, or at university.

If you have left school, college or other educational programme now, please tick this box. ☐ **Now go to the next section on page 11.**

If you are on school/college holidays at the moment, please tell us what you did last term.

3.1 I go to lessons or lectures (or other organised learning sessions such as tutorials or seminars). In general I do this:

Morning and afternoon on every weekday; Part of the day on every weekday; Most days but not every weekday; About once or twice a week; About 2–3 times each month; About once a month or less; Never

3.2 I take tests or exams. In general I do this:

Every day on weekdays; Most days but not every day; About once or twice a week; About 2–3 times each month; About once a month; About once a term or less; Never

3.3 The subjects I take are chosen by me. In general this applies to:

All my lessons; Most of my lessons; About half my lessons; A few of my lessons; None of my lessons

3.4 There are subjects I would like to take but cannot. In general this applies to:

No subjects; One subject; Two or three subjects; Four or more subjects

3.5 I do school/college work outside lessons or lectures (e.g. homework, independent study). In general I do this:

Every day; Most days but not every day; About once a week; About 2–3 times each month; About once a month or less; Never

3.6 I do things in school/college because I have a position of responsibility (e.g. prefect, sports team captain, member of school council, anti-bullying buddy). In general I do this: Response options as 3.5

3.7 I go to a club or play in a team outside lesson time (e.g. chess club, music group or choir, sports team, revision club)

In general I do this: Response options as 3.5

3.8 I take part in informal activities in break and lunchtimes (e.g. chatting and relaxing with friends, using computers, playing sport informally). In general I do this: Response options as 3.5

3.9 I teach or coach others at school/college. In general I do this: Response options as 3.5

3.10 I eat meals with my friends during the school/college day. In general I do this: Response options as 3.5

3.11 I go on trips (including day trips or longer trips as part of an education course and holidays with school/college)

In general I do this: About once a week or more; About 2–3 times each month; About once a month; About once a term; About once a year; Never

4. Work and finance

The next questions are about managing money and about jobs you may have.

4.1 I decide how to spend my money. In general I do this: Response options as 1.1

4.2 I manage my own savings account (e.g. at a bank, building society or post office). In general I do this:

Whenever I need to; Most of the times that I need to; Some of the times that I need to; Very rarely; Never; Not applicable – I don’t have a savings account

4.3 I have an *informal* part-time job for which I am paid (e.g. babysitting, paper-round, selling things you make) *Please do not include housework done to help your family for which you are given money.* In general I do this:

Every day; Most days but not every day; About once a week; About 2–3 times each month; About once a month or less; I don’t have an informal job

4.4 I have a *formal* job (e.g. in shop, restaurant or other business where you receive wages, formal self-employment) On average I do this:

Between 20 and 40 hours per week; Between 15 and 20 hours per week; Between 10 and 15 hours per week; Less than 10 hours per week; I don’t have a formal job

4.5 I spend breaks at work with colleagues (e.g. having a drink or meal break). In general I do this:

Every time I am at work; Most of the time; Some of the time; Very rarely; Never; Not applicable – I don't have a formal job

4.6 I chat informally with people I work with (e.g. whilst working, during breaks). In general I do this: Response options as 4.5

4.7 I attend social events organised through work (e.g. work parties, day trips). In general I do this: Response options as 4.5

4.8 I have applied for a job Once; Twice; Three or more times; Never

5. Community and political life

5.1 I take part in a community club or group *for young people* (e.g. youth club, Scouts or Guides). In general I do this: Response options as 2.7

5.2 I take part in a community club or group *for people of all ages* (e.g. drama group, community sports team, church or other religious group). In general I do this: Response options as 2.7

5.3 I take part in voluntary or charity work (e.g. sponsored fundraising events, helping out in community groups, working in charity shops). In general I do this: Response options as 2.7

5.4 I take part in the activities of a political party (e.g. active member of Conservative Future, Young Labour, Young Liberal Democrats, Young Greens). In general I do this: Response options as 2.7

5.5 I take part in a campaigning organisation (e.g. environmental organisation, human rights or animal rights organisation, local issue campaign group). In general I do this: Response options as 2.7

5.6 I vote in elections. (e.g. local or national elections, elections for members of school council or other local democratic bodies). In general I do this:

About once a week or more; About 2–3 times each month; About once a month; About 2 or 3 times a year; About once a year; Never

6. Recreation and leisure

The next questions are about what you do in your spare time – when you are not in school, college or university or at work.

6.1 I have private time by myself (e.g. at home, outside). In general I do this: Response options as 2.7

6.2 I choose *whom* I spend my spare time with. In general I do this:

All or almost all of the time; Most of the time; Some of the time; Very rarely; Never

6.3 I choose *how* I spend my spare time. In general I do this: Response options as 6.2

6.4 I spend time relaxing or chilling out In general I do this: Response options as 2.7

6.5 I read books for pleasure. In general I do this: Response options as 2.7

6.6 I read newspapers or magazines. In general I do this: Response options as 2.7

6.7 I listen to music. In general I do this: Response options as 2.7

6.8 I watch TV. In general I do this: Response options as 2.7

6.9 I watch videos or DVDs. In general I do this: Response options as 2.7

6.10 I play electronic games (e.g. computer games, video games). In general I do this: Response options as 2.7

6.11 I go shopping for pleasure. In general I do this: Response options as 2.7

6.12 I go to parties with my friends. In general I do this: Response options as 2.7

6.13 I go to my friends' houses to hang out or socialize. In general I do this: Response options as 2.7

6.14 I go to places in the evenings to have drinks with my friends (e.g. cafes, pubs or bars). In general I do this: Response options as 2.7

6.15 I go to discos or nightclubs. In general I do this: Response options as 2.7

6.16 I eat meals with my friends at their homes. In general I do this: Response options as 2.7

6.17 I eat meals out in cafes or restaurants. In general I do this: Response options as 2.7

6.18 I go to the cinema. In general I do this: Response options as 2.7

6.19 I go to live music events (e.g. concerts, gigs, festivals). In general I do this: Response options as 2.7

6.20 I go to the theatre (e.g. plays, shows, pantomime). In general I do this: Response options as 2.7

6.21 I go to live sporting events. In general I do this: Response options as 2.7

Please remember all these questions are about your leisure time – don't include what you do as part of school or college

6.22 I visit museums or galleries. In general I do this: Response options as 2.7

6.23 I do art or craft activities (e.g. drawing, painting, needlework, woodwork). In general I do this: Response options as 2.7

6.24 I do music or performing arts (e.g. playing a musical instrument, singing, dancing, drama). In general I do this: Response options as 2.7

6.25 I take part in other hobbies or interests (e.g. collecting things, trains, natural history). In general I do this: Response options as 2.7

6.26 I play board or card games (e.g. Monopoly, Trivial Pursuit, rummy). In general I do this: Response options as 2.7

6.27 I take part in organised sport (e.g. organised team sports, sporting competitions, sport or fitness lessons). In general I do this: Response options as 2.7

6.28 I take part in informal sport or fitness at an indoor venue (e.g. swimming, going to gym) ***Please do not include sport or fitness as part of an organised team or lesson.*** **In general I do this:** Response options as 2.7

6.29 I take part in informal sport outside (e.g. playing ball games in park, skateboarding, cycling) ***Please do not include sport or fitness as part of an organised team or lesson.*** **In general I do this:** Response options as 2.7

6.30 I go for a walk, or move myself in a wheelchair, as an activity in itself. In general I do this: Response options as 2.7

6.31 I go on holiday with my family. In general I do this:

About once a month or more; About once every 2–3 months; About twice a year; About once a year; Never

6.32 I go on holiday with my friends. In general I do this: Response options as 6.31

Please remember all these questions are about your leisure time – don't include what you do as part of school or college

6.33 I go on day trips to tourist attractions (e.g. theme parks, historic buildings). In general I do this:

About once a week or more; About 2–3 times each month; About once a month; About once every 2–3 months; About once a year; Never

6.34 I use public transport (e.g. bus, train, tram, underground or Metro) ***This may be alone or with other people*** **In general I do this:** Response options as 2.7

6.35 I travel in a car (include being driven and driving yourself). In general I do this: Response options as 2.7

7. Preparing for the future

7.1 I sleep overnight at friends' houses (e.g. at a "sleepover", crashing at a friend's). In general I do this:

Most days but not every day; About once a week; About 2–3 times each month; About once a month; About once every 2–3 months or less; Never

7.2 I have discussions about when I might leave home to live independently. In general I do this: Response options as 7.1

7.3 I have discussions about my possible future job or career In general I do this: Response options as 2.7

7.4 I have done work experience in a business or other workplace. (This may have been organised by your school or by you or your family). I have done this:

Once; Twice; Three or more times; Never

7.5 I have done work experience *within* my school or college (e.g. working in the school office, with the caretaker). I have done this: Response options as 7.4

7.6 I have written my c.v. or record of achievement Yes; No

Extra Information

Is there anything else you do, that has not been covered in this questionnaire?

Yes; No **If yes, please write the activity here:**

In general you do this: Response options as 2.7

You have now finished the questionnaire!

Please check you have answered all the questions.

Thank you very much!

APPENDIX G – Data from NECCPS dataset

Impairment	Level	Frequency	Comparing with QYPP data
Walking	Able to walk with or without aids Not able to walk	493 199	p=0.31[1]
Hand function	Put on T-shirt with no or minor assistance Unable to put on T shirt	515 197	p=0.19[1]
Learning	IQ 80+ IQ 50–80 IQ<50	346 179 181	p=0.0008[2]
Vision	Not blind Blind or no useful vision	654 43	p=0.8307[1]
Hearing	No profound or severe hearing Profound or severe loss	673 28	p=0.0117[1]
Seizures	Never had seizures (excluding neonatal seizures) Has had seizures(excluding neonatal seizures)	470 237	p=0.0496[1]
Feeding difficulties	No problem Fed orally Not fed orally	528 136 45	p=0.608[2]
Communication	No problem Speech with difficulties Formal alternative communication No formal communication	317 191 83 117	p=0.206[2]

1 – Fishers exact test, 2 – Chi-squared test

Table G1 Data on levels of impairment from the NECCPS dataset for young people aged 13–17years

APPENDIX H – QYPP and Proxy QYPP Question Changes: First and second revisions

Section 1:

No changes

Section 2:

2.1 Revision 1 – Extra information added: *Please also include communicating in other ways e.g. sign language, using a communication aid*

2.7 Revision 2 – Question wording changed from 'I do leisure activities with my parent(s) or guardian(s)' to 'I do activities in my spare time with my parent(s) or guardian(s) *Please include things you do together at home and when you go out'*

2.8 Revision 2 – Question wording changed from 'I do leisure activities with members of my extended family (e.g. grandparents, aunts, uncles or cousins)' to 'I do activities in my spare time with members of my extended family (e.g. grandparents, aunts, uncles or cousins) *Please include things you do together at home and when you go out*'

2.9 Revision 2 – Question wording changed from 'I spend leisure time with my friends *Please do not include time spent with friends in school, college or work*' to 'I spend spare time with my friends *Please do not include time spent with friends in school, college or work*'

Section 3:

3.1 Revision 1 – Response option '4' changed from 'about once a week' to 'about once or twice a week'

3.2 Revision 1 – Response option '3' changed from 'about once a week' to 'about once or twice a week'

3.5 Revision 1 – Response option '3' changed from 'about once a week' to 'about once or twice a week'

3.6 Revision 1 – Response option '3' changed from 'about once a week' to 'about once or twice a week'
3.7 Revision 1 – Response option '3' changed from 'about once a week' to 'about once or twice a week'
3.8 Revision 1 – Response option '3' changed from 'about once a week' to 'about once or twice a week'
3.9 Revision 1 – Response option '3' changed from 'about once a week' to 'about once or twice a week'
3.10 Revision 1 – Response option '3' changed from 'about once a week' to 'about once or twice a week'

Section 4:

4.4 Revision 1 – Response options changed (to be inclusive of evening and weekend work).Response options now read: 'Between 20 and 40 hours per week', 'Between 15 and 20 hours per week', 'between 10 and 15 hours per week', 'less than 10 hours per week', 'They don't have a formal job'

Section 5:

5.6 Revision 1 – Response option '4' changed from 'about once a term' to 'about 2 or 3 times a year'

Section 6:

6.34 Revision 1 – 'when they want to' deleted. Extra information added: *This may be alone or with other people*
6.35 Revision 1 – 'when they want to' deleted

Section 7:

7.4 Revision 1 – Extra information added after question: (This may have been organised by their/your school or by them/you or their/your family)

7.5 Revision 1 – Extra information added after question: (e.g. working in the school office, or with the caretaker)

New section

New section '**Extra information**' added.

Is there anything else they/you do, that has not been covered in this questionnaire? If yes, please write the activity here:

Impairment Questionnaire Question Changes

Fits:

Questions altered:
'If yes, how old were they when they last had a fit?' changed to 'If yes, is the young person still having fits?' followed by a yes/no response option, and an extra question following these: 'If not, about how old were they when they last had a fit?'

'How old were they when they last took medicine to stop fits?' changed to 'If yes, are they still taking medicine to stop fits?' followed by a yes/no response option, and an extra question following these: 'If not, how old were they when they last took medicine to stop fits?'.

Feeding Difficulties:

Extra response option added: 'They feed by mixed methods (e.g. by mouth and by gastronomy/nasogastric tube)

APPENDIX I – Item level data

Below are the data for each item which have not been included in the main text. Table I1 contains the results for the test-retest reliability and internal consistency with Cronbach's alpha. Table I2 shows the results of Mann-Whitney U tests comparing the cerebral palsy and general population results for each item as well as differences seen within the cerebral palsy population comparing levels of impairment.

Item	**Test-retest reliability**	**Decreases internal consistency**
1.1 daily routine	0.931	No
1.2 snacks	0.963	No
1.3 cooker hob	0.865	No
1.4 food/drink heated up	0.947	No
1.5 meals with family	0.816	Yes
1.6 meals with friends	0.844	Yes
1.7 family birthdays	0.617	Yes
1.8 tidy own room	0.905	No
1.9 wash clothes	0.762	Yes
1.10 chores in home	0.894	No
1.11 chores outside	0.852	No
1.12 shop essentials	0.885	No
1.13 help friends	0.906	No
2.1 talk with friends	0.718	No
2.2 talk with family	0.804	Yes
2.3 phone	0.956	No
2.4 on-line communication	0.960	No
2.5 talk to neighbours	0.854	No
2.6 talk to strangers	0.836	No
2.7 activities with parent	0.611	No
2.8 activities with family	0.725	No

2.9 time friends	0.858	No
2.10 on my own with friends	0.919	No
2.11 friends' birthdays	0.818	No
2.12 boy/girlfriend	0.871	No
2.13 on own boy/girlfriend	0.839	No
3.1 lessons	0.638	No
3.2 tests/exams	0.894	No
3.3 subjects chosen	0.757	No
3.4 subjects would like to take	0.762	No
3.5 homework	0.896	No
3.6 position of responsibility	0.692	No
3.7 club/team	0.736	Yes
3.8 breaks	0.616	No
3.9 teach others	0.628	No
3.10 mealtimes	0.874	No
3.11 school trips	0.713	Yes
4.1 spend money	0.953	No
4.2 saving money	0.947	No
4.3 informal job	0.524	No
4.4 formal job	0.945	No
4.5 work breaks	0.892	No
4.6 chat at work	0.916	No
4.7 work socials	0.699	No
4.8 applied job	0.953	Yes
5.1 community club young	0.775	No
5.2 community club all ages	0.862	No
5.3 voluntary work	0.903	No
5.4 political	Zero variance in repeat QYPP	No
5.5 campaign organisation	0.834	No
5.6 vote	0.691	No
6.1 private time	0.779	No
6.2 with whom spend time	0.848	No

6.3 how spend spare time	0.908	No
6.4 chilling out	0.325	No
6.5 read books	0.863	No
6.6 newspapers	0.862	No
6.7 listen to music	0.765	No
6.8 TV	0.863	No
6.9 videos/DVDs	0.883	No
6.10 electronic games	0.941	No
6.11 leisure shopping	0.776	No
6.12 parties	0.872	No
6.13 friends houses	0.927	No
6.14 drinks	0.884	No
6.15 discos	0.773	No
6.16 meals at friends' homes	0.932	No
6.17 eat out	0.711	No
6.18 cinema	0.846	No
6.19 live music	0.913	No
6.20 theatre	0.748	No
6.21 live sport	0.029	No
6.22 museums	0.730	No
6.23 art or crafts	0.572	No
6.24 performing arts	0.806	Yes
6.25 hobbies	0.747	No
6.26 board games	0.792	No
6.27 organised sport	0.864	No
6.28 indoor informal sport	0.733	No
6.29 outdoor informal sport	0.781	No
6.30 walk	0.654	No
6.31 holiday family	0.910	No
6.32 holiday friends	0.880	No
6.33 day trips	0.811	No
6.34 public transport	0.887	No
6.35 travel in a car	0.920	No

7.1 sleepovers	0.824	No
7.2 leave home	0.822	No
7.3 future job	0.832	No
7.4 work experience in business	0.955	No
7.5 work experience in school	0.785	No
7.6 cv	0.860	No

Table I1 Reliability analysis for each item

Item	Difference between CP and GP	Responses differing by GMFCS	Responses differing by MACS	Responses differing by learning	Variables remaining significant with regression
1.1 daily routine	p<0.001	p<0.001	p<0.001	p<0.001	GMFCS, MACS, Comm, Learning
1.2 snacks	p<0.001	p<0.001	p<0.001	p<0.001	GMFCS, MACS, Learning
1.3 cooker hob	p<0.001	p<0.001	p<0.001	p<0.001	Learning
1.4 food/drink heated up	p<0.001	p<0.001	p<0.001	p<0.001	GMFCS, MACS, Learning
1.5 meals with family	p<0.001	NS	NS	NS	–
1.6 meals with friends	p<0.001	NS	NS	p=0.002	Learning, Fits
1.7 family birthdays	p=0.022	p=0.072	NS	p=0.002	–
1.8 tidy own room	p<0.001	p<0.001	p<0.001	p<0.001	Learning, GMFCS
1.9 wash clothes	p<0.001	p=0.021	NS	p=0.058	Age
1.10 chores in home	p<0.001	p<0.001	p<0.001	p<0.001	GMFCS, MACS
1.11 chores outside	p=0.030	p<0.001	p<0.001	p<0.001	–
1.12 shop essentials	p<0.001	p<0.001	p<0.001	p<0.001	–
1.13 help friends	p<0.001	p<0.001	p<0.001	p<0.001	Learning
2.1 talk with friends	NS	p=0.010	p=0.001	p=0.004	Vision, Fits, MACS
2.2 talk with family	p<0.001	NS	p=0.006	NS	MACS, Gender
2.3 phone	p<0.001	p<0.001	p<0.001	p<0.001	Learning, MACS

2.4 on-line communication	p<0.001	p=0.003	p<0.001	p<0.001	learning, Gender
2.5 talk to neighbours	p=0.019	NS	p=0.002	p=0.005	Vision
2.6 talk to strangers	p<0.001	P=0.006	p=0.001	p<0.001	Learning
2.7 activities with parent	p<0.001	NS	NS	NS	–
2.8 activities with family	NS	NS	p=0.003	NS	–
2.9 time friends	p<0.001	p<0.001	p<0.001	p<0.001	Learning
2.10 on my own with friends	p<0.001	p<0.001	p<0.001	p<0.001	Learning, Hearing
2.11 friends' birthdays	p<0.001	p=0.091	p=0.019	p<0.001	Learning, Hearing
2.12 boy/girlfriend	p<0.001	p=0.053	p=0.022	p=0.033	–
2.13 on own boy/girlfriend	p<0.001	P=0.009	p=0.036	p=0.011	–
3.1 lessons	p<0.001	NS	NS	NS	Feeding, Learning
3.2 tests/exams	p<0.001	p<0.001	p<0.001	p<0.001	Learning
3.3 subjects chosen	p<0.001	P=0.015	p=0.002	p<0.001	Learning, Age
3.4 subjects would like to take	p<0.001	NS	NS	p=0.026	Learning, Feeding, Fits
3.5 homework	p<0.001	P=0.001	p<0.001	p<0.001	Learning
3.6 position of responsibility	p<0.001	NS	p=0.037	p=0.014	–
3.7 club/team	NS	NS	NS	NS	–
3.8 breaks	NS	P=0.053	p<0.001	p=0.001	MACS, Feeding
3.9 teach others	NS	P=0.028	NS	p<0.001	Learning
3.10 mealtimes	NS	NS	NS	NS	Feeding, Learning, Gender
3.11 school trips	p<0.001		NS		–
4.1 spend money	p<0.001	P=0.001	p<0.001,	p<0.001	Learning, Vision, MACS, Age
4.2 saving money	p=0.018	P=0.013	p=0.001,	p<0.001	Learning, Age
4.3 informal job	p<0.001	NS	NS	NS	–
4.4 formal job	p<0.001	NS	NS	p=0.001	Learning, Age
4.5 work breaks	p<0.001	NS	NS	NS	Learning, Age

4.6 chat at work	p<0.001	NS	NS	NS	Learning, Age
4.7 work socials	p<0.001	NS	NS	NS	Age
4.8 applied job	p<0.001	P=0.004	p=0.036,	p=0.011	GMFCS, Age
5.1 community club young	NS	NS	NS	NS	–
5.2 community club all ages	NS	NS	NS	NS	–
5.3 voluntary work	p=0.021	P=0.004	NS	p=0.015	Age
5.4 political	p=0.002	NS	NS	NS	–
5.5 campaign organisation	p=0.005	NS	NS	NS	–
5.6 vote	NS	NS	NS	NS	–
6.1 private time	NS	NS	p=0.009,	NS	Vision, MACS, Feeding
6.2 with whom spend time	p<0.001	NS	p<0.001	p<0.001	MACS
6.3 how spend spare time	p<0.001	p<0.001	p<0.001	p<0.001	Comm, Learning, Vision, MACS
6.4 chilling out	p=0.024	NS	NS	NS	–
6.5 read books	p=0.073	NS	p=0.001	p=0.003	Hearing, MACS
6.6 newspapers	p<0.001	p<0.001	p<0.001	p<0.001	Learning, GMFCS
6.7 listen to music	p<0.001	p=0.044	NS	NS	Comm
6.8 TV	NS	p=0.001	p=0.001	p<0.001	Vision
6.9 videos/DVDs	NS	NS	NS	NS	Vision
6.10 electronic games	NS	p<0.001	p<0.001	p<0.001	MACS, GMFCS, Vision, Age, Hearing
6.11 leisure shopping	p<0.001	NS	NS	NS	–
6.12 parties	p<0.001	NS	NS	p<0.001	Learning, Hearing, Age, Fits
6.13 friends houses	p<0.001	p<0.001	p=0.005	p<0.001	Learning, Hearing, Fits, GMFCS, Age
6.14 drinks	p<0.001	NS	NS	p=0.025	Age
6.15 discos	p<0.001	NS for both	NS	NS	Age
6.16 meals at friends' homes	p<0.001	NS	NS	p<0.001	Learning, Fits, Comm

6.17 eat out	p=0.001	NS	NS	NS	–
6.18 cinema	p<0.001	p=0.003	p=0.007	p<0.001	Learning
6.19 live music	p<0.001	NS	NS	NS	Comm
6.20 theatre	NS	NS	NS	NS	Gender
6.21 live sport	p<0.001	NS	NS	p=0.045	Fits, Comm
6.22 museums	NS	NS	p=0.009	NS	MACS
6.23 art or crafts	NS	NS	NS	NS	Gender
6.24 performing arts	p<0.001	NS	NS	NS	Age
6.25 hobbies	p=0.021	p=0.05	NS	p=0.004	Comm
6.26 board games	NS	NS	p=0.012	p=0.001	Learning
6.27 organised sport	p<0.001	NS	NS	p=0.007	–
6.28 indoor informal sport	p=0.007	p=0.036	NS	NS	–
6.29 outdoor informal sport	p<0.001	p<0.001	NS	p=0.022	GMFCS
6.30 walk	p=0.046	NS	p=0.030	NS	–
6.31 holiday family	p=0.019	NS	NS	NS	Hearing, Age
6.32 holiday friends	p<0.001	NS	NS	NS	Age
6.33 day trips	NS	NS	NS	NS	–
6.34 public transport	p<0.001	p=0.009	NS	p=0.001	Learning
6.35 travel in a car	p=0.051	NS	NS	NS	–
7.1 sleepovers	p<0.001	p<0.001	p=0.001	p<0.001	Hearing, Fits, Comm, Learning
7.2 leave home	p<0.001	NS	p=0.005	p=0.008	–
7.3 future job	p<0.001	p<0.001	p<0.001	p<0.001	Learning
7.4 work experience in business	P=0.005	NS	p=0.017	p=0.013	Comm, Age
7.5 work experience in school	NS	NS	NS	NS	–
7.6 cv	p<0.001	p=0.007	p<0.001	p<0.001	Hearing, fits, MACS, Age GMFCS, learning

Comm = communication impairment
Feed = feeding difficulties
Fits = ever had fits
NS = not significant

Table I2 Differences between CP and GP samples and within CP sample for each item

APPENDIX J – The final version of the Questionnaire of Young People's Participation (QYPP Version 2.0)

Questionnaire of Young People's Participation

Version 2.0 (February 2011)

Catherine Tuffrey
Belinda Bateman
Allan Colver

Questionnaire of Young People's Participation

Please read this section before you start

What is this questionnaire about? This questionnaire aims to measure what young people do in their everyday lives. It contains a number of different sections, which ask questions about different areas of life. Please try to answer all the questions if you can. There are no right or wrong answers! Everyone's lives and interests are different.

Remember, we will not tell other people what answers you have given.

How do I answer the questionnaire? Each question starts with a statement. This is followed by a choice of answers about how often someone might do this. For each question, you should tick the box next to the answer that best matches your life at the moment. The exact frequency with which you do something may not be listed, so choose the answer nearest to how often you do it.

Please only tick one box for each question, and answer every question if you can. If you don't do a particular activity, tick the "never" box for that question.

On the next page we give an example of how you fill in the questions.

The questionnaire will take around 25 minutes to complete.

Here is an example question:

Statement: **I play golf**

Answers:

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐	☐	☐	☐	☐	☐

If you play golf about once every 2 months, you would tick the box next to “about once a month or less” and your questionnaire would then look like this:

1. I play golf

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐	☐	☐	☐	☑	☐

Thank you very much for taking the time to fill in this questionnaire.

A. HOME LIFE

This section asks questions about your life at home. Please tick the box which best matches your life.

A1. I get myself food and drink that doesn't need cooking (e.g. snacks, cold drinks, breakfast cereals)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

A2. I prepare and cook meals using the top of the cooker (cooker hob)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

A3. I make food and drink that I heat up (e.g. hot drinks or food heated in a toaster, microwave or oven) ***Please do not include food you cook on the cooker hob***

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

A4. I do chores at home (e.g. vacuuming, washing up, dusting, gardening) ***Please do not include tidying your own room***

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

A5. I shop for essential or day-to-day items (e.g. groceries for myself or the household, toiletries)

Please do not include shopping for pleasure or for buying "luxury" items such as non-essential clothes, games, DVDs etc

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

B. GETTING ON WITH OTHER PEOPLE

This section is about your relationships with other people

B1. I help friends or family when they are upset (e.g. by listening to them and supporting them)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐ 6	☐ 4.8	☐ 3.6	☐ 2.4	☐ 1.2	☐ 0

B2. I use on-line communication (e.g. email, MSN messaging, Facebook)

In general I do this:

Twice every day or more	About once every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

B3. I talk to people I don't know when I need to (e.g. asking for directions in the street, talking to shop assistants)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

B4. I spend time with my friends on my own without my parents, carers or other adults present

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

B5. I attend birthday celebrations for my friends (e.g. having a party, special meal, trip out)

In general I do this:

About once a week or more	About 2–3 times each month	About once a month	About once every 2–3 months	About once every 6 months or less	Never
☐ 6	☐ 4.8	☐ 3.6	☐ 2.4	☐ 1.2	☐ 0

B6. I spend time on my own with a boyfriend/girlfriend, without other people present

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐ 6	☐ 4.8	☐ 3.6	☐ 2.4	☐ 1.2	☐ 0

B7. I go to my friends' houses to hang out or socialise

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

B8. I sleep overnight at friends' houses (e.g. at a "sleepover", crashing at a friend's)

In general I do this:

Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 4.8	☐ 3.6	☐ 2.4	☐ 1.2	☐ 0

C. SCHOOL OR COLLEGE LIFE

This section is about your education. Please answer these questions if you are at school, college, or at university.

If you have left school, college or other educational programme now, please tick this box. ☐
Now go to Section D.

If you are on school/college holidays at the moment, please tell us what you did last term.

C1. I go to lessons or lectures (or other organised learning sessions such as tutorials or seminars)

In general I do this:

Morning and afternoon on every weekday	Part of the day on every weekday	Most days but not every weekday	About once or twice a week	About 2–3 times each month	About once a month or less	Never
☐ 5	☐ 4.17	☐ 3.33	☐ 2.5	☐ 1.67	☐ 0.83	☐ 0

C2. I take tests or exams

In general I do this:

Every day on weekdays	Most days but not every day	About once or twice a week	About 2–3 times each month	About once a month	About once a term or less	Never
☐ 5	☐ 4.17	☐ 3.33	☐ 2.5	☐ 1.67	☐ 0.83	☐ 0

C3. The subjects I take are chosen by me

In general this applies to:

All my lessons	Most of my lessons	About half my lessons	A few of my lessons	None of my lessons
☐ 5	☐ 3.75	☐ 2.5	☐ 1.25	☐ 0

C4. I do things in school/college because I have a position of responsibility (e.g. prefect, sports team captain, member of school council, anti-bullying buddy)

In general I do this:

Every day	Most days but not every day	About once or twice a week	About 2–3 times each month	About once a month or less	Never
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

C5. I take part in informal activities in break and lunchtimes (e.g. chatting and relaxing with friends, using computers, playing sport informally)

In general I do this:

Every day	Most days but not every day	About once or twice a week	About 2–3 times each month	About once a month or less	Never
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

D. WORK LIFE

The next questions are about jobs you may have.

D1. I have an *informal* part-time job for which I am paid (e.g. babysitting, paper-round, selling things you make) *Please do not include housework done to help your family for which you are given money*

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	I don't have an informal job
☐ 4	☐ 3.2	☐ 2.4	☐ 1.6	☐ 0.8	☐ 0

D2. I have a *formal* job (e.g. in shop, restaurant or other business where you receive wages, formal self-employment)

On average I do this:

Between 20 and 40 hours per week	Between 15 and 20 hours per week	Between 10 and 15 hours per week	Less than 10 hours per week	I don't have a formal job
☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

D3. I spend breaks at work with colleagues (e.g. having a drink or meal break)

In general I do this:

Every time I am at work	Most of the time	Some of the time	Very rarely	Never	Not applicable – I don't have a formal job
☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ 0

D4. I attend social events organised through work (e.g. work parties, day trips)

In general I do this:

About once a week or more	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never	Not applicable – I don’t have a formal job
☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ 0

E. RECREATION AND LEISURE

The next questions are about what you do in your spare time – when you are not in school, college or university or at work.

E1. I have private time by myself (e.g. at home, outside)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E2. I read newspapers or magazines

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E3. I listen to music

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E4. I play electronic games (e.g. computer games, video games)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E5. I go shopping for pleasure

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E6. I go to places in the evenings to have drinks with my friends (e.g. cafes, pubs or bars)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E7. I eat meals out in cafes or restaurants

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E8. I go to the cinema

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E9. I go to live music events (e.g. concerts, gigs, festivals)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Please remember all these questions are about your leisure time – don't include what you do as part of school or college

E10. I do music or performing arts (e.g. playing a musical instrument, singing, dancing, drama)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E11. I take part in organised sport (e.g. organised team sports, sporting competitions, sport or fitness lessons)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E12. I take part in informal sport outside (e.g. playing ball games in park, skateboarding, cycling, horseriding) ***Please do not include sport or fitness as part of an organised team or lesson***

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E13. I take part in voluntary or charity work (e.g. sponsored fundraising events, helping out in community groups, working in charity shops)

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 6	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

E14. I go on holiday with my friends

In general I do this:

About once a month or more	About once every 2–3 months	About twice a year	About once a year	Never
☐ 6	☐ 4.5	☐ 3	☐ 1.5	☐ 0

F. AUTONOMY

This section is about the choices you make about your life and your independence.

F1. I decide how I organise my daily routine (e.g. when to get washed, dressed, hair brushed)

In general I do this:

All or almost all of the time	Most of the time	Some of the time	Very rarely	Never
☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

F2. I use the phone to communicate (e.g. making calls, receiving calls, texting) ***Please do not include using a mobile phone for taking pictures or for email***

In general I do this:

Twice every day or more	About once every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month or less	Never
☐ 4	☐ 3.33	☐ 2.67	☐ 2	☐ 1.33	☐ 0.67	☐ 0

F3. I decide how to spend my money

In general I do this:

All or almost all of the time	Most of the time	Some of the time	Very rarely	Never
☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

F4. I choose how I spend my spare time

In general I do this:

All or almost all of the time	Most of the time	Some of the time	Very rarely	Never
☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

G. PREPARING FOR THE FUTURE

G1. I have discussions about when I might leave home to live independently

In general I do this:

Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

G2. I have discussions about my possible future job or career

In general I do this:

Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

G3. I have done work experience in a business or other workplace. ***This may have been organised by your school or by you or your family***

I have done this:

Once	Twice	Three or more times	Never
☐ 1.67	☐ 3.33	☐ 5	☐ 0

G4. I use public transport (e.g. bus, train, tram, underground or Metro) ***This may be alone or with other people***

In general I do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less	Never
☐ 5	☐ 4.17	☐ 3.33	☐ 2.5	☐ 1.67	☐ 0.83	☐ 0

G5. I have written my c.v. or record of achievement

Yes	No
☐ 5	☐ 0

EXTRA INFORMATION

Is there anything else you do, that has not been covered in this questionnaire?

Yes	No
☐ 1	☐ 2

If yes, please write the activity here:

In general you do this:

Every day	Most days but not every day	About once a week	About 2–3 times each month	About once a month	About once every 2–3 months or less
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

You have now finished the questionnaire!

Please check you have answered all the questions.

Thank you very much!

Glossary

Activity	In the ICF, a task executed by the individual
Classical measurement theory	The original theory used for developing measurement scales. It has a strong focus on maximising instrument reliability.
Clinimetrics	Term used to refer to a form of psychometrics more relevant to clinical measures, where the latent variable is measured using defining rather than effect indicators
Construct validity	The extent to which an instrument measures what is intended
Content validity	The degree to which the items on a scale cover all facets of the construct of interest
Content validity index	Proportion of reviewers who deem an item to be relevant to the construct being measured
Defining indicator	Instrument item which contributes to the latent variable, rather than being caused by it
Effect indicators	Instrument item which is a facet of the underlying construct
Instrument	Questionnaire used to measure a latent variable

Latent variable	A construct which cannot be directly observed and so is measured by an instrument made up of a number of items
Field-testing	The use of a questionnaire instrument to test properties such validity and reliability
Frequency of endorsement	Proportion of respondents with a score at either end of the scale
Internal consistency	Degree to which items correlate with one another, making a homogeneous scale
Item	Question on an instrument
Item response theory	A theory for scale development which focuses on the behaviour of individual items
Known groups validity	One facet of construct validity. The extent to which instrument scores distinguish between different groups of people who are known to vary in relation to the construct being measured.
Optimal scaling	A statistical technique which enables the identification of optimal item responses
Participation	In the ICF, involvement in life situations
Psychometrics	Science of the construction and validation of psychological tests and other instruments used in

	the social sciences
Reliability	Degree to which a scale gives consistent results when administered at different times or by different raters
Spline	Curve on the graph used in optimal scaling
Super Output Area	Geographical area of the UK used for calculation of the Index of Multiple Deprivation, lower layer SOA being the smallest unit

List of abbreviations

ASD	Autistic Spectrum Disorder
CAPE	Children’s Assessment of Participation and Enjoyment
CP	Cerebral palsy
CVI	Content Validity Index
DIF	Differential Item Functioning
GMFCS	Gross Motor Function Classification System
HRQoL	Health-related quality of life

ICC	Intraclass correlation coefficient
ICF	International Classification of Functioning Disability and Health
ICF-CY	International Classification of Functioning Disability and Health – Children and Youth version
ICIDH	International Classification of Impairment, Disability and Handicap
IMD	Index of Multiple Deprivation
Life-H	Assessment of Life Habits
LSOA	Lower layer Super Output Area
MACS	Manual Ability Classification System
NECCPS	North of England Collaborative Cerebral Palsy Survey
PCA	Principle Components Analysis
SCPE	Surveillance of Cerebral Palsy in Europe
SEM	Standard Error of Measurement
SUDEP	Sudden Unexpected Death in Epilepsy