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Improving the Well-being of Disabled Young People

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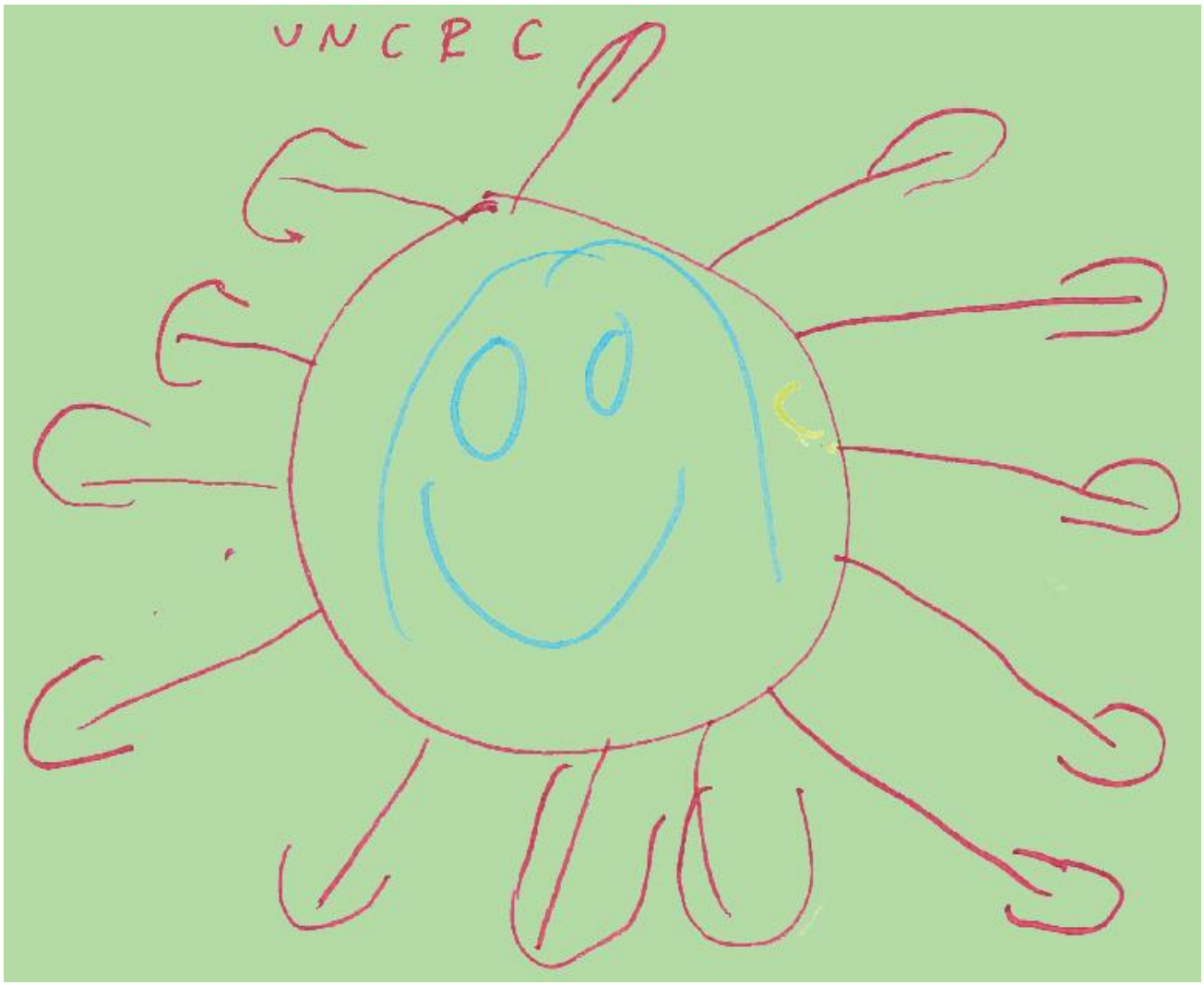
Improving the Well-being of Disabled Young People



Drawing by Olivia, aged 13

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March 2016

Queen's University Belfast

HSC Public Health Agency
Research and Development

Foreword

Caitlin, Chrissie, Jamie, Rosemary, Sophie and Laura are members of the Barnardo's Advocacy Group 6th Sense who reviewed this report. They have asked me, as Project Manager, to convey how proud they are to have been involved in the research, "Improving the Well-being of Disabled Young People".

Young people first presented the research proposal on the emotional well-being needs of adolescents with disabilities to QUB and DHSSPS at Stormont in 2008. Their aim was to gain evidence which would enable them to influence and co-design policy and services that would improve the well-being of young people with disabilities. When reviewing this report the group believe that the recommendations, if implemented, could achieve the outcomes cited in their initial presentation: improved recognition by services providers of emotional health and well-being issues and improved support service response, leading to better emotional health and well-being for adolescents with disabilities.

Since its inception in 2002, 6th Sense have practiced child led participation and adult shared decision making. One of the stark findings in this report is that young people with disabilities who participate in influencing activities are likely to have better emotional well-being than those who do not. The report reflects the research team's willingness to respect our participation practice, ensuring that participants were involved in all aspects of the research design, implementation and evaluation. One young person designed the cover page of the report and the report review group gave the report its title.

I observed the young people's delight when they recognised their individual contributions. They felt what they said was accurately reflected and that all the issues raised were highlighted. One young person, who was a member of the initial research proposal group of 2008, suggested the findings also reflected the issues her and her friends had highlighted previously. Having had the pleasure of facilitating the young people's involvement in this research I would like to say that the "Improving the Emotional Wellbeing of Disabled Young People" report is a credit both to the young people who initiated the research proposal, some of whom are no longer with us, and to all those young people who participated in the research.

The young people would like me to say a special word of thanks to Dr Grace Kelly for becoming a friend in which they had the confidence to share their experiences. I would like to add my thanks to Grace for her patience and co-operation in involving the young people. I feel the report is testimony to the research team's commitment to improving the lives of young people with disabilities.

Finally, it is the hope of all those involved that the recommendations made in the report will lay the foundation to improving the well-being of young people with disabilities.

Rosemary Murray

Acknowledgements

We would like to express our sincere thanks to the Public Health Agency for Northern Ireland for responding positively to a call for funding to explore the emotional well-being of adolescents with disability. The call came from a group of young people from the Barnardo's Advocacy Group 6th Sense. These young people were determined to have their voices heard in an effort to make things better – not just for themselves – but for other young people with similar experiences. We thank Hillary Harrison in particular for facilitating this expression of opinion. Quite simply, it was the young people's strength of character which secured the financial support that made this research possible. The group also acted as advisors and provided guidance to the researchers on research methodology and communication strategies. In the true spirit of participatory research, their input did not stop there but continued throughout the study period.

Special thanks are due to those who provided essential research support in the initial stages of the study. In particular, Seaneen Sloan and Aideen Gildea who carried out important fieldwork and Anne Lazenbatt and Laura Dunne for their contribution to the literature review. We would also like to acknowledge Catherine Coyle for her help with data collection.

Our sincere appreciation goes to the people who agreed to act in a professional advisory role for the study: Mark Conachy, Goretti Horgan, David Marshall, Paschal McKeown, Monica Wilson, Gerard Slevin. Rosemary Murray deserves special recognition, not only for her on-going support, but because her faith in this project never wavered.

We would like to recognise the key role played by the Northern Ireland Clinical Research Network (Primary Care). The Network adopted the study and put us in touch with a range of young people with disabilities who were invited to participate. This widened the geographical scope of the study, and helped to bring a range of experiences into the study. Their support has been instrumental in firmly establishing the relevance of the research findings. We are indebted to the Network's team of research nurses (led by Claire Leathem) whose professionalism, commitment and enthusiasm remained resolute throughout. This research also benefited immensely from the support given by GP practices who, they told us, were enthused by the inclusive nature of the study.

Finally, our greatest thanks goes to each and every young person who participated. What all participants had in common was a generosity of spirit and a willingness to contribute to this study in the best way they possibly could. They all succeeded in doing so.

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Introduction

The main aim of this study was to help to address some important gaps in our knowledge about the well-being of disabled adolescents, specifically how they manage the stresses they encounter and what they identify as impediments to their well-being and how they perceive their support needs. The study was developed in response to a direct request from a group of young disabled people in Northern Ireland, who were concerned that little attention was given to issues of their emotional and mental health and well-being, even though the issue had been brought to the attention of policy makers in Northern Ireland some ten years (Bamford, 2006).

The study set six main objectives:

1. To ascertain the well-being of a sample of adolescents with disabilities
2. To identify the supports and resources that young people with disabilities perceive to be important for them in living full, happy and active lives
3. To identify what is happening in their life and the perceived barriers to well-being
4. To identify the coping mechanisms that disabled adolescents use to improve well-being
5. To identify areas where change and service support developments are required
6. To explore the utility of 'salutogenesis' as a theoretical framework for investigating the well-being of disabled adolescents

These objectives were addressed by means of an exploration of the young people's own lived experiences. This approach was chosen as it recognises the importance of engaging disabled young people in shaping a framework against which their emotional well-being can be assessed and the design and philosophy of future support services can be informed. It is also an appropriate methodology for an exploratory study.

The study was commissioned at a time when the emotional well-being and mental health of individuals was becoming an established concern within government, with calls for a strong evidence base to inform policy and practice (Cameron, 2010). This concern was driven by an expanding body of work from different intellectual disciplines, particularly economics and positive psychology. These challenged the validity of standard economy based measures of societal progress such as Gross Domestic Product (GDP) and called instead for a greater understanding of well-being, happiness and quality of life. This was mirrored internationally, with societies being urged to '*shift emphasis from measuring economic production to measuring people's well-being'* (Stiglitz et al., 2009: 12). Since then, the promotion of well-being has been a priority for national and local governments worldwide, giving this research a political, as well as principled, imperative for examining whether adolescents with disabilities have the opportunities to experience positive emotions, life satisfaction and a sense of purpose in life.

Background

The group of young disabled people who argued that this was a priority area for research (the Barnardo's Advocacy Group 6th Sense), felt that friends, family members and professionals in their formal and informal networks, were preoccupied with 'service' issues, and that issues pertaining to their mental health and emotional well-being often went ignored.

In response, the Institute of Child Care Research (ICCR) engaged in a lengthy process of consultation with policy makers, service providers and commissioners and service users to propose a research study that would help unpack these issues whilst engaging young disabled people in shaping relevant and effective services. This is the context in which this study began.

Investigating how happy or unhappy people feel with aspects of their lives requires asking a person to reflect on their life and put these thoughts into words. As Beresford (2012: 234) points out, this requires a sophisticated level of cognition, self-awareness and verbal expression which may put children and young people with particular impairments or communication difficulties at risk of exclusion from research on well-being.

This may account for the somewhat limited number of studies investigating the well-being of disabled youth. Prominent among existing studies include SPARCLE (A Study of Participation and quality of Life of Children with Cerebral Palsy Living in Europe) which investigated the influence of the environment on the participation and quality of life of children with cerebral palsy aged 8-12 years in seven EU countries[1]. A follow-up study, SPARCLE 2, extended this investigation to look at the aspects of these children's lives that continued to influence their quality of life and that of their families at age 13-17. Among the key findings, the quality of life of children (SPARCLE 1) and adolescents (SPARCLE 2) with and without cerebral palsy was found to be similar. However, a reduction in the quality of life of adolescents with cerebral palsy was noted in the domain of social support and peer relationships, particularly in adolescents with more severe impairments. More information on the study, including study summaries, published research papers, related papers and country reports, can be found on the SPARCLE website (www.ncl.ac.uk/sparcle/).

Fewer studies of disabled children and adolescents have focused attention specifically on the emotional aspects of well-being, or have included young people with intellectual disabilities. Notable exceptions include the work of Emerson and his colleagues in Australia, whose work focuses on understanding better the social determinants of health (such as poverty, social exclusion, discrimination), how these factors influence the well-being of young people with disabilities and people with intellectual or developmental disabilities and their families, and how these issues can be addressed (for example, see Emerson et al. 2009; 2011; 2012; Honey et al. 2011; Wedgewood 2011).

[1] Denmark, France, Germany, Ireland (North and South), Italy, Sweden, England.

This study makes a valuable contribution to existing knowledge in this area; namely how adolescents with disabilities manage the stresses they encounter, what they see as the impediments to well-being are and where opportunities to enhance well-being may lie.

Structure of the report

Chapter one provides a brief account of the policy landscape, focusing on those key policy documents that are relevant to this project and that inform work with disabled children and young people. The prevalence of adolescent disability in the UK is estimated from a variety of sources including government surveys, general population studies and key administrative statistics, and the challenges of establishing accurate or meaningful prevalence rates are discussed

Chapter two focuses on the concept of well-being and the significant emphasis now being attributed to the quality of life that people experience beyond their objective conditions – their subjective well-being (SWB). Also discussed is the growing desire (nationally and internationally) to capture wider measures of well-being which can be integrated into existing statistical systems. It is argued that the intensified international focus on measuring SWB, together with a rights based agenda requiring the views of children be taken into account, gives this research particular significance.

Chapter 3 provides details of the study design, research methods, theoretical influences and analytical approach chosen to carry out the investigation. A scoping review of the literature on the emotional health and well-being of disabled children and adolescents set the context for, and informed, the primary data collection. The scoping review will be published in a separate document. The study set no limitations for participation apart from age and the presence of a disability, thereby ensuring the participation of individuals who are often excluded from research projects due to accessibility and language barriers. This presented a number of challenges in obtaining data from young people such as those with intellectual impairments or behavioural disorders. A combination of strategies were employed to overcome these, including the use of photography, pictorial aids, observational methods and the use of simple vocabulary. Some of these approaches were more successful than others and this is critically appraised and the implications considered.

The study's main findings are set out in chapters four to seven. Chapter four examines the extent to which adolescents are satisfied with their life and chapters five and six discuss how their experiences (positive and negative) build the conditions that can enhance or diminish well-being. Chapter seven focuses on the factors that young people perceive to be the most valuable for building their capability to enjoy a happy and fulfilled life. The study looks to the growing body of literature in this area and makes use of the general framework being used internationally to measure SWB. A very simple framework is used to analyse a very complex concept. This is not to imply that SWB can be compartmentalised into neat components; there are overlaps, interconnections and close associations

between the multi-dimensional elements of well-being. The purpose of the analytic framework is to aid organisation of the data and help identify the drivers which enhance a person's well-being and the factors which deplete well-being. In that way, we can examine the basis of these determinants more carefully (for example, are they structural, societal and so forth). This gives good leverage for explanations and resolutions.

Chapter eight sets out the main conclusions and key messages for policy and practice. This includes the need to protect disabled young people and their families from poverty; the importance of formal sources of participation for social interaction and their value for enhancing well-being; how relevant involvement of young people with particular needs in the design stages of programmes can overcome barriers to participation; well-being is not a standalone outcome but an on-going process of fulfilling one's potential and development.

Chapter 1: Policy Context and the prevalence of disability

Internationally, the major development in disability policy has been the United Nations Convention on the Rights of Persons with disabilities (UNCRPD). This was adopted by the United Nations (UN) General Assembly in December 2006, came into force in May 2008 and was ratified in the UK in 2009. The UNCRPD contains 50 articles and its Optional Protocol contains a further 18 articles. The treaty addresses a wide range of civil, political, economic, social and cultural rights of both disabled children and adults. Obligations are placed on State Parties to respect, protect and fulfil the human rights of all disabled people and to ensure that people with disabilities enjoy the same rights and freedoms as others. The guiding principles of the UNCRPD include the right of disabled people to respect; non-discrimination; equality of opportunity; accessibility; autonomy to make individual choices; full social inclusion and participation; and respect for, and recognition of, developing competencies (http://www.un.org/disabilities/convention/conventionfull.shtml). State Parties are required to submit periodic reports (State Report) to the UN Committee detailing progress in the implementation of the convention. The Optional Protocol facilitates a complaints procedure, allowing individuals and groups of individuals to bring appeals to the Committee if they believe there has been breaches of their rights.

Another key international human rights instrument is the United Nations Convention on the Rights of the Child (UNCRC) which covers the rights of all children across most aspects of their life. The United Kingdom (UK) signed the Convention in April 1990, ratified it in December 1991 and it came into force for the UK on 15 January 1992. The UNCRC defines a child as a person below the age of 18. The UNCRC has 54 articles that cover civil and political as well as economic, social and cultural rights. No one article, or right, takes precedence over another, all are interrelated, but four general principles guide the convention and are considered necessary for the realisation of the UNCRC as a whole. These guiding principles are:

- *Non-discrimination (article 2)*. This means that the legislation applies to all children, regardless of race, religion, gender, whether they have a disability or not, where they were born or whether they are rich or poor.
- *The best interests of the child (article 3)*. The best interests of children must be the primary concern in making decisions they may affect them. This places an obligation on adult decision makers to think about how their decisions will impact on children's lives. This particularly applies to budget, policy and law makers.
- *Survival and development (article 6)*. Governments should ensure that children survive and develop healthily. Children have the right not just to life but more specifically they have the right to the maximum available resources that are necessary to support them to achieve their maximum possible potential.

- *Respect for the views of the child (article 12).* When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account. It requires the opinions of children be taken into account in decision-making and is complemented by other participation rights that assure children the information they need, i.e. freedom of expression and association. (http://www.unicef.org/crc/)

Like the UNCRPD, a system of periodic reporting on progress of implementation is the primary enforcement method for this legislation. The Westminster Government is responsible for the co-ordination of the Convention across the United Kingdom, with the Department for Education (DfE) taking the lead in the implementation of the UNCRC and the co-ordination of reports.

The principles of the UNCRPD and the UNCRC has informed much of the legislation and policy for children and young people at national and regional level (Kelly, 2013).

At the national (UK) level, key strategies, reports and initiatives relevant to promoting the emotional well-being and mental health of children and young people with disabilities include the following:

- *Every Child Matters* (DfES, 2003) which was produced following an enquiry into the death of Victoria Climbíe. This Green Paper proposed a range of measures to reform and improve children's care (from birth to 19 years) based on the principle that child protection cannot be separated from policies to improve children's lives as a whole. The policies set out in the paper were designed both to protect children and maximise their potential. It was underpinned by five key universal outcomes for every child, regardless of their background or circumstances: be healthy (enjoy good physical and mental health); stay safe (be protected from harm and neglect); enjoy and achieve (get the most out of life); make a positive contribution (positive social participation); achieve economic well-being (not be prevented by economic disadvantage from achieving life's full potential).
- The *National Service Framework for Children, Young People and Maternity Services* (NSF) (2004) was a ten year strategy produced by the then Labour government to tackle child poverty and inequalities in childhood through improving the lives of children and their families. Closely aligned to Every Child Matters, the NSF proposed that all young people should have access to quality services which were responsive to their specific needs as they made the transition into adulthood. All agencies were to work to promote children's welfare and prevent harm through the provision of services and safeguarding. The strategy set eleven national core standards for children's health and social care all of which contribute to mental well-being with standard nine setting the vision for mental health embracing both universal and specialist services, signalling strong commitment to the development of comprehensive Child and Adolescent Mental Health Services (CAMHS).
- The task set for the *Children and Young People's Health Outcomes Forum* (DH, 2012) included identifying the health outcomes that matter most to children and young people and consider how

well these concerns were being addressed by existing health outcome frameworks. Central to the forum's recommendations was an overarching focus on improving children's mental health outcomes. The Chief Medical Officer's Annual Reports in 2012 and 2013 have supported the emphasis on improving children's mental health outcomes at national level (DH, 2015).

At the local (Northern Ireland) level, where the research was carried out, policies and expectations are set out in a range of legal instruments, strategies and initiatives. The *Disability Discrimination Act* (DDA) (1995) contains provisions which make discrimination against disabled people unlawful. The *Northern Ireland Act* (1998) incorporates disability among nine dimensions of equality specified in Section 75 of the Act. The legislation requires public authorities to promote equality of opportunity between persons of different religion, political opinion, racial group, age, marital status, sexual orientation, gender, between those with dependants and those without and between persons with a disability and persons without. Under Section 75 duties, public bodies are required to implement equality schemes which include equality impact assessments on existing and new policies to identify any possible adverse impact on any group.

The Northern Ireland Executive's Disability Strategy *A Strategy to Improve the Lives of People with Disabilities 2012-2015***,** was launched in February 2013. The strategy covers people of all ages with a disability. Its stated purpose is to bring together key areas of policy relating to disability and give more structure to the disability related functions of government departments. In turn, it is believed that this will lead to improved services for people with a disability, while opening up the opportunity for social inclusion[2]. The Disability Strategy (DS) builds on the recommendations made by the Promoting Social Inclusion (PSI) Working Group in their major report on disability (OFMDFM, 2009). The influence of the PSI report is reflected in the setting of 18 strategic priorities within the DS, embedded within 12 cross-cutting thematic domains, and based on an inter-departmental approach to bring forward each strategic priority.

The themes cover areas such as participation; awareness-raising; accessibility (environmental access and personal mobility); independent living; standard of living; employment; justice and community participation. Themes also encompass significant transitionary life periods, which are recognised as presenting additional barriers for people with disabilities such as the transition from childhood to adulthood for example, and the physical and emotional changes which occur at this time. Another theme of the DS with specific relevance to the adolescent stage of life is 'Children, Young People and Family'. For example, the vulnerability of young disabled people within the 14-25 age group to

[2] The Disability strategy is being extended until 2017 to "to provide additional time to fully implement the recommendations" (Northern Ireland Assembly question AQO 8246/11-15). However, there are no ring-fenced funds available to cover individual departmental projects planned to deliver the objectives of the strategy. Departments have been asked to cover these costs from their own core funding.

exclusion was one of the key issues identified. Focus is placed on ensuring the rights and freedoms of children and young people with disabilities equally with other children. The strategy notes the difficulties young people with disabilities face during this crucial life transition stage:

> *This transition prompts issues around emotional well-being as well as the complications and additional resources (especially time) that people with disabilities need if they are to share equality of opportunity with non-disabled people. We believe that young people with disabilities should be supported in addressing these needs so that they have the same opportunities for growth and fulfilment as non-disabled young people. (OFMDFM, 2013: 20)*

Hence the setting of Strategic Priority 11:

> *Transform the process of transition to adulthood for young people with disabilities. (OFMDFM, 2013: 21)*

OFMDFM has responsibility for monitoring the DS. The first strategic priority was to increase the opportunity of people with disabilities to influence policies and programmes in Government, including the delivery of the strategy and a subsequent Action Plan (ibid: 15). Progress of the strategic priorities is to be monitored against a set of indicators of success. In addition, each government department is required to report to OFMDFM on the progress of their commitments under the 18 strategic priorities. At the time of writing, the Action Plan has not been published and the set of indicators has not yet been fully settled. An interim list of draft indicators was put out for consultation (OFMDFM, 2014). Some gaps remained where no suitable data is available and OFMDFM were keen to receive suggestions on how this can be developed. A report of the actions undertaken to progress the strategic priorities is in the process of development.

The Northern Ireland Children's Ten Year Strategy *Our Children and Young People – Our Pledge* (OFMDFM, 2006) set out six high level outcomes in key areas relating to children and young people's lives. The strategy is embedded within a rights based approach with one of the six priorities being that children and young people are living in a society which respects their rights. The other priorities are healthy; enjoying learning and achieving; safety and stability; economic and environmental well-being; and contributing positively. It differs from the UNCRC in that it applies to children under the age of 18, but up to age 21 if the young person has been in care or have a disability. The method for delivering these outcomes is through strategy action plans. Impediments to the effective delivery of the strategy, such as a lack of commitment to and awareness of children's rights, have been identified in previous research (Byrne and Lundy, 2011).

Delivering Social Change (DSC) is the Northern Ireland Executive's new delivery framework which seeks to provide a co-ordinated departmental approach to progress key priority social policy areas. These are: to reduce poverty, promote equality and tackle disadvantage across all ages; and to improve

the health, well-being and life opportunities of children and young people (http://www.ofmdfmni.gov.uk/delivering-social-change).

The draft strategy *Delivering Social Change for Children and Young People* (DSCCYP) (OFMDFM, 2014) initially proposed the integration of key child related areas under the DSC framework – the Child Poverty Strategy, the ten year Strategy for Children and Young People 2006-2016 and work required to fulfil obligations under the UNCRC.

Concerns regarding the extent to which the strategy, in its proposed form, was capable of delivering the key commitments and fulfilling the statutory obligations formed much of the responses from OFMDFM's consultation on the draft strategy. At the time of writing, a Child Poverty Strategy will now be produced separately and the ten year Strategy for Children and Young People has been extended until 2017 while a new children and young people strategy is being developed under the DSC framework.

The prevalence of adolescent disability and mental health

Disability

Population and demographic statistics are commonly gathered by countries to develop state policies and plan future policy. In many instances, the direction of policy may be determined by changes in population trends or living patterns. However, as a demographic characteristic, disability is difficult to define and measure (Heslop and Gordon, 2014). Current thinking has shifted from a 'medical model', where the focus was on the biological impairments of an individual and their functional limitations, to a 'social model' that identifies disability as a form of social disadvantage associated with having an impairment, for example, the disabling attributes of inaccessible buildings and transport systems. The social model prevails as the theoretical approach used in the UK today although the balance between the impact of an individual's physical or mental impairment and society's disabling effects on the individual continues to be debated (ibid: p 210).

The current definition of disability within the DDA 1995 defines a disabled person as '*a person with a physical or mental impairment which has a substantial and long term adverse effect on a person's ability to carry out normal day-to-day activities*'. The DDA 1995 also states that an impairment is to be taken to affect the ability of a person to carry out normal day-to-day activities only if it affects that person in respect of one or more of a 'list of capacities'. The Equality Commission in Northern Ireland (EQNI) recommends the removal of the capacities list from the DDA definition, to reflect the 'social model' of disability, in line with the approach adopted within the UNCRPD, which recognises disability as:

> *"an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".* (www.un.org)

In April 2010, Great Britain (GB) introduced the Equality Act 2010 which provides a broader interpretation of the way a person's impairment may impact on their ability to carry out normal day-to-day activities. However, legislation in Northern Ireland has not been amended (Byrne et al 2014).

Information on the number of disabled children and young people and their impairment specific conditions is difficult to estimate as there is no systematic registration of individuals with a disability. Much of the information on disability prevalence rates comes from existing survey data from general population studies or administrative statistics.

The Family Resources Survey (FRS) collects data on the giving and receiving of informal care and on disability. It can be a key source of information on adult and child disability. The most recent report for the UK (DWP, 2014) estimates that 7% of children were disabled compared to 16% of adults of working age and 43% of adults over State Pension age. The rates are similar for the Northern Ireland population, except percentages for older adults which, in NI, are slightly higher at 46% (DSDNI, 2014a). The estimated percentage of children who are disabled has remained generally stable from 2002/03 to 2012/13. However, the way the FRS identifies disabled people has changed over time so this is not a straightforward comparison. Previously, disability was ascertained on the basis of responses to questions about barriers across a number of areas of life. In line with the harmonisation of government data collection (led by the Office for National Statistics), disabled people are now categorised as those who report any physical or mental health condition(s) or illness(es) that last or are expected to last 12 months or more and which limit their ability to carry out day-to-day activities. People classified under this definition would also be classified as disabled under the DDA. However, some individuals classified as disabled and having rights under the DDA would not be captured by this definition (DSDNI, 2014a: 91).

The Northern Ireland Survey of Activity Limitation and Disability (NISALD) revealed that 6% of children under 16 years in Northern Ireland are disabled (NISRA, 2007). The data reveal that the risk of being disabled differed between boys and girls with 8% of boys aged 15 and under found to have a disability compared to 4% of girls. Just over 2% of young people have one type of impairment while almost 4% live with two or more (NISRA, 2007: 21). For young adults the age pattern was similar with a prevalence rate of 6% for males aged 16-24 and 4% for females. However in older adults the prevalence rates are reversed, with disability being higher in females than males.

The 2011 Northern Ireland Census data show that approximately 3% of 10-14 year olds and the same percentage of 15-19 year olds have a long-term illness which limits their ability to carry out normal day-to-day activities 'a lot'. (see http://www.ninis2.nisra.gov.uk/).

The 2011 Census also contained a further question on health that asked about specific long-term conditions. Approximately 14% of children aged 5-9 and 16% of children aged 10-14 were reported as experiencing at least one of the long-term conditions listed on the Census questionnaire[3] (NISRA, 2013).

Administrative data sources also provide indicative information on disability prevalence rates through the publication of claimant and recipient numbers of disability related benefits such as Disability Living Allowance (DLA). For example, in August 2014 in Northern Ireland there were 17,950 children under the age of 16; 2,620 young people aged between 16-17 years; and 7,950 young people aged 18-24 in receipt of DLA (DSDNI, 2014b). For children and young people aged up to 24 years, the main disabling condition for which DLA was awarded was 'Learning difficulties' with 12,420 in receipt of an award (44%). The second most common disabling condition was 'Other mental health issues' with a total of 3,550 children and young people in receipt of a DLA award (12%)[4]. While the robustness of government administrative statistics make them a reliable source of information, they do not capture those people who may have a disability but who do not make a claim for a disability related benefit or whose claim has been classified as ineligible.

Surveys with a focused interest on particular populations provide more condition-specific details. For example, data from the Northern Ireland School Census in 2013 estimate that the prevalence of autism (including Aspergers Syndrome) amongst school age children in Northern Ireland, has increased by 67% across all Health and Social Care Trusts between 2008/09 and 2013/14, from 1.2% of the compulsory school age population to 2% (DHSSPS, 2014a).

Mental health

Estimates of the prevalence of mental health problems in the population vary, but it is generally estimated that one in ten children will experience a mental health problem ranging from short periods of depression or anxiety to severe and persistent depression (DH, 2015). The FRS reports 16% of children and 24% of working age adults experiencing a mental health impairment across the UK. The Health Survey for Northern Ireland (2013/14) concluded that around one-fifth of all respondents (19%) showed signs of a possible mental health problem. Generally, more females that males reported poor mental health with the largest differential being in the youngest group – 23% of young females (aged 16-24 years old) had a high GHQ12 score (indicating possible mental health problem) compared with 13% of males in that age group (DHSSPS, 2014b: 7).

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[3] Communication difficulty; mobility or dexterity difficulty; learning, intellectual, social or behavioural difficulty; emotional, psychological or mental health condition; long-term pain or discomfort; shortness of breath or difficulty breathing; confusion or memory loss; chronic illness, other.

[4] Personal correspondence from Department for Social Development.

The Northern Ireland Young Life and Times Survey (YLT) has contained questions on the mental and emotional health of 16 years olds since 2004. High prevalence of serious emotional and mental health problems were recorded using YLT data (Schubotz, 2010). This included significant numbers of 16 year old respondents who scored 4 or more on the GHQ12, meaning they could be regarded as having potential mental health problems. More recent YTL survey results for 2013 show similar patterns – 29% of young respondents scored high on the GHQ12 indicating possible mental health morbidity (http://www.ark.ac.uk/ylt/results/ylthealth.html).

Adolescent mental health and disability

The incidence of poor mental health among vulnerable children, such as those with a disability or experiencing poverty, is disproportionately high (Bamford Review, 2006). Children and adolescents with intellectual disabilities are more than six times likely to have a diagnosable psychiatric disorder than their non-intellectually disabled peers, with one in three (36%) having a diagnosable psychiatric disorder in Britain (Einfeld and Tonge 1996; Emerson and Hatton, 2007).

In 2004, two studies reported significant gaps in service provision for children and young people with complex health care needs in the UK (including NI), despite evident need (Townsley et al. 2003; Morris, 2004). Meanwhile, mental ill health among young people across the UK is a growing problem, with large proportions not receiving the help they need (Orr, 2015; https://www.minded.org.uk/).

A review of CAMHS in Northern Ireland conducted by the relevant inspectorate (RQIA) in July 2010, reported improvement in services since the Bamford Review '*A Vision of a Comprehensive Child and Adolescent Mental Health Service*' (2006). However, the RQIA review identified a continuing absence of policy guidance and a lack of clinical standards which resulted in variability and quality of service provision across Trust areas in Northern Ireland. In response, the DHSSPS (2012a) produced a framework for CAMH service provision which would promote a more consistent approach across all Trust areas. The approach taken was based on a Stepped Care Model. Step One focuses on targeted prevention for potentially vulnerable children and their family/carer through to Step Five which focuses on children and young people with highly complex mental health and emotional difficulties which severely restrict daily psychological/social functioning (DHSSPS, 2012a: 16-17). However, inadequacies and inconsistencies in CAMH services remain, including issues of access, gaps in service provision, lack of consensus on transition processes between CAMHS and adult mental health services and severe underfunding of the service in general (CLC, 2015).

Summary of Chapter 1

- The UNCRPD enshrines the rights of disabled people to respect; non-discrimination; equality of opportunity; accessibility; autonomy to make individual choices; full social inclusion and participation; and respect for, and recognition of, developing competencies.
- The principles of the UNCRPD and the UNCRC underpin much of the legislation and policy for children and young people at national and regional level within the UK.
- Promoting the well-being and mental health of all young people, including those with disabilities, remains a key aspect of UK government policy at national and local levels.
- Much of that policy takes a rights based approach in order to meet the international obligations set out by the UNCRPD and the UNCRC.
- Disability is difficult to define and measure, but the importance of social models of disability are widely recognised.
- Much of the information on disability prevalence rates comes from existing survey data or administrative statistics.
- At least one in ten children will experience a mental health problem, the actual number may be much higher.
- Poor mental health among vulnerable children is disproportionately high.
- CAMHS remain inadequately resourced.

Chapter 2: The concept of 'well-being'

The first step in capturing well-being is to define what it is we mean. This is not a simple task; what constitutes a person's well-being has been a source of debate since the time of the ancient Greeks (Phillips, 2006). Here we seek to place the present study in context.

There is a large literature which discusses the meaning of well-being, but no universal definition has been agreed. It is not uncommon to see 'well-being' used interchangeably in the research literature with 'quality of life', 'happiness' and sometimes 'welfare'. Broadly speaking, three approaches are used in determining what constitutes well-being. The first is situated within the social indicators tradition of the social sciences (Diener and Shu, 1997). The emphasis here is on identifying a collection of measures that reflect people's objective circumstances across the wide range of societal domains deemed necessary by the collective norms of that society. The second approach defines well-being in economic terms, based mainly on the exercise of preferences and underpins much of modern economic thinking. Here, well-being is measured in terms of consumers' choices and behaviours, and whether or not an individual can obtain the things that they desire, relative to their level of resources and economic constraints. The third approach describes well-being in terms of the subjective experience of individuals. In this approach, well-being is framed subjectively, and focuses on how people experience their lives; actual feelings of joy, happiness and satisfaction are the principal components by which to define life's quality. On one level, this has made subjective well-being (SWB) synonymous with happiness, but it is much more complex than simply measuring levels of happiness. SWB is also interested in negative feelings and why some people experience their life in more positive ways than others (Seligman and Peterson, 2003). However, precisely which elements of subjective experiences should count as SWB has also been the subject of much debate. Some experts argue that how people reflect on their life overall is the most important aspect, while others argue that how life is experienced in the here and now (both positively and negatively) should be the main concern (Ryan and Deci, 2001). Others believe that SWB is reflected not by individual happiness, but rather by personal fulfilment and self-actualisation (Huppert et al., 2009).

Traditionally, an economic interpretation of well-being has been the most prominent view. However, a growing body of work from different academic fields, including political science, environmental sustainability, positive psychology and other branches of economics, has increasingly challenged this opinion. Notwithstanding the divergent conceptual backgrounds, a common belief is that economic measures, like Gross Domestic Product (GDP), cannot adequately capture societal progress. Hence, well-being needs to be viewed as multidimensional, including objective and subjective components, and embracing people's own experiences of life. Growing interest in positive states of mind, and the cultivation of positive attitudes and emotions, have been highly influential in placing SWB as the

preferred definition. This shift in thinking has prompted recent international efforts to measure well-being and to incorporate this information into existing national statistics.

For example, in 2011, the Organisation for Economic Cooperation and Development (OECD) launched its 'Better Life Initiative' which aimed to establish a set of well-being indicators that would be comparable internationally. A statistical report 'How's Life?' has been released every two years since then, documenting a wide range of well-being outcomes, and how they vary over time, between population groups, and across countries (see http://www.oecd.org/statistics/measuring-well-being-and-progress.htm).

The European Commission's 'Beyond GDP' initiative has been pivotal in achieving a consensus among member states that existing measurements of progress should include environmental and social dimensions to complement GDP (see http://ec.europa.eu/eurostat/web/gdp-and-beyond/background).

In 2010, the UK government tasked the Office for National Statistics (ONS) to begin developing measures of national well-being. Following a wide public consultation, the ONS incorporated four questions on SWB as part of the annual Integrated Household Survey (IHS).

All these initiatives, and the framework chosen to measure well-being, mirrors the recommendations made in 2009 by the Commission on the Measurement of Economic Performance and Social Progress, commonly known as 'the Stiglitz Report' (Stiglitz, 2009).

How is SWB measured?

Two main theoretical approaches have been taken to measuring SWB – the 'affective' and the 'cognitive'. Sometimes these are referred to as 'hedonic' and 'eudaimonic' (Ryan and Deci, 2001) or 'hedonic' and 'evaluative' (Kahneman and Riis, 2005). The 'affective' or 'hedonic' approach is concerned with mood or emotional state and how individuals experience life in the moment. The 'cognitive' or 'eudaimonic' approach is associated more with reflective assessments of life and how a person remembers their experiences (Kahneman et al., 1999). It is also associated with individual choice and conscious decision making (Kahneman and Krueger, 2006). Falling within the eudaimonic tradition is the notion of psychological well-being which emphasises positive psychological functioning and human development. Here, well-being is not an outcome but an on-going process of fulfilling one's potential and development (Deci and Ryan, 2008).

The UK is viewed as being at the forefront of operationalising the concept of well-being by developing indicators which capture hedonic and eudaimonic dimensions of SWB information (Venkatapuram, 2013).

The ONS framework for SWB contains three categories of measurement – satisfaction (evaluative), experience and eudaimony. This very much reflects the work of the OECD and the emerging consensus around the nature of the concepts to be measured (O'Donnell et al. 2014).

Evaluative measures

These represent a person's reflective evaluation of how satisfied (or happy) he or she is with their life overall. When using evaluative measures, the person is asked to think back over their life in general and give a global assessment. A range of personal, economic and social factors such as age, health, income and the type of work a person engages in has been shown to be associated with overall life satisfaction and happiness (Dolan et al., 2008). In addition to a global evaluation, this measure can also include information on satisfaction with specific aspects of a person's life such as their physical and mental health, employment situation, income, where they live and the status of personal relationships. Evaluations with different dimensions of life have been found to correlate with overall life satisfaction or happiness. For example, Peasgood (2008) found that satisfaction with a partner and with one's social life correlated most strongly with overall life satisfaction.

Experience measures

These measures seek to capture particular feelings or emotions, usually as they are experienced contemporaneously, (for example, yesterday or last week). Such measures are better able to distinguish between how people experience their life, from how they remember it (Kahneman and Krueger, 2006). This category of measurement distinguishes two affective dimensions – positive experiences (for example joy, happiness, contentment) and negative experiences (for example sadness, anger, fear, anxiety, worry, stress) (OECD, 2013: 31).

Both types of measures have philosophical roots in the utilitarian traditions of philosophers in the 18th century (Diener and Suh, 1997). Jeremy Bentham, in the 18th century, identified pain and pleasure as the only intrinsic values in the world, arguing that the moral worth of an action (its utility) was determined by its outcome and that actions that brought about the maximum happiness were of the greatest value (Phillips, 2006). For Bentham, utility was the mental state of pleasure, or happiness, and as individuals would rationally choose pleasure over pain, an ideal society is one where individual utility is maximised.

Both evaluation and experience measures could be viewed as hedonic approaches to SWB.

Eudaimonic measures

Going beyond life evaluations and emotional feelings, eudaimonic measures draws on Aristotle's philosophy of 'the good life', focusing on self-realisation and the achievement of a person's potential (Phillips, 2006: 32). Unlike hedonic measures, the focus here is on good psychological 'functioning'

elements of well-being such as autonomy, achieving goals, having a sense of purpose in life, an interest in learning, resilience, all independent of pleasure (Huppert et al. 2009). It also has similarities with Martha Nussbaum's version of capability theory which incorporates Aristotelian values and notions of social justice (Phillips, 2006). For Nussbaum, all human beings should have equal opportunity to achieve a 'good life', which she describes as '*to do well and live a flourishing life'* (Nussbaum, 1995: 81). With this focus on capabilities, eudaimonic perceptions of well-being are said to have a more instrumental focus and associated closer with what the majority of people think should be valued in life (OECD, 2013).

While life evaluation, affect or experience and eudaimonic well-being are conceptually distinct, there is evidence of an association between these different aspects of SWB (Ryan and Deci, 2001). Most would consider that SWB is best viewed as a multidimensional phenomenon incorporating both aspects of hedonic and eudaimonic well-being, while acknowledging that tensions and conflicts exist between the two structures.

It needs to be acknowledged that good emotional and psychological well-being are also affected by a wide range of different factors including gender, age, income (Dolan et al. 2008) and personal factors like health status and social connectedness (Boarini et al. 2012). Biological factors, including a person's genetic predisposition, have also been closely linked with a sense of increased well-being (Ebstein et al. 1996; Hamer, 1996).

This suggests that ideally, both hedonic and eudiamonic elements of SWB should be taken into account when investigating the overall individual well-being that people experience beyond their objective conditions – not forgetting the significance of personal and environmental factors.

Table 1 below sets out the basic components of SWB with some examples of what each component is said to capture. It reflects the broad consensus from the literature on what components should be measured and is based on the general framework being used internationally to measure SWB, such as those of the OECD and the European Commission discussed above.

The main focus of this research is on the well-being of adolescents, in particular their emotional well-being, broadly defined to include an individual's reflective feelings, their current experiences and the factors that promote psychological well-being.

For the purpose of this research, we use the broad definition of SWB employed by the OECD (2013: 29) and based largely on Diener et al. (2006). Well-being is taken to represent:

> *Good mental states, including all of the various evaluations, positive and negative, that people make of their lives, and the affective reactions of people to their experiences.*

Table 1: The basic components of subjective well-being (SWB)

Subjective Well-being	**Hedonic**		**Mitigating factors (personality, environment etc.)**
	Evaluation	**Satisfaction or happiness with:** Life overall Personal relationships Social life Income School/work life Education Physical and mental health	
	Experience	**Experiencing positive affect:** Happiness, joy, pride, fulfilment. **Experiencing negative affect:** Sadness, anger, disappointment, anxiety, fear.	
	Eudaimonic		
	Psychological well-being	Purpose in life Aspirations Autonomy Self-fulfilment Choice Self-esteem	

Summary of Chapter 2

- A growing body of international work has questioned the relevance of traditional economic based measures for measuring societal progress.
- The argument for measures which embrace people's own life experiences has had significant impact worldwide.
- Subjective measures of well-being are being incorporated into national and international accounting systems.
- SWB is best viewed as a multidimensional phenomenon incorporating both aspects of hedonic and eudaimonic well-being, while acknowledging that tensions and conflicts exist between the two structures.

Chapter 3: Methodology

The primary objective of this study was to ascertain the extent and meaning of well-being in the lives of disabled adolescents. As discussed in the previous chapter, existing evidence strongly suggests that well-being is best viewed as a multifaceted concept, incorporating both aspects of hedonic and eudaimonic well-being – that is, how people evaluate their life overall, the emotions they feel (positive and negative) and a person's capability to realise their potential (Boarini et al. 2014). This is the theoretical basis upon which this qualitative study was designed and carried out.

The study design was qualitative, and sought to capture young people's perceptions of contentment or satisfaction with aspects of their life, building a picture of how their life was experienced and the degree to which young disabled adolescents are able to fulfil their potential. The work involved identifying the supports and resources perceived by young people to be important in living a happy and fulfilling life. This included highlighting perceived barriers to well-being and recognising opportunities for addressing circumstances that reduce capacity to experience good emotional well-being.

Recruitment and informed consent

Originally, the study focused only on the group of young people from the Barnardo's Participation Project, that were instrumental in initiating the study, and who were based in the Southern Trust. However, the study was later widened to include young people from a special school who expressed interest in taking part in the study; the school was situated in the Northern Trust. In June 2014, we applied to the Northern Ireland Clinical Research Network (NICRN) to have the study adopted and added to their portfolio of research studies. The NICRN is funded by the Northern Ireland Health and Social Care (HSC) Research and Development Division and supports high quality research across all five HSC Trusts. The aims of the NICRN are to promote research within Northern Ireland and develop close partnerships with key individuals and groups across the Network and the wider research community. The NICRN focused on recruiting participants from the Belfast Trust. The total number of young people recruited to the study was 37. The distribution is as follows:

Southern Trust 20 participants

Northern Trust 6 participants

Belfast Trust 11 participants

Informed consent was sought separately from young people (and their caregivers if under 16 years). Consent was viewed as a process rather than a one-off event. From this perspective, any verbal or non-verbal indications that the participant did not want to continue their involvement in the research, or any one part of the research process (e.g. an interview), was acted upon by the researcher and brought to a

close. This included signs of tiredness (like yawning) or distraction (like moving about the room) and the use of a 'stop card', which the participant held up if s/he did not want to answer a question or wanted to end the session altogether.

We aimed to be inclusive of young people with disabilities, including intellectual and communication difficulties. To ensure potential participants could truly understand what participating in a study might involve, we tailored information leaflets and agreement forms for different levels of understanding, for example, by incorporating pictures and keeping written information to a minimum. Four participant information sheets and consent forms were designed for potential participants; each one adapted to the particular level of comprehension (see Appendix A). An information sheet and consent form was designed for parents (see Appendix B). All information sheets set out the aims and objectives of the study, research methods, plans for dissemination and how the data would be used.

In addition, to facilitate the participation of young people who found written material difficult, we recorded two videos, each replicating the study information, one of which was subtitled. A link to these videos was included in the information sheets[5].

Ethical approval

Ethical approval for the study was received from the Office for Research Ethics Committees Northern Ireland (ORECNI) in December 2010. Further ethical approval was obtained from ORECNI in September 2014 to reflect the adoption of the study by the NICRN.

Data collection

The main method of data collection was individual semi-structured interviews. The interview schedule was guided by the conceptual underpinnings of the study and asked for views on neighbourhood, school, and what a usual week (Monday to Friday) and what a weekend would look like. A small number of questions asked about how life was going more generally and whether there were things that made participants feel happy or sad. Questions were short and simply worded. A combination of open and closed questions was asked to suit individual participant communication styles. The length of the interview depended on the individual participant and ranged in length from approximately 20 minutes to one hour (see also below).

A range of strategies was used to engage with participants and aid data collection. Young people taking part met with a member of the research team at least once before being interviewed. The purpose of the

[5] See (www.qub.ac.uk/research-centres/InstituteofChildCareResearch/Video/WiLDA).

first contact was to explain the study, to secure informed consent and to prepare for the semi-structured interview. Participants were offered the opportunity to take photographs of things that made them experience positive and negative emotions and/or things that they felt encouraged or prevented them from feeling good. This approach (Photovoice) has been used extensively in international research projects, especially with marginalised and disempowered groups who are often excluded as a result of barriers around language and accessibility (Booth and Booth, 2003; Streng et al. 2004; Wang and Pies, 2004). Participants were offered disposable cameras and arrangements were made to return the camera to the researcher, who would organise for the images to be printed. A set of guidelines (adapted from O'Grady, 2008) on taking photographs in public places was discussed with young people, and their parents if appropriate. Participants who wished to use photography were given a letter from ICCR explaining the research project, and advised to keep this letter with them should anyone query the taking of photographs. Any queries were to be directed to the researchers whose contact details were included in the letter. For those participants who chose to take pictures, Individual interviews used the photographs to explore what was important in their lives. However, this approach proved less popular than anticipated, with very few young people opting to use a camera. We have no clear explanation for this. For example, one young person was enthusiastic about using a camera and took photos. However, when the researcher arrived to conduct the interview, he decided he did not want to share his photos and did not want to participate in the study anymore. In total, only three people participated fully in the Photovoice approach by both taking pictures and discussing them during interview. Their pictures proved a very successful way of supporting the structure of the interview by holding the attention of the participant and encouraging a much richer description than would have been possible without the aid of this additional stimulus. Nonetheless, our experience suggests that researchers planning to use this method of data collection would be advised to consider the popularity of this method among young people early on in the planning stages.

Feeling cards were used as prompts to stimulate participants' responses, if and when the participant wanted to engage in this approach. Each card had the name of an emotion in writing (e.g. sad, happy, positive, worried, good) together with a pictorial image. A blank card was included in the set in case a particular emotion or feeling was experienced that was not included in the existing set. This allowed the participant to put their own words onto the blank card. A set of emoticons was another visual technique used to encourage participation and encourage discussion. Here, the emoticons acted as a five point Likert scale ranging from a very happy face (1) to a very sad face (5). Both these methods proved more popular with younger participants who appeared to enjoy the exercise. But of the two, the feelings cards were the most popular. On one occasion, the researcher had to leave the 'happy' feeling card with the participant because he liked it so much.

Certain specific conditions made communication very difficult. For instance, in the majority of interviews where the young person's intellectual disability was profound, or where physical and/or

behavioural impairments were severe, or where the participant had little or no speech, reliance on a trusted intermediary or facilitator was considerable. One interview lasted just eight minutes before the young person called a halt. During another interview, the participant (Danny, 17 years old and who attends a special school), stood behind a door in the hall while the researcher sat in the living room, coming in and out of the living room intermittently. The point we would wish to emphasise is that, despite a range of apparent barriers to participation, there was no interview that did not yield some level of data and every single participant who consented to this study, contributed to it in their own way.

All interviews were audio-recorded, with the participant's permission, and transcribed for recall purposes. Pseudonyms are used throughout.

Field Notes

Substantial field notes were made as soon as possible after each meeting with the participants. These played an essential part in the overall analysis as they provided additional understanding of the data which could not be captured in a tape recorded interview. For example, some participants had difficulty in expressing themselves clearly and used gestures like head nodding or shoulder shrugging or hand movements. Sometimes the presence of others (or their absence) gave extra clues to participants' disposition. For example, during one introductory meeting with a group of young people, and prior to individual interviews, the group dynamics provided important information about personality traits like confidence and reticence, and so forth. On a few occasions, parents or guardians made comments, or added observations at the end of the interview, which were looked upon as an additional source of information. Field notes also provided a useful record of researchers' on-the-spot feelings and general intuition about issues that may be highly relevant at the analytic stage (Arthur and Nazroo, 2003).

Analytic approach

One of the study objectives was to explore the utility of 'salutogenesis' as a theoretical framework for investigating SWB of adolescents with disability. Antonovsky (1987) proposed that well-being is shaped by socio-cultural factors of the individual, their family and their community, and that life experiences produce positive ways of responding and adapting to situations ('generalised resistance resources'). These comprise cognitive, behavioural and emotional components: i) the ability for young people to understand what is happening around them and to identify barriers to well-being (Comprehensibility – cognitive); ii) the extent to which they are able to manage the situation on their own or with the help of significant others (Manageability – behavioural); and iii) the ability to cope and find meaning in life (Meaningfulness – emotional) (Erikson and Lindstrom, 2007). Together, these resources are said to produce a Sense of Coherence (SOC). The strength of a person's SOC is determined by experiences of emotional well-being; psychosocial support; coping ability and deficits

(e.g. isolation; poor self-esteem; depression; feeling a burden (Antonovsky, 1987). SOC is thus an indicator of their resilience and personal strength, with unique value at times of crisis and distress (Eriksson and Lindstrom, 2007).

The core dimensions of 'salutogenesis' therefore place more focus on individual capability and capacity in the face of adversity, rather than disease and innate inability. The sense of meaningfulness focuses on the ability of young disabled people to fully participate in the processes shaping their future well-being. In this respect, salutogenesis strongly resonates with the concept of resilience – a very valuable, but at the same time, highly contested theory.

One of the main advantages of taking a resilience-oriented perspective is the shift in emphasis towards individual agency and control as opposed to passivity. Obvious limitations include the possibility that individuals who express resilience and positivity in adverse situations may be viewed as coping perfectly well, requiring no additional intervention or help. Alternatively, the absence of a resilient or positive attitude may be viewed as an individual failing, whereby the solution is seen as changing the individual, as opposed to tackling, for example, existing inequalities. Although salutogenesis acknowledges that resources are both social and structural, it can sometimes lead to interventions that aim to strengthen individual resources (like personal behaviour and attitude) rather than focusing on environmental and structural factors, failing to appreciate that some people (e.g. those in poverty) often have very limited control over their circumstances (Harrop, 2007: 49). We believe a more cautious approach is called for to capture the complexities of well-being, which pays attention to both social and environmental contexts, as well as individual resources, and which provides more detailed explanations for how SOC works in certain contexts.

Data analysis

Interviews were recorded and transcribed. The interview data were analysed using a 'thematic framework' approach, which is a matrix based method for ordering and synthesising data (Richie and Lewis, 2003). A set of themes and associated subthemes were developed from the interview data. Following refinement of the thematic schema, a more in-depth conceptual analysis of the interconnections between key questions, themes and dimensions of analysis was undertaken. This allowed the data to be sorted and categories to be identified and refined and linkages made.

Although very few chose this approach, the photographs were most useful for drawing out issues that were important to the young person. The show cards and emoticons proved most useful for prompting discussion and dialogue and to hold the interviewee's attention. Information elicited by these methods were incorporated into the overall analysis.

The sample

In total, 37 young people took part in the study No exclusion criteria were set, other than age (i.e. adolescent), and in one case this was waived to accommodate a young person who specifically expressed a keen desire to take part in the study. That is why one participant is aged 10 years.

Table 2: Age and gender of participants

Age	Male	Female	Total
10		1	1
12-18	15	12	27
19-24	7	2	9
TOTAL	22	15	37

The youngest participant was aged 10 and the oldest participant was 24 years of age (see Table 2). Participants included young people with physical impairments and intellectual and communication difficulties. The nature of the young people's conditions varied in type and severity and included physical and or mental disabilities such as muscular dystrophy; downs syndrome; cerebral palsy; autism; ADHD; intellectual, visual and hearing impairments. The existence of co-morbidities was common for almost all young people who took part.

As indicated earlier, achieving high levels of participation proved particularly problematic in a small number of cases where the nature of the disability was profound. However, the initial premise of the research was that if we did not try to include the young person, then their voice would certainly never be heard. This research aimed to address the under-representation of disabled adolescents in studies that capture young people's views and experiences; these studies are relatively rare in that disabling conditions which often exclude a person from taking part in research, such as severe intellectual disability, or clear communication difficulties, were not a barrier to participation.

This is particularly relevant in the context of Personal and Public Involvement (PPI) which is now a legislative requirement for Health and Social Care organisations as laid down in the Health and Social Services (Reform) Northern Ireland Act 2009.

Chapter 4 – Results: Life satisfaction

To collect data on their overall level of contentment with life, participants were asked how they thought things in their life were going nowadays. This was followed by simply worded questions about how they felt about their family and social relationships, their neighbourhood, their school or work life and their social life.

Young people were encouraged to talk about how they thought things might work out in the future, followed by questions about whether they experienced positive feelings like happiness and pride and/or negative feelings like sadness, worry and frustration. The young people were then prompted to expand on what sorts of things provoked these emotions.

Making the connection between satisfaction with aspects of life and particular emotional experiences was not straightforward, often overlapping and sometimes conflicting. For example, a young person could be very content with one aspect of life, for example family relationships, experiencing happiness and pride, but under certain circumstances, family relationships could produce negative experiences such as worry or guilt. Incidents which exemplify this tension are drawn out in this chapter to demonstrate how they impact on each other.

The chapter sets out key positive and negative emotions as a basis for helping to identify the key experiences that, according to the views and experiences of the young people, generates these emotions. However, it is important to point out that these are complex interconnected emotions. They are not a set of independent constructs that can be completely isolated one from another.

With that in mind, some common areas emerged as important for the promotion of a good quality of life, as previously reported by young disabled people (Beresford, 2012; Allard et al. 2014). These were: positive family relationships, personal relationships and social participation. Positive experiences like happiness and pride were commonly bound up with family life, school life and personal traits like resilience or confidence. Negative experiences such as worry, guilt, sadness and anger were apparent when young people were coping with problems at home or at school, or where they felt disrespected by others.

Family relationships

Overall, family relationships emerged as one of the most important factors which impacted on how emotional well-being was experienced. The majority of young people talked positively about their family life and described close, loving relationships with supportive parents/guardians. It was clear that enjoying a positive family life was the most significant factor contributing to good emotional well-

being. This was discernible in the way the majority of participants described experiencing positive emotions like happiness and pride when talking about their family.

There was a strong sense throughout the interviews that having a large extended family instilled a sense of pride. When talking about their family environment many young people included extended family living in other parts of the country or in other countries. Those who were fostered or adopted talked about their birth family as well as their adopted family.

For some young people with a more complicated background, such as Susan, family remained one of the most important aspects associated with feeling good about life. Susan was 13 years of age and a wheelchair user. She attended a special school a considerable distance from home. Susan's grandfather had been her main carer and, when he died, she was placed into foster care. Her foster family subsequently adopted Susan. When asked what made her feel really good about herself, Susan explained it in terms of being cared for and loved. This is how Susan explained what made her feel happy:

> *My mummy, my other mummy, cause I was adopted, she didn't really look after me properly. She says it was because she couldn't look after me properly but I know it was because she told the social workers lies… so then my granda took over and looked after me. That made me feel happy. Then when my granda was old and couldn't look after me, my other family, my new family foster cared me and then they said they wanted to adopt me and that was my happiest moment.*

Throughout Susan's interview, references to family were frequent. She talked about having '*a big family'* and '*a good family'* and included grandparents, aunts, uncles and other extended family members in her portrayal of family life. She recounted how an on-going disagreement between two family members made her feel sad.

The achievements of family members was a point of discussion in many interviews. For example, a number of young people talked about their siblings being at university or being in a professional occupation. When Ruth (a 16 year old still at school) was asked if there was anything that made her feel really happy about life at the minute, she associated her happiness with her brother's academic achievements:

> *I'm happy for my brother, he got into [university]. He passed his…he got an A, B and C in his A levels. I was really proud of him and mummy was proud. My whole family was proud of him.*

Individual feelings of pride in another family member's accomplishments was evident in other interviews. When one young person talked about spending time with his father, he wanted to let the interviewer know his father had a reputable occupation and added spontaneously '*well he's a qualified electrician you know'.* Another respondent talked about how his father built a ramp for an office in his

local area. He emphasised how it was not built for his own personal benefit, but for the benefit of all people in the neighbourhood. He explained:

> *My dad made a wee ramp for the office so he did, and it was handy you know.*

He explained further:

> *He done it himself so he did. It's not for me, the step wasn't too bad for me, it wasn't too high. But it's not just for me, it's for other people in the village. Usually they might trip, so emm, my father, he gave them it…I could handle it alright so I can.*

The association between pride in family achievements and increased personal well-being was quite a strong underlying theme. However, when and if people framed their family in terms of pride it was much more likely to be pride in other family members rather than in themselves.

The centrality of family in the lives of disabled adolescents is similar to that of non-disabled children found in other studies, for example the Children's Society studies on young people's views on what things matter for a good life (Children's Society, 2006; 2012). However, there were aspects to how participants in this study described and discussed their family lives which are not so common amongst their non-disabled peers and more akin to young people with high level needs: one was the level of instrumental support provided by their immediate family, a second was the degree to which children felt a responsibility for their parents and a third was the extent to which family was a source of social interaction.

When talking about sources of support in their lives, the majority of participants identified their parent/s as being the main people who supported them. A small number included their siblings and other extended family members like grandparents as care givers, but in most cases the foremost supportive role was attributed to the main parent/s and here, mothers featured highly. Discussion mainly referred to instrumental assistance and included transport, help with dressing, administering medication and addressing other personal needs. The extent of support was primarily dependent on the nature of the main disabling condition, the existence of comorbidities and, to a lesser degree, the age of the young person.

The substantial level of support received from parents and the complexity of emotions this evoked was most evident in interviews with older adolescents who were more inclined to express a desire for independence away from their family. Older adolescents' acknowledged that such support promoted their ability to live a more active life, but felt that being in receipt of such extensive parental help also triggered conflict between dependence and independence. Older adolescents recognised they were of an age where their peers were branching out into self-sufficiency, whilst they continued to need constant support. This presented an imbalance in the dynamics between adolescent and parent relationships over and above the typical relationship between non-disabled adolescents and their parents. These

circumstances present a further layer of complexity when ascertaining the well-being of disabled adolescents. So, whilst older adolescents identified family support and the quality of family relationships as key components enabling them to live full, happy and active lives, the majority experienced this as a push-pull type of relationship. Older adolescents wanted to push against dependency but were pulled back to a dependent state by the need for support. This is discussed in more detail later in the chapter.

Regardless of the conflict between dependence and independence, respondents recognised the need for, and attributed great value to, the support from their family – the words of one respondent is an apt summary statement - *'I've a great family'*.

Friendships and social participation

Outside of family relationships, having good friendship bonds has consistently been found to be among the main influences of children's SWB (Rees et al. 2010a; 2010b; Children's Society, 2012; Bradshaw et al. 2013). In this study also, good friendships emerged as a very important determinant of contentment and happiness with life.

Good relationships with peers helps adolescents to develop social skills, enhance their self-esteem and establish autonomy (Currie et al. 2012). Positive friendships provide the opportunity for young people to interact socially and have been found to have a protective effect on adolescent health, including their psychological well-being (Zambon et al. 2010). Key health outcomes highlighted by disabled children and young people have prioritised aspects beyond morbidity and mortality, such as social participation and friendships, because they enable them to live an ordinary and fulfilled life (Allard, 2014). This is particularly salient, and the promotion of opportunities for social interaction are increasingly being viewed as necessary to encourage friendship development in young people with disabilities (Kampert and Goreczny, 2007 quoted in Solish et al. 2010).

However, children and young people with disabilities often face additional barriers which make it more difficult to create and maintain friendships than their non-disabled peers. For example, they may lack social experience and have less developed language and communication skills than their typically developing peers (Solish et al. 2010). Participation in formal and informal activities with peers is an important way of promoting social interaction, and young disabled people value social activities which help them to maintain existing friendships and develop new ones (Aitchison 2000; Petrie et al 2000; Thompson et al 2000; Keil et al 2001; Murray 2002; Turner 2003; Ludvigsen et al 2005).

Approximately two-thirds of adolescents we spoke to reported taking part in some sort of social activity which provided an opportunity to interact socially with others. Mostly these could be described as formally structured activities affiliated to organisations providing services for young people with complex needs. Attachment to a more formal type of club or society was highly significant for the

young people in this study because, as the literature suggests, most participants did not socialise informally within their neighbourhood and opportunities for making friends in their locality was very limited.

The experience of bullying deterred some participants from seeking to socialise with locally-based peers. For example, Danielle did not socialise with other young people in her neighbourhood because, she explained *'they bully me'*. For others, their friendship networks were some way from where they lived, often because of attending schools a considerable distance from where they lived. Susan, for example, attended a specialist school quite a distance from her home, and was socially isolated from her friends once home.

Julie was 18 years old, visually impaired, and had cerebral palsy and additional complex comorbidities. She talked about her 'club' frequently[6], explaining how she preferred arts and crafts and how the people there helped guide her way around the club. The high level of importance that the youth club represented in Julie's life was evident, not just from how she talked about it, but also by the fact that she intended to become a volunteer in the club before she left school. The opportunities that the club provided for promoting social interaction for children and young people with disabilities was something that Julie related to strongly. This was pronounced by Julie's anxiety over pending government cuts to youth clubs such as hers, which she articulated succinctly. In fact, the interview had finished and Julie asked if she could add another comment that had been troubling her:

> *"I forgot to say this bit. I also think there should be more youth clubs, especially for people with disabilities because normal children they can go out and play on the streets and things like that, where people with disabilities those clubs are the only way they can socialise out of school and I don't think the government should be cutting funding from those."*

An important factor associated with the structured nature of social activities means there is little room for spontaneity with less flexibility over events and schedules. Some of the clubs provided transport but operated on a strict timetable. For example, Julie's bus picked her up from her house at 4.30 pm to take her to her club. This meant that someone had to be present at home to assist her. In the absence of other responsible adults or siblings, a parent or guardian would need to be either unemployed or working flexibly or part-time to accommodate this.

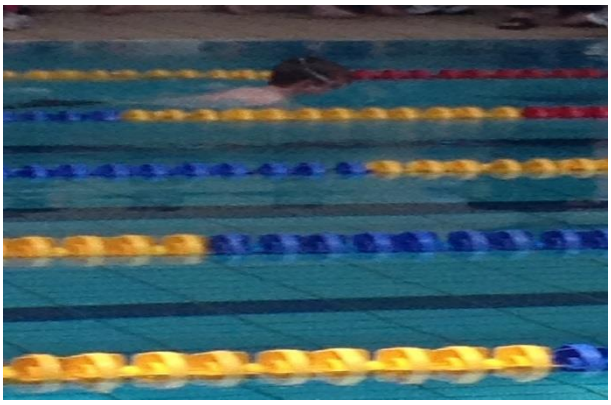
Nine young people said they did not participate in any social activity at all, not even of a structured nature. This was because either there were no existing clubs or centres accessible or they simply did not want to participate, preferring their own company.

[6] A Gateway Club established with the aim of advancing the personal development of young people with intellectual disabilities through social, recreational and sporting opportunities.

Existing research suggests that, compared with children without a disability, children with disabilities spend more time interacting on a social basis within a family setting; either with their parents or with members of their extended family or with other adults (Modell et al. 1997; Buttimer and Tierney, 2005; Solish et al. 2009). This pattern of social interaction was evident in the current study as the social lives of most were closely bound up in many ways to family interaction. For example, for Alan (17 year old) *'accompanying mum to the supermarket'* was what he said he did at the weekends, while *'playing snooker with dad'* was his interest outside of work.

Patrick, who was aged 18 years, was one of the very few participants who used photographs during the study. Patrick was visually impaired with an intellectual disability. He chose the things to photograph which made him happy and his mother took the actual photographs for him. Among the photos were a bicycle, a football, the family car, a bowl of strawberries, a packet of sweets, a swimming pool and the family dog.

The photographs initiated a discussion, which revealed that Patrick belonged to a swimming club and also played football in the leisure centre at weekends. This allowed Patrick to meet up socially with friends outside of school. When asked why he chose these particular photographs, he replied: *'It makes you happy'*. He explained how his parents would accompany him and support him from the side-lines:



'...they'd say to me 'come on boy, you can do that, you can go swimming.'

He talked at length about his favourite football team (Manchester United) and how he sometimes went to matches with his mum and dad; the bicycle he rode with his father - *'I'm the stoker and dad's the captain'*- as Patrick explained it.

The significance of the family car became more apparent as Patrick described how his mother always drives him to swimming and football:

'…it's got six gears actually and then they'll be driving me to say like swimming or football and they'll be saying 'come on, come on, get your football gear.'

When asked which photograph was his favourite, Patrick replied:

'I think I'll go with the football actually.'

There are at least two important themes emerging from this aspect of Patrick's interview. First, how closely Patrick's social life is interweaved with parental involvement and second, the high level of transportation required to arrange Patrick's social activities. Dependence on transport for engaging in social participation was high for the majority of participants. This mostly involved specialist buses arranged by organisations or a family car. There were very few references made to the use of public transport. Comments relating to family transportation was particularly noticeable for events taking place at weekends. It is likely that only participants whose parents had a car discussed this, suggesting that for young people whose family do not have a car, participating in weekend social events is less frequent.

In at least one instance, the adolescent's mother was pivotal in creating the conditions necessary for the promotion of any social contact, outside of her club. When asked whether she had any friends where she lived, Julie explained that she did not have any friends close by:

The only real social circle I have are the friends at my school and at my club. Apart from that, no one else where I live, except for sometimes if my mum would ask my cousin to come up and stay with me for a wee bit of company.

When prompted to expand further, she explained:

You see the problem is, with my disability I can't go out on my own because of my vision…The only time I really go out is if I'm with my mum or with another family member or with my club.

Tommy, a 20 year old young man with autism, talked about spending time with his mother and another neighbour and her two younger children. It transpired that both of the neighbour's children also had

autism and the two families had become close. They now regularly socialise together – *'our wee group'* as Tommy described it.

The close involvement of family within the social life of an adolescent is also very demanding on parents/carers – emotionally, practically and financially. The structured nature of social activities means there is little room for flexibility over timetabled events and schedules. This means parents are more constricted by time considerations in facilitating their child's engagement in social activities. For parents employed in jobs offering little autonomy over their terms and conditions, this presents additional barriers to enhancing participation. Heavier reliance on transportation means that participation is likely to be particularly affected by the availability of support services and access to a car. Environmental factors such as these have been shown to impact negatively on the social inclusion of disabled children, as participation is positively influenced in families who have higher incomes and are in a better socio-economic position (Clarke, 2006). Respite services provide an important support for families to continue their caring role and, understandably, there is high demand for their services. However, their allocation is restricted because of a lack of resources to meet this demand (DHSSPS, 2012b).

Respite services also played an important role in enhancing quality of life for the person being cared for. Young people placed high importance on centres that provided short-term and longer-term breaks away from family, like an activities day out or a weekend away. This is because centres like these provided an opportunity to nurture existing friendships and help develop new friendships without the interference of family members. It was a crucial way of gaining some independence. In these instances, it proved an important step towards autonomy. When Carol was asked why she loved getting away, she explained:

> *To give my family a break and to give me a break from them as well.*

Only three respondents spoke about participating in informal activities with peers. This included going to the cinema, playing football, Playstation and going to the local pub. Two factors were common here – participants were older and the places they visited were very localised. As one participant explained, any recreational or leisure activity that required travel beyond a short distance presented a major barrier to participation. During Brian's interview (one of the oldest participants at 24 years of age and a wheelchair user), it was clear that transport was not the only barrier to socialising he faced – access was another major difficulty:

> *I used to have a girlfriend but the problem with that is I was relying on my dad taking me all the time…my mum can drive but she feels she can't cope with heavy traffic and you know it's kind of hard when you're relying on one person to take you somewhere. I just want to be like any other young person, to decide 'oh I'll get up this morning and*

go and see [friend] or somebody or do something'. Whereas for transport, you have to sort of book it far in advance you know. And the other thing too is access to buildings.

It may be the case that older adolescents 'outgrow' existing clubs and societies as they age and go through different stages of development. Given the known physical and mental health benefits of social participation, it would be beneficial to encourage opportunities for age appropriate social participation as young people go through adolescence and transitioning to adulthood. Structural and environmental interventions to encourage participation such as improving physical access, providing specialist equipment and increasing parental awareness of what is available can be helpful but, as noted in Shikako-Thomas et al. (2014), these interventions do not automatically correspond with improvements in participation. To our knowledge, there is little available systematic research on non-structural types of intervention to encourage the actual social participation of adolescents with disability.

Summary of Chapter 4

- Good family relationships and support are absolutely central for promoting enhanced well-being.
- Family represents a more significant element of the social life of a teenager with disabilities than would be typical of their non-disabled peers.
- This involvement places high demand on a family's emotional, physical and financial resources.
- Outside of family relationships, strong friendships are a major determinant of contentment and happiness with life.

Chapter 5: Results - Positive life experiences

Participants were asked whether there was anyone or anything that made them feel very happy or very good about their lives at that time. When appropriate, this was followed by asking them who or what helps them most to feel good or happy. Table three below sets out the most positive emotions discussed during the study and the common sources which triggered these emotions.

Table 3: Positive emotions and their common sources

Happiness/Joy	Pride/self-esteem	Confidence/Resilience
Family achievements	School achievements	Having a positive attitude
Family time together (days out, family holiday)	Sporting achievements	Sense of independence
Good relationships with peers	Personal development	Communication with others
Having a pet		

It must be stressed that these are complex, overlapping and interconnected emotions. They are not stand alone constructs and cannot be isolated from each other. Separate incidents or experiences, like family closeness for example, can elicit joyful experiences; but, as we will see later in this chapter, can also act as a conduit for less positive emotions in certain circumstances. The sources are presented in this way to provide a useful instrument for examining their basis more carefully. With this in mind, these positive feelings are discussed in more depth below.

There is evidently considerable overlap between the contribution made by good relationships and quality time spent with family, friends and peers to overall life satisfaction and contentment, and their contribution to personal happiness and joy. This reinforces the findings of the growing number of quantitative studies that reveal the importance of positive family life and relationships for the overall well-being of all children and young people (UNICEF, 2013; 2014). Importantly, it corroborates the views and experiences of the much smaller number of qualitative studies that have explored SWB from the perspective of disabled young people themselves (Beresford, 2012; Allard et al. 2014).

Colette was 14 years old and attended a learning support unit within a mainstream school. She expressed a wish to use the show cards during the interview. When asked to pick a card that would be like a feeling she had 'now', she picked 'excited'. When asked what makes her excited, she explained she felt that way when her uncle came home from abroad because it meant her family size increased, with this additional member. When asked if there were any other feelings she would experience now, she picked 'good'. She explained what it was that made her feel this way:

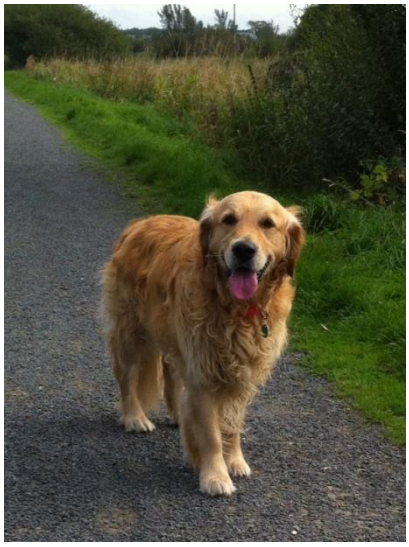
If anything good happens to my mummy.

A small number of young people (seven) mentioned their pets when discussing what made them feel happy or good about their lives.

For example, at the beginning of each interview, participants were usually asked where they lived and who they lived with. Louise, a 16 year old with an intellectual disability, described who all lived at home in the following way:

My mummy, my daddy, my dog, my sister and me.

For Louise, the dog was very much a part of her family and an important member at that. When asked later on in the interview if the dog belonged to everyone, Louise was emphatic in her reply '*No, she's my dog'.*



One of Patrick's photographs was of his dog and, when asked why he included this photo, Patrick explained how he had had his dog from when he was a pup and that he was happy when they went out for walks. Patrick's visual and intellectual impairments mean that his parents also accompanied him on these walks and it was clear that this was an activity that Patrick really enjoyed, not least because it provided an opportunity for spending time together with his parents.

(Patrick's dog)

The importance of animals in the life of 16 year old Ruth was perhaps explained by the fact that she lived on a farm. Ruth had developmental delay and was living with foster parents. She took photos of cows, cats, hens and roosters and explained how she helped her foster family by tending to the animals. There was a strong sense that Ruth took pride in the contribution she made to the work on the farm. However, when asked about things that made her happy, she showed the interviewer photographs of her dogs that she had on her phone, adding that her friend also had a dog and what the dog was called (indicating the possibility that a shared interest provides a connecting bridge between Ruth and her friend).

Clare is 15 years old; she has ADHD and is a young carer for her adoptive mother. A range of complex emotions were very much in evidence during the interview with Clare, which reflects the difficult family circumstances and her role as a young carer. Negative psychological feelings such as low self-esteem, guilt and worry were discernible alongside contradictory expressions of toughness. The following is a short excerpt from Clare's interview where she was responding to a question asking if she ever worried about the challenges she faces:

Clare: *No. I'm one of these people who will go "it will be OK in the morning."*

Interviewer: *...if you were worried about something, or something was making you not too happy, who would you chat to?*

Clare: *I wouldn't talk to my ma about it. Who would I talk to? I probably wouldn't talk to nobody.*

Interviewer: *What about your dad?*

Clare: *I'd talk to the cat. The cat is hardly going to solve your problems but just tell the cat and you will be alright.*

In this short excerpt, we see Clare firstly denying she ever worries and putting forward a show of resilience. Her protectiveness towards her mother is tangible when she rebuffs the idea of revealing her worries. Her vulnerability to isolation and poor well-being is exposed when she admits she probably would not confide in anyone. In Clare's case, her cat is her chosen confidante.

Clare was one of the three participants who wanted to take photographs. Her photos included scenes typical of a teenager her age and included her dressing table with make-up and a wardrobe full of clothes. Quite a few photos were of her pets. These included a dog, a cat and chickens. The short passage above suggests that Clare's cat confers much in term of psychological health benefits.

(Clare's cat)

Research on the health benefits of pet ownership suggest that having a pet increases a person's physical, social and psychological well-being (Wells, 2009; 2011). Much of the social and psychological benefits are often associated with the companionship that pet ownership extends, thus reducing feelings of isolation and depression (Barker et al. 2003). Improved physical health has been linked with increased exercise and activity required for looking after a pet (Anderson et al. 1992; Headey, 1999; 2008). Consequently, animal based interventions for improving physical and mental health among adults are generally considered conventional, with pet focused interventionist programmes increasing among children and young people (Morrison et al. 2013). In contrast, other studies have suggested that the physical health related

benefits associated with owing a pet are too often confounded by the failure of most studies to control for the demographic characteristics of the pet owner (Pachana et al. 2005; Utz, 2014).

A longitudinal study of children's social and emotional development, carried out by the University of Cambridge, found that vulnerable children (those suffering bereavement or serious illness for example) were more likely to have a stronger relationship with their pets than their peers. These relationships were, however complex, insofar as while these children displayed more pro-social behaviour, they also under-achieved academically and reported more mental health problems. One possible explanation was the susceptibility of children, already experiencing vulnerable lives, to such problems (see http://www.cam.ac.uk/research/news/childs-best-friend).

When considering that a small, but not insignificant, number of young people in this study linked their well-being with pet ownership, the importance of understanding the role of pets in people's lives becomes more salient. Young people like Frank (19 years old), who, when asked what made him happy in life replied:

> *My friends, my family and my pets.*

Pride/self esteem

When young people expressed feelings of pride in themselves, this was commonly engendered by sporting achievements, school achievements, and personal development.

Sporting achievements

The association between involvement in sporting activities and direct physical and mental health benefits are increasingly recognised and actively supported in health policy documents across the UK and internationally. For example, Northern Ireland's new Strategic Framework for Public Health (DHSSPS, 2014c) stresses the importance of equipping children with the life skills and behaviours needed to influence later life chances and tackle health inequalities. Initiatives that encourage participation in sport and leisure activities, together with social and cultural activities, are seen as particularly relevant to influencing the determinants of health and well-being. This is because participation impacts positively on other issues such as creativity, social inclusion, and good relations as well as promoting lifelong enjoyment and fulfilment (DHSSPS, 2014c: 53).

Increased activity and sport has been found to positively impact on psychological development by providing opportunities for fostering close friendships and peer networks, particularly for socially isolated and vulnerable individuals (Martin and Smith, 2002). The link between improving physical fitness and mental well-being is reflected in the Department for Culture, Arts and Leisure (DCAL*) Sport Matters: The Northern Ireland Strategy for Sport and Physical Recreation 2009-19.* Top-level

government commitments to sport and physical recreation include a list of targets, one of which is the promotion of increased participation among under-represented groups (specifically people with a disability, as well as women and older people). For example, by 2019 '*to deliver at least a 6 percentage points increase in participation rates in sport and physical recreation among people with a disability (from the 2011 baseline)'* (DCAL, 2009: 15).

The Council of Europe (2001) defines sport as: *All forms of physical activity which through casual or organised participation, aim at expressing or improving physical fitness and mental wellbeing, forming social relationships, or obtaining results in competition at all levels*. Around a quarter of young people in this study expressed feelings of pride associated with their participation in sport. Bobby was a case in point. Bobby was 14 years old and had learning difficulties; his teacher accompanied him during the interview. His teacher explained how Bobby was very scared when he first attended swimming lessons with his school. However, at the end of the school year he had lost his fear and felt especially proud when he finally learned how to swim. Their accounts align closely with the Council of Europe's definition in that a sense of improved mental well-being was evidenced through respondents' participation in physical activity and through obtaining evidence of their achievements, by being awarded certificates, medals or similar credits.

Brian mostly saw his life in very negative terms. Problems with transport, inaccessibility of buildings and lack of independence were only some of the many difficulties he raised during the interview. However, the one topic that intimated a source of pride was the sporting challenges he had undertaken. These included adventurous actions such as Sky Wire activities and strenuous endeavours like completing a marathon. The fact that these activities had been undertaken while in a wheelchair was a definite source of pride and self-worth for Brian. It was all the more poignant because of the absence of other positive life evaluations or experiences discussed by Brian during the interview. Feelings of positivity were reinforced by the significance of these achievements by his friend, a wheelchair user also, who accompanied him during the interview. Following Brian's description of his sporting activities, his friend explained *'And he does it in his wheelchair, don't you?'*

The connection between sport and the promotion of positive feelings of self-worth were evident in other conversations with young people with physical and non-physical disabilities. One of the youngest respondents at 12 years of age, Martin has autism. When asked whether anything had ever made him feel really proud he replied '*Getting medals and all'*. Probing further, Martin explained that he belonged to a swimming club and had been awarded medals for completing specific distance targets. He said:

> *I got a silver and a few bronze, I don't have a gold yet.*

The relevance of this short sentence is the word 'yet' and the implication that a gold medal is anticipated in the future, suggesting positive associations with aspirations and expectations.

Likewise, for Sammy, positive feelings of pride in himself was instigated by his success in hip hop dancing, as he explained:

> *Well, my proudest moment was winning the trophy in hip hop.*

Danielle, a 16 year old girl with sight impairment and intellectual disability, was involved with Special Olympics. Danielle talked positively about the coaching she received at her club. When discussing possible plans for the future, she explained that her plan was to '*get a gold medal in the Olympics*' – another indication of aspiration. Danielle's ambition was to be a professional athlete and when asked what would be required to bring this about, she explained that she needed to train a lot and she believed the Special Olympics club to which she belonged would take her to the next level in training. Her expectations of success were heightened by the fact that her friend had attended the same club and he had competed in the Commonwealth Games, winning a couple of medals.

Iris, who was older than Danielle at 23 years of age and also had an intellectual disability, was also participating in football training with Special Olympics. The training took part on one of the two nights during the week that Iris attended her club. Her friends also attended the same club. Iris said she really enjoyed this. The fact that Iris spoke positively about her training activities, that this was a place where she met up with her friends, together with the lack of evidence of other opportunities for social inclusion, was interpreted as representing a vital part of Iris's social life.

However, fewer opportunities exist for children and adolescents with disabilities to engage in sporting activities. This is said to be partly due to physical differences between disabled children and their non-disabled peers, together with wider social attitudes and structural barriers to participation (Finch et al. 2001; Shapiro and Martin, 2010). This is borne out in extensive research on sport and physical activity in Northern Ireland (Sport NI, 2010), which shows that people with disabilities are significantly less likely to achieve recommended activity levels of 30 minutes of activity on at least five days per week (23% compared to 35% for the average population). Aside from the fact that people with disabilities are older on average, and participation in physical activity declines with age, breakdown by separate age groups still shows considerable differences in activity levels. In addition, disabled people were less likely to be members of a club where they can participate in sport or physical activities, less likely to take part in sporting competitions or to receive coaching in a sporting activity. This means that disabled children often miss out on the important socialising opportunities that interaction with other children offer.

On the other hand, young disabled people who engage in sports programmes specifically adapted to their needs are said to have greater opportunities to benefit from sporting activities because alliance with other adolescents with similar disabilities promotes stronger peer relationships and a greater sense of belonging (Smith, 2003). This was definitely the case for Danielle and Iris in this study.

Some have argued that Special Olympics separates itself from mainstream sports, thereby reinforcing existing negative stereotypes of people with Intellectual Disabilities (Storey, 2008). However, others have commended specific initiatives within the realm of Special Olympics for attempting to promote the social inclusion of young people with Intellectual Disabilities with their peers in local communities (Dowling et al. 2012).

Disability Sport NI (DSNI), which provides opportunities for people with disabilities to become involved in sport, has been very badly affected by recent cuts in public funding. This has resulted in large cuts in their programme and a threat to their continued existence. The organisation has expressed concern that local government underestimates the significance of participation in sport for individuals with disabilities. Furthermore, DSNI argues that the social and psychological implications of this disinvestment, in relation to the needs of vulnerable people, are being ignored.

> *At a time when the rest of the UK has woken up to the value of disability sport and Britain quite rightly celebrates the achievements of Paralympic athletes, Northern Ireland is going backwards. (Gray, 2015)*

The decision appears to place DCAL's commitment to increase the numbers of people with disabilities taking part in sport in jeopardy.

Arts and Culture

An evidence review of a range of cross-sectional studies by Arts Council England (ACE, 2014) demonstrated how engaging in arts and cultural activities can impact positively on a person's physical health symptoms and their ability to manage those symptoms. Building on this, Gordon-Nesbitt (2015) reviewed international longitudinal studies to examine the long-term benefits of arts engagement by considering the impact of high-quality arts activities in non-clinical settings like galleries and museums, theatres, cinemas and concert halls on a person's physical and mental health. According to Gordon-Nesbitt, the evidence suggests that engaging with the arts and culture has positive long-term effects on health and well-being.

> *Several of the studies in the evidence base acknowledge the intrinsic value of the arts and culture. Beyond this, it suggested that engagement with the arts variously permits people to lose themselves in creative activity and gain perspective upon their individual condition as part of a societal whole. As a consciously chosen leisure activity, engagement in the arts is generally shown to have a positive impact upon the body's physiology, in turn improving health and quality of life. (2015: 57)*

Yet, as this study has found, with the exception of the cinema, very little references were made to any engagement with the arts and culture. This may be a reflection of the possible adverse socio-economic position of some participants, and the fact that people living in areas of high deprivation are less likely

than those living in low-deprivation areas to engage in arts activities (DCAL, 2014). But it also mirrors the pattern of significantly lower engagement with the arts by people with a disability compared with those without. It is likely that when deprivation and disability are compounded, it produces more complex challenges to full participation. Lower rates of engagement is particularly disappointing as the same DCAL survey reported that over a third of people in Northern Ireland believe that engaging in the arts had a positive impact on their well-being (2014: 15).

For Tommy, joining a local drama group was what he described as '*a success story for me and my family*'. Tommy had been asked to play the lead role in a musical and, although hesitant at first, he said he knew his family were keen for him to take part and he did it for them. At the time of interview, Tommy was writing a book about living with autism. His intention was to share his experience in order to help others and their families understand better what living with autism is like. With Tommy's permission, a short extract from his draft manuscript (from a chapter about his success) is reproduced below to demonstrate the positive impact that participating in the play had on Tommy's self-esteem. But more than that, success, as perceived by Tommy, was also having the opportunity to *give* happiness to his family.

> *I was only meant to be a minor cast member but when the lead man took ill and couldn't come for rehearsal I was asked to take the lead role. I only did it for my mum and family…Just seeing my mum and granny happy was enough for me. I proved I could do things for myself and be a success. Success is not about money and it definitely cannot be measured easily. Success is about hard work, determination and most of all, it was a journey for me.*

While this was the only example where drama emerged as a positive influencing factor for increasing well-being, it is important because it draws attention to the possibilities that might have yet to be realised.

The *What Works Network* was launched by the UK government in 2013 to improve public services through the promotion of evidence-based policy (Cabinet Office, 2014). The network is funded by a combination of government and non-government sources including the ESRC, Public Health England, the Office for National Statistics, the Local Government Association and other partners, including government departments. The Network aims to establish a base of high quality evidence across a range of social policy areas, in order to assist the commissioners of public services to make better decisions based on evidence of impact and cost-effectiveness, and to identify gaps in knowledge. The Network is made up of seven independent centres covering policy areas which receive substantial amounts of public spending such as health and social care, education and crime reduction. The *What Works Centre for Wellbeing,* launched in October 2014, is tasked to set up a strong evidence base on interventions that have the biggest impact in terms of enhanced well-being. While participation in cultural and sporting

activities is generally believed to enhance well-being, systematic evidence to this effect is thought to be limited. A culture and sport evidence programme has recently been commissioned to draw together the best evidence on the association between culture, sport and well-being (see http://www.brunel.ac.uk/chls/life-sciences/sport-health-and-exercise-sciences/research/bcshaw).

Some of the accounts provided here by participants illustrate the significance of the association between sporting activities, involvement in the arts and increased SWB, which we believe is highly informative.

School achievements

> *I feel very proud when I achieve something in school.*

These are the words of Alice, a 17 year old girl with hearing loss. These sentiments are indicative of the majority of school aged respondents, where school achievements featured strongly in discussions about the specific experiences that engendered positive emotions such as pride, joy and happiness. This is not to say that attending school *per se* was always a positive experience for young people. In many instances, respondents talked about negative events associated with being at school, with bullying standing out as particularly adverse, as discussed later in this chapter. However, when respondents' efforts were acknowledged, this reinforced positive feelings. Acknowledged achievements did not necessarily have to be academic. It some cases, young people spoke about their joy at getting a prize for the best improved work or for their attendance record, or for doing well in sports. Being acknowledged in school also provided an opportunity to give a joyful experience to their parents.
For example, Julie talked at length about her recent exam results and how prize night was a great event. She explained how her mother was very proud of her achievements and that night she and her family had a celebration to mark the occasion. For Julie, there was a strong sense that her own joy came from making her mother proud of her. This meant that every opportunity for achievement was viewed seriously. One such opportunity was a prize for school attendance. However, Julie expressed a sense of injustice at the attendance rules, which she felt discriminated against her on grounds of her disability and her religion. She explained:

> *For your attendance, you know to get a certificate, you need to be there 95% of the time but I find the people who get it are the people who are able to be back to school after [hospital] appointments, where I can't. I have to take the day off. Say if I have a morning appointment I have to take that whole day off. And there was an occasion where the hospital's admin department had made an error and I wasn't even supposed to be at the appointment and they take a mark off you for each time you're off…I think the attendance should be lowered to at least 80% or 90% because I think that's a more acceptable level, especially for people in my circumstances.*

She explained further what she perceived as a lack of understanding and unfairness, not from the perspective of the School, but of the Education Board:

> *All I can say is that there are certain changes that need to be made and school ways. The Board also takes a mark off you if you take St Patrick's Day off. I don't think that's very good because that's part of our religion and I think you should be entitled to that without people, you know like, taking marks and all off you.*

Certificates and/or medals for school sports featured here also. As did making dishes in home economics class and bringing them home to eat with their family. These examples reinforce the association between making parents proud and increased positive personal feelings. However, when compared to responses from older adolescents, who had left school, it underlined the more limiting opportunities older respondents had for enhancing positive affect in a similar way.

Personal development

A number of young people identified their own journey of self-development as contributing strongly to their overall sense of feeling good about themselves. This is likely a reflection of the fact that a large proportion of participants were linked to a Participation Project, established to develop ways of involving children and young people with disabilities in decision-making in relation to health and social care and children's services planning processes. A central element of this project is the high level of awareness of human rights among the young people, and a heightened perception of the rights-based issues faced by other disabled people in addition to their own personal experiences. Their experience highlights the impact that knowledge building and advocacy awareness can have on good well-being.

The example used here to demonstrate this is that of Olivia, aged 13 years. Olivia has an intellectual disability, and is not counted among the numbers of participants taking part in this study because no actual interview took place. However, in her own way, Olivia made a very important contribution to the study. This is what happened:

> During a researcher visit to the participation project premises to discuss the well-being study with a group of young people, Olivia joined in the group conversation. The group discussed feelings and emotional experiences like feeling happy and feeling sad. During the meeting, a number of young people expressed an interest in taking part in the study. Olivia initially thought she would like to take part, but became upset when people started to talk about sadness and left the group. It transpired that Olivia had experienced bereavement in the past and was very sensitive. About an hour later, when the researcher was leaving the premises, Olivia called the researcher back and gave her a drawing. She said "this is what makes me happy". She drew a sun with a smiley face and, at the top

> of the page, were the initials UNCRC. Olivia's drawing was considered so poignant, it became the cover of this report.

The role of advocacy building activities, such as presentations in front of an audience and having a say in service planning and such like, played an important part in these young people's interviews. However, involvement in personal development endeavours *per se* was not enough to engender good emotional well-being: fundamental to these activities was the belief that their voice was being heard. Ruth talked about her forthcoming presentation at a seminar on the needs of young service users. When asked how she felt about presenting, Ruth explained that she was nervous at the start but was looking forward to it. Ruth then explained how she had told her teacher about the seminar and her thoughts implied a sense of self-esteem and pride gained from the approval of her teacher:

> *Good like. We told our teachers in our school about it and they were over the moon about it, over the moon.*

She explained her feelings further:

> *I'm happy that people's listening to the message and not ignoring it.*

What makes these examples significant, is that it demonstrates how effective an emphasis on meaningful participation embedded within a rights based approach can be, for improving personal development and, as a result, enhance the well-being of young people with more complex difficulties.

The findings here suggest that all children and young people could benefit from knowing that, as a society, we all have a set of rights and what those rights actually mean. Surely, it is more likely that a young person who is in step with a rights-respecting society from an early age, will learn to value other people as rights holders.

The study did not set out to examine adolescents' level of awareness of the UNCRC or the UNCRPD, or any other rights based legislation, but it is a fact that human rights were not alluded to by any young person who was not a member of the participatory group.

Confidence/Resilience

As noted above, good emotional and psychological well-being are affected by a wide range of different demographics like gender and age, income and housing conditions, and personal factors such as health status and social connectedness (Boarini et al. 2012). Biological factors, including a person's genetic predisposition, have also been closely linked with a sense of increased well-being (Ebstein et al., 1996; Hamer, 1996). Studies with sets of twins suggest that the propensity for happiness is, to a significant extent, inherited (Lykken and Tellegen, 1996; Lyubomirsky et al., 2005) while personality type has been found to have a significant impact on how people respond to questions on subjective well-being

(Diener, et al., 2003; Gutiérez et al., 2005). Meanwhile genetic variation is claimed to explain up to 50 per cent of the difference of variance in SWB (Inglehart and Klingermann, 2000).

The concept of homeostasis is based on the belief that when threatened by external adverse change, the body will set in motion physiological processes to restore and maintain normal body equilibrium. It further suggests that we all have an individual 'Set Point Range' (Cummins et al., 2009: 26), which ensures proper functioning of the body by giving everybody a sense of positive well-being. Some people will have a higher or lower 'set point' than others, reflecting differences in optimism and genetics, but all points are within a set range[7]. The theory argues that individuals will eventually adapt to almost any negative life event and return to a state of well-being that is largely determined by genetics and personality.

In this instance, adaptation is viewed positively as feelings of resentment are left behind, instilling a sense of positive well-being (Cummins et al., 2009). Such processes are also said to be natural 'self-defence' mechanisms and, as such, are viewed in a constructive light by proponents of adaptation as a form of resilience (Luthar et al., 2000). While not disputing the positive value of resilience per se, a difficulty arises when resilience to disadvantaged circumstances becomes so entrenched it begins to mask levels of inequality, leading to an unhealthy acquiescence that diminishes an individual's sense of entitlement (Graham, 2011; Kelly, 2014). Central to this discussion is the interaction between adaptation and low expectations; whereby a person becomes grateful that their situation is not as bad as it could be and lowers their aspirations accordingly (Runciman, 1966, Elster, 1983). This has resonance in part with the research of Albrecht and Devlieger (1999) whose took a salutogenic approach to examine the lives of persons with disabilities and the disability paradox. According to Albrecht and Devlieger, part of the explanation for high life satisfaction among moderate and severely disabled respondents was thus:

> *Respondents explain their well-being in terms of acknowledging their impairment, being in control of their minds and bodies…having a 'can do' approach to life…and…feeling satisfied when comparing one's self to one's capabilities and the conditions of others in similar situations' (1998: 984).*

Does this mean that it is a good thing for people with disability to make favourable comparisons with similar others in order to enhance their sense of well-being? Even if that well-being comes as a result of lowered expectations and aspirations? Alternatively, is it better for a person's mental health, to have expectations that are realistic and achievable?

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[7] Accordingly to Cummins et al. (2014), on a 0-100 point scale, set-points have a normal population distribution of 70–90 points, with an average of 80.

The researchers of this study faced similar dilemmas described by Beresford (2012: 238), namely, how to reconcile the views on life satisfaction and happiness of young people, who may have lowered their expectations and/or have limited cognitive ability, when we know that children and young people with disability are more likely to experience health inequalities than their non-disabled peers, and that these inequalities often persist into adulthood, increasing the risk in later life of serious physical and mental illness, poverty and social exclusion (Disability Rights Commission, 2006; Emerson and Hatton, 2007; World Health Organisation, 2008; The Marmot Review, 2010; Allerton et al. 2012).

The literature shows that to some extent, a person's personality and attitude impact on their well-being and contentment with their life. According to our analysis, adolescents who displayed a positive attitude and a confidence in themselves had higher well-being (in that they benefited more from their positive experiences) than young people who were more aware of their limitations.

Younger participants were more likely to speak positively about how they viewed themselves. Martin, who at 12 years of age was one of the youngest participants, has autism. He had described how he is sometimes involved in bullying incidents in school (both as a victim and as a perpetrator). When asked if there was anything he would like to be different about his life he replied:

> *No. I learned this, everyone's different.*

Even though bullying did make him sad, there was little indication that Martin associated the bullying with negative images of his own identity. Earlier in the interview, Martin was asked if he knew what autism meant and he said he did not.

Sammy was 14 years old and also has autism. He attends a special school outside of the local area. Disconcertingly, Sammy had been bullied both at school, by others in the neighbourhood and also on-line, having recently been the victim of cyber bullying. When asked how that made him feel, he explained:

> *It just makes me feel bad because you just want to be left alone. If you have a hard time in school, you just want to be left alone in the house. You don't want any more stuff coming up.*

Despite this traumatic experience, Sammy demonstrated strong resolve to deal with the situation in the way he thought most constructive:

> *Don't let them annoy you, don't let them make you feel like crying. Just walk on.*

He said his parents taught him how to handle situations like this and he believed his teacher was a good support. But it is important to note that other sources of support were instrumental in helping Sammy overcome the damaging impact of bullying. These were the sporting club which he attended twice a week, his aunt and uncle whom he visits regularly, and his girlfriend with whom he goes into town, all of which he said keeps him '*very busy'*. Sammy explained that because his time is occupied, he does

not have to care about the difficulties he faces with particular individuals in his neighbourhood, because, in his own words *'I have something to get me out every day'*. This exemplifies the importance of social support and the availability of social outlets like sporting clubs for alleviating negative influences. Sammy had the following advice for young people who feel they cannot get out or do not have friends:

> *I would say, try to get something, anything like. There is always a club that will take you like karate, swimming, dancing, there is always something like wee youth clubs. Try and get out somewhere.*

Sammy was one of the most engaged respondents in the way he exuded enthusiasm during the interview. It would not be an overstatement to say that Sammy radiated positivity. But even here, with someone as positive as Sammy, it shows the degree of reserves it takes to combat the malevolent nature of bullying. It also puts into sharp relief, the difficulties facing young people who do not have similar support structures or for physical, environmental or other reasons, cannot avail of Sammy's advice.

When asked what he thought most helped the most to feel happy, he replied:

> *The reason I'm happy is because I am positive and I am never negative. I love my life, I know sometimes it's annoying but I love my life like, and I'm happy with my family. I have fun and I never be down.*

So, what is it that helps respondents to stay more positive than others in the face of adversity? In addition to internal resources such as a positive attitude, a common factor was the high and consistent level of strong practical and social support from family and social networks. For example, Martin said his mother brought him up to understand that everyone is different. Sammy had been afraid to tell his mother about the cyber bullying in case she got worried, but he was able to tell an extended family member (his aunt) who in turn told his mother and the situation was resolved. As Sammy explained:

> *I know I usually do talk to my mummy but I just felt I couldn't talk about it so I was worried. So then I told my mummy everything and once I told my mummy I felt happy. I felt good again.*

Another important source of support was the one-to-one help received from classroom assistants. Jack (who was 12 years old and attended a special school) was one of the most difficult participants to interview, in that the severity of his condition meant that the barriers to communication were significant. Initially Jack engaged with the feelings cards, but soon got fed up and, after about five minutes, asked for the interview to stop. But in this short time, what did emerge was how much he was attached to his classroom assistant. When asked about who or what made him feel 'good' or 'happy', he kept repeating a girl's name over and over again. His parents advised that this was his classroom assistant with whom he was very close. They explained how Jack waits for the bus every morning to take him to school. This

routine is very important and weekends are difficult because he gets very agitated when he is not at school.

Owen is also close to his classroom assistant. He has had the same person for three years and his parents explained how she goes out of her way to help him. They believe the continuity of the relationship has been very constructive and of immense help to Owen who, unfortunately had been bullied quite severely in the recent past (Owen described the bullying incidents in detail but the nature of the behaviour was quite distinct in its malevolence so it is not recounted here for fear of risking anonymity).

The main point is that these supports are, in many ways, outwith the control of the individual. It raises the question about what would happen if they were withdrawn or diminished. To what extent would a positive attitude be maintained without these substantial buffers?

Summary of Chapter 5

- Self-esteem was increased by sporting achievements and school based acknowledgements of advances and attainments.
- The availability of opportunities to achieve was an important means of enhancing SWB.
- Few references were made to participation in culture and arts.
- Good relationships with others is an important sense of SWB. These relationships are sometimes precarious, for example, relationships with staff who may leave, or at schools that young people will leave.
- For a small number of participants, having a pet contributed to enhanced SWB.
- Awareness of human rights instruments contributed to the building of personal strengths and skills.
- Development of personal strengths and skills contributes to a better sense of personal well-being.

Chapter 6: Results - Negative life experiences

In order to investigate young people's negative experiences and their origins, we asked if there was anything or anyone that made them feel sad or worried. As far as possible, when participants referred to a current issue, we followed this up by asking if there was anyone they could talk to about it. In many ways, the responses verified the findings reported above – that those who were most unhappy or discontented lacked the resources that the majority of young people identified as promoting positive affect.

Our analysis indicates that four common negative feelings were most often expressed. These were: worry, guilt, sadness and anger. Often, there was one trigger or cause of several emotions. For example, a lack of independence was closely associated with expressions of sadness and anger, as was a lack of proper communication.

However, it became noticeable that there were particular incidents that were more likely to provoke specific emotions than others. For instance, worry was more often expressed in relation to future job prospects and unfulfilled aspirations, while guilt was mostly caused by feelings of being a burden on parents. Anger on the other hand was mostly discussed in relation to structural factors such as lack of transport, communication difficulties, disrespect and lack of proper understanding. Table four below lists the most frequent experiences reported by respondents when talking about these negative feelings.

Table 4: Negative emotions and their common sources

Worry	Guilt	Sadness	Anger
Future job prospects	Feelings of being a burden	Lack of independence	Lack of understanding of others
Parental health	Parental health	Having no-one to talk to if worried	Transport issues
Parental disposition	Parental disposition	Absence of choice	Absence of choice
Unfulfilled aspirations		Lack of proper communication	Lack of proper communication
Family income		Bullying	Bullying
		Low self-esteem and self-image	Inaccessibility (buildings, parking etc.)
			Unprofessional practices
			Disrespect

Once again, it is important to emphasise the interconnectedness of these complex emotions. They cannot be isolated from each other. For example, expressions of anger generated by the inaccessibility of buildings, could bring about a lack of independence, which was closely associated with sadness and depression. The order in which they are presented does not imply a hierarchy of emotions. The sources are listed in this way because it provides a useful mechanism for examining their basis more carefully.

Bearing these issues in mind, we now review in more depth what emerged about these negative feelings from our interviews with young people.

Worry

When worry was expressed, it tended to be most often caused by the uncertainty of future prospects and unfulfilled ambitions, concerns about the general and mental health of parents and, for a small number of young people, the adequacy of the household income was an existing concern.

Most participants had ambitions to gain employment. When asked if they thought this would come about, the majority thought it would. However, four participants believed their job prospects were tenuous.

Ed was a case in point. At 23 years old, he was one of the oldest respondents. He had been working in a part-term temporary office job, which had been organised by a voluntary organisation run by disabled people. The placement had come to an end and Ed talked about how much he liked the work and would like to get a job in an office. However, he spoke about how limited he thought his opportunities were of finding a job that could accommodate his needs:

> *Because it's trying to find somewhere, in an office where it's all flat. Or where there's lifts or something. But some places, there's steps and you can't get into it.*

When asked how that made him feel, Ed replied:

> *Terrible in a way, because I feel as if – 'why can't I get in? Because it shouldn't be like that. For me not to get into the place. It should be all accessible so it should.*

Julie talked about future plans and immediate ambitions. Her plan was to get into college with the ambition of getting a job. However, Julie anticipated facing major barriers due to her high level needs:

> *Well, I'm hoping to get into college and the Vice Principal of the school last year, she was saying that at college I would need a one-to-one [support worker] and apparently they're hard to get.*

Perceived lack of appropriate transport was another contributing factor for believing this was a plan that would not come to fruition.

Nor did Julie see her ambition for employment as uncomplicated. Julie was worried about how a prospective employer would judge her suitability, given her condition:

> *Well, my main ambition for the minute is hopefully to get a job because I'm worried about whenever employers find out about all my conditions and my eye sight, I'm worried they wouldn't take me on because I might be too much of a risk.*

As discussed above, overprotective parenting was an emerging factor when participants discussed their family relationships. However, the reverse was also true – overprotective children was a theme present in some young people's interviews. We did not intentionally set out to ask adolescents about the health of their parents or guardian but this topic came up spontaneously, mostly with young people discussing the health of their parent/guardian in a concerned manner. Martin, who was aged 12, talked about his mum smoking and when asked if he worried about her smoking, he said no because he understood she was smoking to '*keep her nerves calm'*. But when asked if he worried about his mum in general, he said:

> *Yeah, she has a sore back. Plus her liver is not working.*

Another five respondents expressed concern about their parents' general state of health, this included talking about a past or forthcoming operation. Carol's concern was that now she was getting physically bigger, lifting her was putting extra strain on her mother's back. Her worry was acerbated by the fact that her father was soon to undergo a major operation. She explained it this way:

> *I don't know how mummy is going to cope having to look after him and me.*

At least one respondent was a full-time carer for her mother outside of school hours. Clare is 15 years old and explained how her mum was in a wheelchair, so she had responsibility for most of the housework. She lives at home with her parents and an older and younger sibling. However, it became obvious that her sense of responsibility to her mother ran greater then household chores. She explained how, when her mother '*takes sore'*, Clare does not go out and cancels events she had planned with her friends. This in itself causes argument between herself and her friends because her friends get angry for letting them down, and fall out with her. Later in the interview, she talked about times when she felt happy:

> *When mum's not sore I'm happy, when she's getting out and about. I hate it when she's home lying on the couch not fit to move, I hate that. I like it when my whole family is together, no rowing going on.*

It is clear from this excerpt that Clare associates her own happiness to her mother's well-being.

The significance of this overprotectiveness towards parents is that all the young people in this study had their own physical and/or mental health difficulties. Their parents' health and well-being was an extra

layer of concern they shouldered. But their sense of protectiveness towards their parent/s meant they felt the need to keep their anxiety hidden from them.

For Alan, aged 17 years, a significant source of *his* worry was his desire to shield his mother from *her* own worrying. Alan talked about how he fretted about his future, but felt he could not talk to his parents about it. The reason, he explained, was:

> *Because I'm scared of my mother's worrying.*

Notwithstanding health worries, there was some indication that their parents' financial situation was an additional worry. Although not a common occurrence across the study, there was evidence that the income of the family was a consideration for a small but significant number of participants. For example, when Martin was asked to think about wishes and what they might be, he said:

> *Probably my family would not be like not losing money and all, and be rich.*

When asked why he thought his family would lose money, Martin explained:

> *Sometimes I usually ask my mum and dad for toys constantly…*

In this case, Martin's awareness sensitivity to the implications his demands may have on his family's finances is greater than what might be deemed usual for a young person his age. Another young person talked about wishing her mother could win the lotto and be rich.

The link between poverty and disability is well-documented (Burchardt, 2000; Emerson and Hatton 2007; Heslop and Gordon, 2014). For a young person with a disability, the risk of living in poverty is disproportionately higher than that of other children - 40% of disabled children in the UK live in poverty and almost a third of those are classified as living in 'severe poverty' (Children's Society, 2011). The reasons for this are many and complex, but the detrimental impact of exposure to poverty on the health and well-being of disabled children is clear cut, as highlighted recently in the Annual Report of the Chief Medical Officer (Davis, 2014).

Poverty research with children and families (Ridge, 2002; Daly and Kelly, 2015) reveals that children seek to protect their parents from financial worries, and our interviews suggest that this is equally so, if not more so, for some disabled children. In their work on families and poverty, Daly and Kelly (2015) use the term 'curtailed childhood' to explain the way a heightened sense of responsibility for their parents assumed by children in low income families result in a smaller gap between adult and child than in society at large. For a sizeable number of young people in this study, being over-protective of their parents resulted in another concealed level of anxiety, exacerbated by not being able to share this worry.

Guilt

We saw earlier how family relationships were central in the lives of participants. Huge value was attributed to the support provided to meet the physical and social needs of the young person. The extent of support was largely dependent on the functional capacity of the participant, and ranged from low level to high intensity. However, the same provision set in motion a complex suite of emotions, mostly for older participants. This included the conflict between dependence and independence discussed above. For a small number of participants (five participants directly spoke about this), this tension also included feelings of guilt; a feeling which has been described as among the most destructive of emotions (Tuner-Cobb et al. 2014).

There is an increasing literature on the detrimental consequences of negative self-conscious emotions such as shame, embarrassment and guilt (Tangney et al. 1996; Reyles, 2007; Chase and Walker, 2012). Such emotions play a major role in shaping peoples' thoughts, feelings and behaviours and have been linked to a wide range of negative mental and physical health outcomes (Tracy and Robins, 2004). As such, they are of increasing interest within health research (Tuner-Cobb et al. 2014).

Terms like shame, embarrassment and guilt are often used interchangeably, being described as moral emotions with no distinction between them, with embarrassment viewed as a milder form of shame. Some suggest, however, that they are distinct emotions, with different underlying experiences; with shame connected to moral failings and embarrassment and guilt more associated with violations of conventions (Keltner and Buswell, 1997; Tangney et al., 1996). According to Underlid (2005), guilt is said to arise when certain accepted standards are breached, generally of a moral nature. When this goes against an individual's principles, it results in feelings of social devaluation (2005: 280). As this short summary demonstrates, there is no commonly accepted set of definitions, and a fair degree of controversy surrounding specific issues, such as the relationship between shame and guilt and whether or not they are separate or overlapping constructs (Reyles, 2007).

When participants talked about feelings of guilt, it was mostly in relation to feeling a burden on their parents due to the high care demands warranted by their condition.

The extent to which one can rely on family or close kin when needed has often been conceptualised as part of a reciprocal relationship – where support or care is given without the expectation of equal return, but with the implicit norm of future assistance when needed (Finch and Mason, 1993). Thus, family relationships can be thought of as two-way 'give and take' exchanges, where the balance of power shifts over time.

Reciprocation therefore creates the expectation that support will be repaid in some way at a later time, with exchanges of familial support balancing out over the longer-term. When there is a breakdown in this norm, the relationship can become stressful and burdensome (Call et al. 1999). Much of the

literature in this area has been dominated by a focus on caregivers, with the detrimental effects to mental and physical health attached to providing long-term care well documented. Less attention has been paid to those in receipt of care, and the way they are affected by the breakdown of the reciprocate understanding. Of the studies that have investigated this issue, there is evidence that not being able to give back in exchange also elicits negative self-conscious emotions such as guilt and feelings of being a burden. A greater volume of work has focused on older people, whose loss of independence harms self-esteem and pride, than studies investigating the breakdown of the exchange relationship and its effect on young care receivers.

According to our analysis, the long-term, one-way dependence between generations, stimulated a level of gratefulness that was detrimental to young people's well-being in two ways: it generated feelings of guilt and it hindered self-expression and self-determination.

This was demonstrated quite clearly by Brian, who described how he has currently to rely on his parents to socialise with his friends, but wants to find other avenues for socialisation that does not require their support. From his point of view, the difficulty arises partly because he feels like a burden, and partly as a consequence of ambivalence towards parental support – he needs it, appreciates it, but does not want to need it.

> *I know I can socialise at home and go to my local pub and stuff and go about the town. I want to do other things so that I don't have to rely on parents all the time. And you know, at times I feel like, I have been feeling like I have been a burden because I am relying on them. And I can't go and do my own thing because I need that reassurance that they can take me…the other reason I'm not going is my dad works every day so he's out at work so he certainly can't take me every day, even if I'm wanting to go somewhere.*

Similarly, when talking about what she did at the weekends and how her condition often determined her ability to take part in social events, Julie explained how she felt 'bad' when she was not able to participate and felt she was letting her family down:

> *Sometimes I go away and sometimes I rest, depending on what way I feel, because sometimes I be really tired and I suffer from bad headaches and other things like that, so sometimes I have to rest and I feel bad on my family, them making the effort and I'm not going. But sometimes I need to consider myself at times.*

This short excerpt suggests that Julie's emotions are underpinned by a negative evaluation of herself, insofar as she feels responsible for letting her family down, when they have made arrangements to take her out. The final sentence in the quotation suggests a sense of being torn between loyalty and the pragmatic acceptance of her limitations. It transpired that guilt was a contributing factor in her perception of letting her family down as she explained further:

It just makes me feel a bit guilty that they're making the effort and I'm not, you know, going to go on the thing that they've organised.

It was noticeable in at least four interviews that being grateful engendered a sense of loyalty on the part of the young person that partly diminished their desire for independent action. This is because they did not want to go against their parents' wishes. The following quote is from a 17 year old male who talked about his ambitions to become an author, and who had started writing a novel. He is explaining how he is attending a training centre, against his wishes, because his parents believe it is better for him to be out of the house and occupied during the day:

You see, they just want me to do something rather than staying home here. They say it's not good for you, vegetating. And I understand that, and that's what pushes me…But they just don't understand what I want at all.

Overprotective parenting was another perspective that added to the tension between disabled adolescents' loyalty to their parents and wanting autonomy for themselves. A case in point is that of Kate, aged 17 years. She is an only child and described her relationship with her parents as extremely close and loving. However, she had been asking to go on a short break away with other friends her own age for quite a while, but her mother would not permit it. Kate knew her mother's reticence stemmed from love and concern about her safety, but Kate described feeling torn between, on the one hand, wanting to assert her independence by insisting on going on the break, and at the same time being afraid to assert her independence because it would be going against her parents' wishes. She now attends a club one day a month, which is a sort of compromise between Kate and her parents.

Sadness

As noted above, lack of independence was one of the most talked about causes of negative emotions; it permeated all aspects of negative experiences. This gives an indication of the significance young people attribute to having control over one's life. However, a number of specific experiences were discussed by participants which resulted in their feeling sad. The most dominant of these were lack of proper communication, bullying and lack of self-esteem/negative self-image.

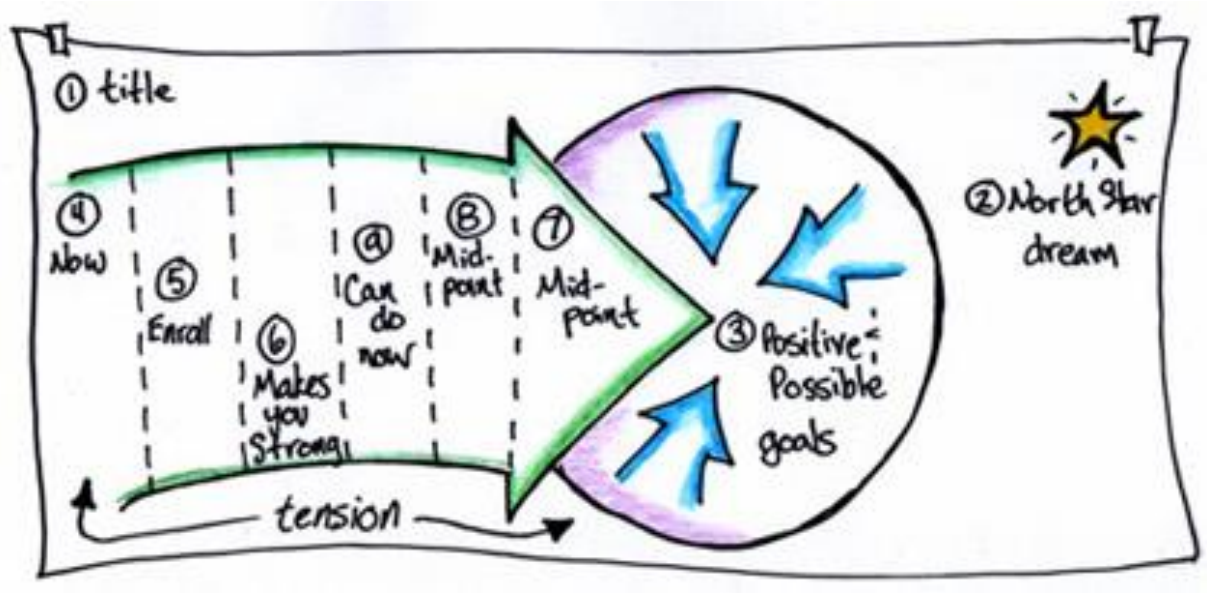
Lack of communication

Drawing on Scottish data from the KIDSCREEN project, Sylvester et al (2014) reported disabled children's health-related quality of life as generally positive. However, their study showed the greater likelihood of disabled children feeling sad than those who are not disabled, with one in three children and young people reporting often feeling sad and depressed. The authors propose a link between sadness and feeling excluded from social and sporting opportunities, although an indication of impairment effects and 'psycho-emotional disablism' are also mooted. The concept of psycho-emotional disablism,

as Sylvester et al (2014: 772) explain, refers to the way non-disabled people interact on an inter-personal basis with people with impairments via intended or unintended hurtful words and actions. In this study, a strong indication of this type of disablism emerged through the references young people made to feelings of sadness brought about by a lack of proper communication. Kate is a case in point. The severity of her cerebral palsy means her communication difficulties are significant. However, she uses several pieces of apparatus to communicate, and her school is well equipped to respond to these forms of communication. However, Kate explained how she had been struggling with the amount of homework she was getting but was unable to communicate her worries to the teacher in a way the teacher could understand. This was causing Kate extreme anxiety. Eventually, she had to get her mother to intervene on her behalf and speak to the individual teacher. This caused Kate a great degree of sadness because she felt not enough effort had been made by the teacher to understand her. It also exacerbated feelings of dependence. Of course, this may not have been the teacher's intention. However, this was the situation as perceived by Kate.

For at least one participant, the lack of communication between her and the professionals working with her was a major contributing factor to overall life satisfaction, feelings of sadness and psychological well-being. Carol was 16 years of age at the time of interview. She exuded a positive attitude and was very engaged in the interview process. Her cognitive ability to reflect on life overall was highly developed. Her means of communicating information was aided by a trusted facilitator who accompanied her during the interview. The participant used an additional strategy for transferring this information to the researcher: by sharing her Planning Alternative Tomorrows with Hope (PATH). A PATH is a person-centred planning programme that helps people understand and take control of their situation. The approach has been used commonly in programme planning in the field of intellectual and developmental disabilities (Claes et al. 2010). It is a graphic process which has been used to help people identify a dream for the future, recognise who best can support them and set positive and possible goals, within realistic periods of time, to move towards achieving the dream. (See O'Brien et al. 2010)

Figure 1: Example of a PATH, from O'Bien and Pearpoint, 2004, p. 38



The PATH had started prior to the interview, when Carol was experiencing a heightened episode of intense anxiety. She had experienced bereavement of a close family member and a further death of a close friend. Reaching adolescence had also brought into focus other worries related to her future and understanding her disability. The PATH process began with a dream for the future and the things that Carol would like to do, and if she could make things happen, these were the things she wanted to happen. Most images were not so different to those things that an average teenager would want or dream of: meeting TV soap stars, going on an overseas holiday, getting married, having children, living independently, making new friends and socialising. What was different in Carol's PATH was the image of a person walking. She always thought her condition meant she would be able to walk eventually. It was only during the PATH process that she realised she would never walk. No-one had ever told her she would never walk:

All my life I thought I could walk and then when we did the path, I realised I couldn't.

No professional had ever talked to Carol about her condition. The full realisation of her condition, together with the lack of communication, left Carol distraught. She felt she could not talk to the professionals and believed they would not talk to her. It transpired that the professionals thought Carol's parents had discussed it with her, and her parents thought that the professionals had talked to her. Carol's dilemma was heightened by the fact that she did not want her parents to be aware of her distress – a typical example of the overprotectiveness discussed above and of disabled children's propensity to feel they need to shield their parents from extra worry. It is also an example of the ambiguous situation between requiring the needs of specialist services (like CAMHS) and independent referral processes. For example, the most common way to arrange a CAMHS referral is through a General Practitioner

(GP). Technically, if a young person has the capacity to make the relevant decisions and would prefer that their parents were not involved, they should not have to be. However, in reality, the safety of the child would be paramount, with the GP erring on the side of caution.[8] Carol explained she had never felt so low and would have been lost without the intervention of the leader of the participatory project of which Carol was a member:

> *I wouldn't have known what to do myself or where to go by myself.*

For Carol, the PATH was conducted within the security of the project she was part of. The theme for the PATH was learning to accept the things that cannot be changed and planning for things that could be changed. Some things in the PATH Carol wanted to keep private from her parents and family. Other things she was happy to share with the professionals in her life. Two separate PATH parties were held – one with family and one with a group of care professionals. The PATH was presented to Carol's transitional worker, who was going to use it to develop Carol's transition plan with her. Unfortunately, no such discussion, based on the PATH, took place between Carol and her transitional worker.

Eileen was 17 years of age at the time of interview and attending a special school for children and young adults with visual and hearing impairment. One of the positive experiences described by Eileen was when people understood her and, as explained above, the reverse was true – not being understood prompted negative feelings like frustration. Eileen explained how her mother had to accompany her to important hospital appointments to act as interpreter. As Eileen gets older, she wants to exercise more independence and gain greater privacy in these situations. She believes an interpreter would facilitate this, but neither she nor her mother knows how to organise this. When asked if she had approached her social worker, Eileen replied:

> *Yes. And mummy asked too. But she [the social worker] didn't know. The social worker said she was there to help me, but she doesn't help with the interpreter.*

It is difficult to understand how Eileen's desire for proper communication and respect for privacy can be separated from other forms of support provided by state bodies. However, the shortage of qualified British and Irish sign language interpreters (identified in Byrne et al. 2014) may explain the difficulties involved in meeting this need.

These are just three examples of how failure to communicate (whether intentionally or unintentionally) can act as a major source of the psycho-emotional disablism (Thomas, 1999; 2007) that young adolescents experience in their everyday lives. Yet, using the general principles of the UNCRC as a point of reference, the experiences relayed by Kate, Carol and Eileen, breach the rights afforded to children and young people under international law. Specifically but not limited to:

[8] When researching this issue, attempts were made to clarify the position definitively, but no clear explanation could be found, with people we spoke to describing it as a '*grey area'* in the health system.

Article 3 – Best interests of the child must be the primary concern when making decisions that affect them.

Article 12 - The right to express views and have these given due weight.

Article 13 – Freedom of expression which includes freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.

In addition, using the UNCRPD as a point of reference, their rights have further been denied. Specifically:

Article 7 - Children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 22 – Respect for privacy and the need for important information on life decisions be made accessible.

Bullying

Incidents of bullying were recounted by 11 young people and emerged as a main contributor of triggers for feelings of sadness, depression and also fear. Unfortunately it was not an uncommon occurrence. Experiences ranged in terms of extent, mostly occurring either within school or the neighbourhood where the young person lived.

The serious consequences of bullying for all young people are well recognised (Macdonald et al. 2011). They include not only mental and emotional damage, but bullying in childhood can have a long-term negative impact into adulthood, impacting on social engagement, educational attainment and even future employability prospects (Hummel et al., 2009).

Susan, who attends a special school suitable for her complex needs, was visibly distressed when recounting her experience at the hands of two pupils in her class. The following quote illustrates the persistent nature of the bullying:

> *They really, really bullied me and I just cried to let it out. Then one day they did it loads and loads and loads of times, one after the other, and then my escort had enough of them and she speaked up.*

Susan was too scared to speak up and it was only after the eventual intervention of her escort and a complaint from her mother to the Vice Principal, that she got any respite. However, her ordeal did not

end there because she explained how the bullies are still in her class and, while they do not directly bully her, they continue to bully her close friend.

> *If they do bully me again I'll be like 'just go away'. But they bully my other friend too. They still bully her. She takes seizures and things and she sometimes takes seizures through the bullying, so it's not very good for her.*

This incident raises a number of issues that are not covered in the wider literature on bullying in any systematic way: recognition of the effects of indirect forms of bullying and the nature and extent of disablist bullying. The fact that Susan was not directly on the receiving end of the bullies' current behaviour, only partially diminished her distress. The 'secondary bullying' she experienced by her peers, through the victimisation of her friend, contributed significantly to her feelings of sadness as she felt she needed to protect her friend but was powerless to do so.

Unlike most other European countries and the majority of states in the US, there is no legal definition of bullying within Northern Ireland anti-bullying legislation (DENI, 2015). The current legislative position in Northern Ireland requires schools to have policies to ensure the good behaviour and discipline of its pupils, including measures to prevent bullying among pupils. At the time of writing, schools are not required to have a separate policy on anti-bullying measures, although many do. A recent review by the Northern Ireland Anti-Bullying Forum (see www.endbullying.org.uk) reported finding wide variation in the quality of schools' anti-bullying policies and procedures and the ways in which they were implemented and reviewed. These findings have prompted the current consultation on proposed legislative reforms by the Northern Ireland Department of Education (DENI, 2015). One such proposal is a common agreed definition of bullying:

> *"Bullying is the repeated and intentional use of physical, verbal, electronic, written or psychological acts or omissions, or any combination thereof, by one or more pupils against another pupil or group of pupils with the intention of causing hurt, harm, fear, distress or adversely affecting the rights or needs of that pupil or group of pupils".*

It is not evident that this definition successfully captures the indirect form of bullying experienced by Susan.

The literature on bullying and young people focuses mainly on the general school population, although some studies have focused on specific disabling conditions such as Autism Spectrum Disorders (ADS) (Humphrey and Symes, 2010; Humphrey and Hebron, 2014). The majority of studies report that children with Special Educational Needs and/or Disabilities (SEND) are at higher risk of being bullied. A major contributing factor is that these children share the characteristics that mark them out as vulnerable to victimisation – they may be socially immature, lacking in self-esteem or have fewer friends (Seals and Young, 2003). Other compounding factors include recent policy reforms which have actively promoted the inclusion of disabled children in mainstream school settings, wherever possible

(DfEE, 1997; DfES, 2001; 2004; Equality Commission Northern Ireland, 2005). Furthermore, as documented by Wigelsworth et al. (2015), monitoring the progress of a school's inclusion policies for children with SEND requires focus on a wider range of school activities such as social relationships and mutual respect, given these children's greater propensity for experiencing bullying and social isolation, but more often progress is measured narrowly on purely educational outcomes.

Considerably less is known about disablist bullying, where those with a disability or SEN are directly involved in bullying – either as a victim (like Susan) or a perpetrator (the two pupils in her class) or both. Most of the literature on bullying among vulnerable adolescent populations has focused almost exclusively on their experiences as victims. However, emerging literature suggests there may be higher risks and involvement in bullying among vulnerable groups than among non-vulnerable groups (Eisenberg et al., 2015; Farmer et al. 2015). For example, students with disabilities are considered more likely to be identified as bullies *and* victims when compared to their peers without disabilities (McLaughlin et al. 2010; Rose et al. 2011). Meanwhile, bully-victims are said to be at higher risk of internalising emotional symptoms and other mental health problems (Kaltialia-Heion et al. 2000).

Investigating the association between bullying (victim, bully, or bully-victim) and the psychological functioning of children with ASD, Zablotsky and colleagues (2013) reported that 38% of the children in their sample had experienced recent bullying, with 28% suffering frequently. Nine percent said they had bullied others. Almost a fifth reported being triggered into fighting back, with 41% of this group having an 'emotional breakdown' or outburst that got them into trouble.

The complexity of the situation can be demonstrated by relating Martin's experience. Martin attends a mainstream school and when talking about his school life he said he had his '*ups and downs'*. When asked to expand further on what they would be, he explained:

> *Sometimes I get merits and such. For the 'downs', sometimes people call me names. Like one day, there's a boy and he annoyed me and then I was saying something to another boy and then I said something bad that I didn't mean to say. But then the other boy chased me and hit me on the back of the head. And my mum said 'oh if someone hits you, you hit them back cause that's self-defence'. There's no harm in hitting someone if they hit you. So I hit him on the back of the head with my PE bag.*

From this excerpt, Martin did not instigate the confrontation. However, his retaliation got Martin into trouble because his actions were deemed 'physical contact' which was against school rules. Martin felt particularly aggrieved at this.

At another point in the conversation, Martin was discussing his favourite subjects in school, one of which was sports. He was explaining the rules for dodgeball when his discussion moved straight to another bullying type incident:

> Martin*: Say one person is the one with the ball, that's my PE teacher – you have to throw it between the waist and there (pointing to his foot). Then one day someone hit me in the face with the ball. Then I got angry. There's this girl and she was laughing. She was the one that threw it. I just lost control that day and pushed her. I didn't mean to.*
>
> Interviewer*: How did you feel?*
>
> Martin*: I cut myself. I was scraping [the back of his hand] along the wall because my school has like brick walls.*

Martin's recollections about the incidents suggest that they were a result of him retaliating to provocation. But his actions were physically violent towards another pupil, which, going by the school rules against physical contact, makes a definite assessment difficult. What is clear, is that the situation triggered within Martin feelings of self-reproach and guilt.

Martin related the 'ups' of his school life with getting merits for achievements. His school also ran a merit system where stickers are collected and exchanged for rewards. He was currently working towards a gold sticker. Martin was one of the very few young people who chose to use the five point emoticons scale ranging from (1) happy to (5) very sad. He indicated that when he got merits for '*doing good work'* he was a one and when he got into trouble in school he felt like a five. For Martin, the consequences of retaliating were significant and resulted in physical harm to himself and damage to his sense of achievement.

What is important is the higher risk that disabled children face and the apparent lack of awareness of the complexity of disablist bullying issues. For example, in their study with student teachers in Northern Ireland and the Republic of Ireland, Purdy and McGuckin (2014) found that none of their participants had received guidance in relation to disablist bullying as part of their initial teacher training. This situation indicates a need for improved understanding of the issue of disablist bullying within schools.

From a NCB survey of 200 primary and post primary schools in NI, the anti-bullying policies of 46 schools were examined in-depth (reported in DENI, 2015). Of these 46, just over half (26) mentioned specific forms of bullying behaviour – 21 mentioned racist bullying, 11 referred to homophobic bullying, only 9 identified disablist bullying, with sectarian bullying the least identified.

While firmer guidance for managing bullying behaviour within schools would be a welcome development, it is important to remember that not all bullying incidents occurred in a school setting. Danielle, who is visually impaired with additional learning difficulties, dislikes her neighbourhood and has no friends in her local area as the young people there bully her. When talking about experiences that initiate feelings of sadness she said:

> *When people call special needs people retards. I get really angry, because we're not.*

In this short quote, Danielle expresses sadness and anger at her treatment but by stating in the plural '*we're not'* suggests anger is felt on behalf of the group of people she associates herself with.

In legislative terms, Article 19 of the UNCRC requires signatory States to 'take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child'. This obligation extends to schools when pupils are in their lawful custody and control (DE, 2014). But when children are not at school the situation is less clear.

Lack of self-esteem/negative self-image

The number of participants whose sadness could be attributed to low self-esteem and/or negative self-image was limited, being restricted mostly to a small number of older participants.

Ed, who was 23 years old, talked about feeling sad and depressed sometimes when he thinks about his disability:

> *Now and again I would feel depressed a wee bit. I know I shouldn't be, but because I'm disabled sometimes it's – why am I like this? Why am I disabled, why should it affect me rather than anybody else?*

When asked if there was anything that would 'bring on' those feelings, he replied:

> *I don't know. Just, I sometimes just look at myself and I don't like it, if you know what I mean.*

Jane is another example where negative self-image was a cause of sadness. Jane, who was 18 at the time of interview, began talking about how she felt different because she had Down's syndrome.

When asked in what way she felt different, she found it difficult to talk about. She explained:

> *It's very upsetting. I don't want to talk about it really.*

When asked if she had anyone she felt she could talk to about her feelings, she gave a clue as to her reticence:

> *Mostly I talk to my mum about it, but she gets upset and I get upset.*

It is clear that Jane has become very sensitive to her mother's feelings as she is getting older which strongly suggests that concealing negative emotions may be a preferred option.

These examples have been used here to demonstrate the differences in attitude which were apparent between younger and older participants in relation to self-image. That is not to say that the issue was clear-cut; there were instances where older adolescents viewed their disability as a positive or

commonplace aspect of their identity. But it does raise the question as to why disabled adolescents seem more vulnerable to emotions like sadness and depression as they reach a post-16 transitionary stage. Research suggests that, as young disabled people progress through adolescence, they become more aware of feeling different, with experiences of impairment and disability impacting on their construction of self-identity (Kelly, 2013). If those experiences are particularly negative or problematic, then it is little wonder that they produce additional stressors capable of triggering emotions such as these.

One such stressor facing all young people is the 'coming of age' transition between childhood and adulthood. For most adolescents, this is a period in life marked by key events such as leaving school and gaining employment, eventually leaving parental care and setting up home independently and such like. It is a difficult time for all young people, more so today as young people contend with a highly competitive job market, unavailable or unaffordable housing and an economically austere welfare administration with diminishing public services. For young disabled adolescents, the transition to adulthood is even more complex, as it includes the additional challenge of the transition from child to adult health and social care services.

A review of research in this area by Beresford (2004) detailed the problematic and, in many cases, unsatisfactory nature of transition practices from child to adult status and from child to adult services. These included huge disparities in employment, living standards and aspirational outcomes between non-disabled and disabled young people when reaching young adulthood. In addition, the transition from child and adult services often resulted in a reduction of services and/or incompatible services. As noted earlier, major developments in disability policy have taken place since 2004, with principles relevant to this issue now embedded in international and national law. However, despite the statutory nature of the policy directives, recent research suggests that young disabled people continue to encounter significant difficulties in making the transition from child to adult services and from childhood to adulthood (Lundy et al. 2012a; Byrne and McAlister, 2014).

Anger

It was noticeable that the things that made adolescents angry were predominantly structural in nature – issues relating to transport, inaccessibility issues, lack of communication and unprofessional practices were often cited. This was followed by societal attitudes, where people's lack of understanding and perceived disrespectful approach, were mentioned as triggers for anger.

Brian used the word 'frustrated' rather than angry to explain a set of common experiences in relation to transport. He recalled how, when using a specially adapted taxi bus, the driver used one seatbelt between two people. Brian knew that this was inadequate and that an individual seatbelt was required. Furthermore, he recognised that this mode of transport was unsafe. It transpired that Brian was correct

in his assertion - not only did a lack of care result in an injury which Brian still has, the whole experience has left Brian with a lasting fear of transport:

> *Another bad experience I've had was I remember my chair…my wheelchair wasn't secured and they had me in sideways, my chair curled up against the side door. And the lump's still in the back of my head to this day. So that's my concern, safety is an issue, you know. But the other thing would be, is not being able to get access too. Because if I decide to go somewhere with my mates, the problem is getting, you have to book it far in advance. You just can't do it like youse where you just get up and decide to go shopping and you simply get in the car. That's the problem that I'm finding, I'm finding it hard to get my social life back on track because I'm having to rely on my parents to take me from A to B when they say so.*

What is most striking about the quote from Brian is the way in which transport difficulties impact so significantly on other areas of his life. His confidence in travelling independently has been eroded by the experience. Because his mode of transport has to be planned far in advance, this is having an adverse effect on his social life, exacerbating feelings of social exclusion. His reference to that fact that he '*can't do it like youse'* suggests he is drawing negative comparisons between himself and non-disabled individuals. In addition, the last sentence suggests ambivalence at having to rely on his parents. It also hints at resentment towards his parents because they respond to his request for transport '*when they say so'*. Another important question remains – Brian knew using one seatbelt was unsafe so why did he not voice his concerns? From the tone of Brian's interview, it is highly likely that Brian perceived the taxi driver's disregard for safety measures as an indication of disrespect towards him, to the extent that Brian felt somewhat intimidated at speaking out. This is a clear example of the psycho-emotional disablism which Thomas (1999; 2007) refers to. Whether or not it is intentional, Thomas (1999) argues that this type of behaviour can adversely impact on what people believe they can be or achieve – what the author identifies as 'barriers to being'.

Ed spoke about his annoyance when people parked in a disabled parking space. He felt it was inconsiderate of people but his anger was focused on the fact that, despite there being a law against it, he had never witnessed any action being taken against those who break the law. He explained that he was not alone in feeling this way, he knew other disabled people with similar views:

> *I know some people, they're not the same as me but they're disabled if you know what I mean. For instance, I know a man that, he's the same, he hates it too and he goes behind their car and blocks them in, in anger, just to show that, so he does.*

Expressions of anger, based on perceptions of unprofessional practices, were voiced by seven participants. During our interview with Susan, her wheelchair became a focus for discussion. Susan explained that her first wheelchair had been unsuitable because it lacked proper armrests and bumpers

to hold her upright. The chair was having a detrimental impact on her spine, exacerbating existing back problems so it was replaced with a second one. The second one was unsuitable for her size and, following repeated insistence from her parents, it was replaced a third time with her current chair. Her current chair is not right either (Susan demonstrated how the armrests were shaky and unstable). Earlier adjustments to the third chair had been unsuccessful. Difficulties with finding a proper wheelchair had been going on for a few years and Susan could not understand why her occupational therapist (OT) had not dealt with the matter earlier. When asked how she felt about this, she explained:

> *I was kind of angry because the OT knew, so why did they not sort it out at the time?...They don't really think outside of the box.*

At the time of interview, Susan was still awaiting repairs to be carried out on her chair:

> *I think the people are coming back in a couple of weeks maybe. They were supposed to fix it last year but they didn't. They came and they tried to fix it but they didn't…We went to see a man that fixed my wheelchair and mummy was like 'you didn't fix this' and he was like 'yes I did' and I was like 'ah, no you didn't' (shaking the arm of her chair). When it was all over, my mummy went back to the car and my mummy said 'why did that man not fix that?'...I think they might come one day and probably fix it for me.*

Susan's anger was directed at the professionals whom she believed did not do their job property. There is also an underlying suggestion that her anger was fuelled by the dismissive way she felt her parents were treated.

Channelling anger for positive results

In many ways, the structural nature of the cause of participants' anger means it should be less difficult to challenge, because of the legal obligations required under international human rights law. For example, Article 23 of the UNCRC upholds the principle that children and young people with disabilities have the same rights as any other young person and they have a right to special care and assistance. Under the UNCRPD Article 7 recognises the right of children and young people with disabilities to express their views freely on all matters affecting them on an equal basis with other children and have their views heard while Article 9 states that persons with disabilities must be enabled to live independently and participate fully in all aspects of life, and appropriate measures must be taken to ensure access, on an equal basis with others. The Northern Ireland Disability Strategy addresses Article 9 in strategic priority 5, which aims to eliminate barriers in the physical environment, goods and services, so that disabled people can participate fully in all areas of life (OFMDFM, 2013: 17).

Societal attitudes, on the other hand, may be more difficult to challenge, but here too, there are laws protecting the rights of people with a disability in this regard. Under Article 8 of the UNCRPD, countries

are charged with taking action to challenge stereotypes and prejudices relating to people with disabilities (see also the NI Disability Strategy, Strategic Priorities 3 and 4 (OFMDFM, 2013)).

A recent review of all Government Disability Action Plans (Byrne et al. 2014) observed how all plans made commitments to raising awareness of the issues facing people with disabilities by training staff, and each Department's Equality Scheme noted how these commitments would be monitored.

The Equality Commission Northern Ireland measures public attitudes towards specific equality groups and general awareness of a range of equality related issues. Overall, findings from the 2011 Equality Awareness Survey were similar to those of 2008, with mostly positive attitudes towards different equality groups. However, these surveys also show how attitudes differ, depending on 'type' of disability. For example, when three types of disability were considered (physical, learning or mental ill-health), mental ill-health generated the greatest numbers of negative responses. The 2011 survey showed that negative attitudes towards those experiencing mental ill-health increased more over time than attitudes towards any other group (EC, 2011: ii).

Societal attitudes often have structural drivers. For example, there are heightened concerns among organisations representing disabled people that the increasingly negative tone of the media's coverage of issues like welfare reform and access and eligibility to disability related benefits, feeds into negative preconceptions and prejudices – to the point where public attitudes have been adversely transformed (Briant et al. 2011; Sykes et al. 2011).

Such fears have been echoed by public bodies, including independent bodies like the UK Statistics Authority, who have questioned the negative way in which benefit statistics are sometimes covered in press stories, and how the language used in government press releases and ministerial media comments accompanying releases of benefit statistics actually impact on this (House of Commons, 2014).

These are all areas that are, technically, within our control to challenge. Article 8 (2c) of the UNCRPD states that measures which foster respect for the rights and dignity of persons with disabilities include encouraging the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention.

The Disability Strategy states that the Government is committed to finding innovative ways to raise awareness of the positive contributions made by people with disabilities in all areas of our society and to challenge negative perceptions (OFMDFM, 2013: 16). However, as noted by Byrne et al. (2014) there are no targets in the Disability Strategy for either priority, so it not clear how they will be met.

> *Article 8 remains a significant cross-cutting theme and one that was understood to impact on other rights such as the ability to access services and quality of services provided by public bodies. The positive obligations on the state party as contained in article 8 are in many ways key to the fulfilment of other rights in the UNCRPD. Awareness-raising needs to be more*

systematic and coordinated and should be aimed at addressing negative stereotypes of people with disabilities by the general public, including negative perceptions of children with disabilities in relation to adoption. Training programmes or awareness-raising strategies should be developed in conjunction with people with disabilities. Education and training on the UNCRPD is also needed. It is not clear what impact any existing awareness raising programmes have had as, at the time of writing, there was no evaluative overview of the impact of either training or awareness raising programmes by public authorities in the public domain. (2014: 69).

To date, there remains no evaluative overview of the impact of training or awareness raising programmes by public authorities.

Summary of Chapter 6

- Concerns about future prospects and unfulfilled ambitions were common triggers of worry.
- For some older participants, an extra layer of anxiety was brought about by a heightened sense of responsibility for their parent's well-being.
- Experiences of guilt were intensified by feelings of being a burden.
- A high percentage of young people in this study reported being bullied in school and outside school. This was a major trigger for negative emotions and lower well-being.
- Older participants were more likely to have lower self-esteem and negative self-image. Common stressors were transitionary periods in life.
- Anger was more associated with structural factors such as inaccessibility and unprofessional practices.

Chapter 7: Results - Psychological well-being

How happy or content individuals are with their live overall (their SWB) is impacted by the interactions between how life is evaluated and experienced (including the tensions and conflicts that exist between positive and negative events in life) and good psychological well-being.

In this chapter, we look at the factors which emerged as essential components for influencing good psychological well-being. The findings concur with other studies of well-being as to the core dimensions for the promotion of positive psychological functioning (see Ryff, 1989; Ryff and Keyes, 1995; Ryan and Deci, 2001). In general, these are: self-determination, choice and autonomy; respectful relationships with others and having a purpose in life.

According to our analysis, the participants who were most satisfied with their lives and exhibited good mental health were those who believed that opportunities existed for them to make their own decisions, to realise their potential and continue to develop as a person, that what they did in life reflected helping others as well as themselves and who had positive social relations with others.

The young people identified in the study as having lower well-being than others were noticeable, due to the lack of reference made to most of these core dimensions. That is, they did not display signs of autonomy in the way their life was going, they perceived themselves as having little choice over major aspects of their life, and self-acceptance was low. In some cases, adolescents had never experienced the components which appear to articulate well-being, like Alan who, when asked if he ever felt sad or depressed replied:

> *Well I don't know what depressed means. But I know, well, if I feel depressed then maybe I am because I've never been happy.*

For some participants, previous feelings of well-being, generated by positive experiences, became weakened by a change in circumstances. For example, some adolescents believed they lost any sense of autonomy when moving from a school setting into training because they were not involved in decision-making whilst there. Other examples include decreasing self-acceptance when faced with unresolved bullying. In some cases, a decrease in well-being was activated by the feeling that opportunities available to non-disabled individuals were unavailable to them.

The findings correspond closely to the belief that well-being is not an outcome but an on-going process of fulfilling one's potential and development (Deci and Ryan, 2008). This is important because all indications point to a desire by national governments, including the Northern Ireland Executive, for 'outcomes-based assessment' and the linking of budgets to outcomes for the purpose of financial allocation and priority setting (NIA, 2012). It is difficult to see how there would be room in this type of

cost-benefit analysis approach for considering things identified in this study as contributing most to well-being, such as respect, autonomy etc.

In order to do that, disabling barriers to achieving good psychological functioning need to be challenged and, crucially, enabling factors need to be maintained and developed further.

Self-determination, choice and autonomy

Self-determination theory suggests that human beings need to meet the basic psychological needs of autonomy; competence and relatedness in order to 'thrive and grow psychologically' (Ryan and Deci, 2001: 147). It is not suggested that these basic components are valued equally across all social groups and cultural settings, but it is argued that when people face barriers in achieving these needs, then negative psychological consequences occur across all contexts.

The significance of self-determination and its relationship with increased quality of life has been the focus of much interest (Burchardt 2004; 2008; Lachapelle et al. 2005; Nota et al. 2007; Brown et al. 2013). More recently, research on the association between self-determination and quality of life for people with disabilities has attracted growing attention, with a growing focus on young people, particularly in an educational setting (Chambers et al. 2007). An examination of the impact of self-determination on various domains of life for young people with chronic conditions and disabilities (McDougall et al. 2010) found self-determination strongly predicted higher levels of perceived satisfaction with personal development and fulfilment.

In carrying out this research, the concept of self-determination was interpreted as relating to a young person's perception of the choices available to them in life, their aspirations, future planning and goal setting. Whether or not participants had goals, and the extent to which adolescents believed these goals would be achieved, was an important aspect of the enquiry as the literature strongly suggests that expectations play a significant role in determining how SWB is experienced. Respondents were asked open-ended questions like '*Have you ever thought about what you might do when you leave school*?' and '*Do you have any plans for the future*?' followed up by '*How do you think things will work out?*'

The majority of young people did have goals or had future plans. Most goals related to gaining paid employment. Career choices ranged from wanting to be a baker, gardener, hairdresser, nurse, childminder, athlete, fashion designer, writer, cartoonist, working with animals – all careers that you would expect a young person of that age to choose. Ten young people said they did not have any plans for the future or they had not thought about it yet.

Where differences with their non-disabled peers were apparent, these related to the near absence of any reference to higher education or university in future plans or expectations. Only two respondents said

they wanted to go to university or college, and one other person said he might think about it but he was not sure what it entailed.

Not all goals were employment related, and included wanting to learn to drive, to go on a plane, to get married and to be able to do things independently.

Of significance here are the differing expectations of whether or not these plans and/or goals would be achieved. Of the 27 respondents who discussed this issue, almost two-thirds (16) were confident, or at least hopeful, that their goals would be achieved. Eight people doubted their goals would be realised and three did not know if they would achieve their set plans or not. Those participants who displayed higher expectations of achieving goals tended to be younger and all were still in post primary education. There was also a strong sense of determination and self-belief, often in spite of the complex nature of some of the young people's circumstances and the daily challenges these conditions presented.

Carol, whose cerebral palsy leaves her with severe activity limitation, has quite a few plans, one of which is to get married. She exuded strong determination that this would come about:

I'm not giving up on walking down the aisle. I promise you I'll do it.

Danielle is another participant who was confident that her goal of being a professional athlete would not be hindered by her sight impairment or her intellectual disability. When asked how she thought her plan would work out, she said she knew what she needed to do to bring it about:

I need to train a lot.

For another respondent, Susan, her plan for the future when she leaves school is to raise awareness of difficulties facing disabled people.

Well, I'd like to be…I'd like to show people how hard it is to be in a wheelchair.

Louise wants to be a nurse when she's older. When reflecting on how it might come about, she thought carefully before responding:

Well, I'd need a costume and see if the nurses would let me do the job, you know.

While Louise may not have the cognitive ability to fully contemplate the situation, she does not anticipate many barriers and her expectations are positive. This is a further example of the difficulties faced by researchers in exploring the well-being of adolescents with disability - how do you reconcile the fact that Louise does not see any barriers, and reports high well-being, with the likelihood of Louise becoming a nurse doubtful.

On the other hand, the young people who thought their plan would not materialise, or expressed doubt about it, tended to be older, had left compulsory education, and were either looking for employment or were on the cusp of transitioning from school to work or training. For some of these young people, low expectations can be said to have impacted on their views.

We heard from Julie earlier that she feels the odds are stacked against her regarding entry into further education, because of the difficulty of getting one-to-one support and where future employment is dubious. Ed is worried he will not be able to find employment with suitable access. Such concerns impact directly on further aspirations and expectations in life. If a person does not believe that can achieve their goals, they will be more likely to lower their expectations and adapt their aspirations to what they have come to expect. In other words, ask themselves why they should bother setting goals in the first place.

When Alan was asked about goals or ambitions, he talked excitedly about his wish to be a writer. He had already started on a novel at the time of the interview. Yet, when prompted about his thoughts on the outcome, he was pessimistic. Alan did not give a clear indication of why he felt negative, but his despondency was palpable in his reply:

> *It's like chasing a dream really.*

The low expectations of other people have been cited as barriers to children maximising their potential (Allard et al. 2014), and this emerged in this research as a significant factor in how disabled adolescents perceived their level of self-determination. The experiences of two respondents (Brian and Iris) are noteworthy because they clearly illustrate how other people's low expectations can restrict the choice opportunities of others.

Brian got a placement in college after leaving school. He had wanted to work with computers but felt disheartened because he felt the software they were using in college was '*babyish*'. In many ways he felt insulted because he believed the college assumed he was incapable of using a more sophisticated package, simply because of his disability. Brian explained it as a problem that many other young disabled people faced:

> *I find that the biggest problem, including for myself and other young people, the biggest problem that I find is that at present they find it hard to understand our capabilities, you know. And to me, I feel like I do have more than I…I feel I'm not given the chance, the skills to translate what I feel I have. And I feel that some of my skills are being wasted because I'm not getting the opportunity to use them.*

Evident in this quote from Brian is the sense of indignation at the college's low expectations of his abilities, frustration at being denied the chance to show how much he has to give, and despair at the lack of any opportunity to reach his full potential.

Iris attends a training centre designed for people who need guidance and a high level of support. She explained how she had been told at an information event that a range of courses were available, including ones that specifically appealed to her – childcare and catering. However, when she attended the training centre, she was told that childcare was unsuitable for her and that they no longer offered

courses in catering. At the time of interview, Iris was doing joinery. When asked if she had been given a choice, she replied:

> *No. No, we don't have a – they don't give you a choice to do what you want.*

She felt she had not been listened to at all. Not only did she express dislike for the joinery course, the following excerpt suggests her full involvement was not an expectation by the trainers.

> *...we don't do joinery and things, they do it for you. Whoever makes – see, we don't make the benches. They do them for you, we stand and watch them.*

Despite national and international developments in disability policy over the past decade, specifically set up to ensure that disabled people have access to further education, training and employment on an equal basis with others, a sizeable number of young people in this study still feel that education and employment could be beyond their reach.

Julie's concerns and fears over the opportunities and supports available to her, Ed's worry about finding a job that can physically accommodate him and Brian and Iris's distress as a result of other's low expectations of their abilities are not exceptional. Similar concerns were raised in two separate reports carried out by the Equality Commission Northern Ireland (ECNI), which evaluated how well existing measures address the needs of disabled people relative to the key requirements of the UNCRPD. The ECNI 2012 research (Harper et al. 2012) highlighted key shortfalls in provision and policy - including measures specifically relevant to transitional experiences such as education and employment. Similar issues were exposed in a follow-up report (Byrne et al. 2014). But neither are they new concerns. Transition to adult life was an area of key concern highlighted by the Bamford Review (2002-2007) in 2005. Findings from subsequent research studies document the limited progress on the many recommendations for improvement made by the Bamford committee, including those focused on this important transitionary period in life (Lundy et al. 2012b). Lack of choice and participation in decisions that reflect young disabled adolescent's aspirations, together with limited opportunities to help them reach their full potential remain as significant as ever (Kelly, 2013).

We saw earlier (chapters five and six) how independence, or the lack thereof, had significant influence in terms of promoting positive and negative feelings. Not having to be dependent on another person for transport, personal needs and such like, were held in high regard by respondents. Ryan and Deci (2001: 160) differentiate between independence (described as non-reliance) and autonomy (described as volition), arguing that they are conceptually different. Meanwhile Ryff (1989) proposes that a person who reports high levels of autonomy is able to resist social pressures and can regulate their thoughts and behaviour whereby '*one does not look to others for approval, but evaluates oneself by personal standards'* (1989: 1071).

In this chapter we examine the concept of autonomy as defined by a sense of freedom from feeling judged by others and having the ability to evaluate oneself by one's own personal standards, rather than having to look to others for approval. To do so, we asked participants if they felt any different about their life now, compared to when they were growing up. A second question enquired whether there was anything they would like to change about their life.

These questions were not suitable for all participants and judgement was used in each individual situation. However, those participants who engaged in this conversation and who displayed a high level of self-acceptance (not wanting to change anything about their life), displayed higher psychological well-being and general well-being overall. For example, Tommy believes his life has changed – '*some good changes and some bad changes'*. The good changes he described as being '*out in the world more'* and the bad changes were those family and friends who had passed away. The bereavements he was able to accept because he knew they were '*in a better place'*. There was nothing about his life that Tommy wanted to change. In fact, his response to this question was '*Of course not'*. When talking about his autism, he described it as *'a gift'*. When prompted to expand, he described his feelings thus:

> *Because that's what autism is, a gift. Yes. It helps, it makes people like me who we are.*

Sammy felt happier with his life now than he did when he was younger. He says this is because he has learned to control his emotions and feels more in control of the bullying situation he found himself experiencing. He has learned how to accept that it is the bullies who have the problem, not him.

Mary was 12 years of age and attended mainstream school. She faced annual lengthy hospital appointments and in addition, attended regular classes for speech and physiotherapy in relation to her cerebral palsy. She disliked having to take time out of school and felt the extra classes were unnecessary and only drew attention to her difference.

> *I don't really like going to them [the classes]. I don't like this year because I've had a lot to go to and stuff. I'm happy being me and I don't feel the need for speech and language or physio or anything.*

Another young participant expressed his autism as something special. Owen explained his condition thus:

> *It's really nothing, it just makes you special. It just makes that you can be a little bit more excited. Like you jump around a lot more, you talk a lot more and you don't want to go to bed a lot more. It's basically just this exciting thing in your body. You have excitement.*

In terms of the contribution that feelings of autonomy make to a person's sense of psychological well-being, our findings align closely with the general principles (Article three) of the UNCRPD, namely:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women;
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Purpose in life

Among the study participants, there were examples of how actions which assisted others, as well as themselves, had a positive effect on a young person's self-esteem. A number of participants discussed how drawing attention to issues that they saw as discriminatory, not just towards themselves but to others in similar situations, and putting forward proposals for improvement, increased their individual feelings of self-worth. For example, Carol had had a bad experience in a theatre when going to see a concert. She had been seated in the balcony, despite the fact that the company had been advised in advance that Carol would require wheelchair space and access. She decided to write a letter (using intellikeys and writing with her nose). As a result of her letter, the theatre changed their policy and anyone in a wheelchair now sits in front of the stage. When relating this incident, Carol was visibly gratified because she had changed circumstances for the better for everyone in a similar situation to herself. Again, this may reflect the number of young participants who were part of the participatory project which specifically aims to involve children and young people with disabilities in decision-making and capacity building activities. Nevertheless, the benefits of working for improvement for all were evident. They included an enhanced feeling of purpose, self-respect and, crucially, the belief that their actions could and would make a difference. Some examples are given below.

Two participants mentioned volunteering as a worker in their youth club as a worthwhile endeavour, where they thought their own skills could be put to good use, such as helping the younger members with arts and crafts.

When talking about things that would make her happy, like most young people her age, Carol talked about going shopping with her friend Clare and their trips away together. Their friendship was an

important source of feeling socially included for them both. However, during conversation, Carol explained how she first met Clare in the participation project. The project brought together children and young people with a range of physical, learning and sensory impairments. It transpired that the first day Clare attended the project she was petrified, because she had never met somebody in a wheelchair who moved like Carol or talked like Carol. Clare said she did not want to come back to the group because she thought she could not talk to somebody who was not like her. Carol understood that Clare's reticence was because she was only familiar with her own difficulties and did not know what other people's difficulties were. She taught Clare how to communicate with her and now they are best friends. Carol's insightful comprehension of the situation, and her shared experience, meant she was able to positively influence Clare's attitude towards other people. Carol did not set out to give her friend lessons; by just being herself she was able to teach her so much about how to respect and value people who do not have the same method of communication and/or mobility.

The value of this type of peer influence (where trust and rapport are established through a mutual relationship) for increasing adolescent psychological health and well-being is evident. Because they have shared experiences, peers are more likely to understand each other's position, particularly the anxieties related to understanding their disability, or feeling different, which are known stressors as a young person moves through adolescence.

Positive influences

The United Nations International Year of Youth was launched in 2010. The UN was committed to creating awareness of the importance and benefits of youth participation in all aspects of society, to promote better understanding of inequalities amongst youth and how the needs of the most disadvantaged could be addressed and to generate greater commitment and investment in youth related programmes around the world by 2015 (UN, 2010). The UN resolution noted that: '*the ways in which the challenges and potential of young people are addressed will influence current social and economic conditions and the well-being and livelihood of future generations'*. This provided a framework for bringing youth development to the forefront of debate on a global scale.

The key aims of the New Priorities for Youth policy for Northern Ireland (DENI, 2013) are underpinned by the commitment that youth work contributes to the vison that every young person should reach their full potential at each stage of their development. The contribution of youth work is seen as helping young people to overcome barriers to learning and engagement; providing personal and social development opportunities; helping young people to gain confidence, develop their self-esteem and have high expectations and aspirations for themselves (2013: 19). In line with the UN initiative, greater emphasis is placed on the needs of disadvantaged young people. However, there is no direct discussion of what role youth work could exert in promoting positive mental health and, as noted by Schubotz and

McArdle (2014), the restricted focus on individual educational achievements and narrow view of youth work, limits its potential reach.

This seems a wasted opportunity, given the potential for youth work to promote mental health and well-being. For example, calls for youth work interventions that develop opportunities for young people to explore emotional health issues, and the development and delivery of activities that promote peer support, has been made by the Scottish Government (see Scottish Government, 2011: 14).

Despite the increased focus on promoting youth confidence and self-esteem, together with the rise in interest in positive psychology and well-being, there remains a limited, but growing, literature on how positive coaching methods could improve psychological well-being amongst young people and enhance good practice within youth services (Leach et al. 2011).

The process of coaching centres upon a collaborative relationship between a coach and the person being coached. The role of the coach is to facilitate the attainment of personal outcomes that the person being coached deems valuable (Spence and Grant, 2007). The use of peer coaching is commonly associated within education to promote learning and teachers' classroom skills (Parker et al. 2008). Formal coaching within executive organisations has grown significantly within the past 20 years, with the improvement of professional performance, workplace well-being and organisational effectiveness a key aim (Grant et al. 2009).

Theoretically, peer coaching has been associated with social cognitive learning theories, which value the influence of a reciprocal partnership, built on mutual trust and honesty, in contrast with more authoritative traditional models of learning (Moore et al. 2015). Peer coaching has been described as one type of 'helping relationship' where the primary purpose is to enhance the learning of both individuals (Parker et al. 2008). In that way, it differs from a therapeutic type intervention because there is no power differential between the people involved (Parker et al. 2012).

However, there has been a noticeable growth in what is called 'Peer Support Services' in the US, Australia and more recently the UK, in the provision of mental health services. This has been triggered by recent policy initiatives within the US health system including moving from a provider-focused to patient-focused approach, and a shift in mode of service delivery from mental health care to primary care.

The peer support services model includes more formal professional-led groups, together with informal peer coaching and support groups. Peer workers with a diagnosis of a mental disorder play an important role by providing support to others with a mental illness, as part of this service. However, evaluation of the peer support services is restricted by the lack of a consistent model (Daniels et al. 2012).

Tensions between peer-orientated approaches and more traditional, medical models of service delivery remain. These include a reluctance to collaborate by some professionals more used to prescribing

services and concern that involving peers is simply a way of saving money. However, as noted by Swarbrick (2013), some US states are considering changes that will put specialist peer-coaching on a more certified basis. The line of reasoning being that peer coaching can be considered as an important complement to a traditional model of integrated care.

While not a widespread occurrence, the evidence from the young people who engaged in this type of peer coaching activity suggests that, in an informal context at least, there may be an opportunity to improve the psychological health and well-being of the coachee and the coach. Think of Tommy and the way he helped his neighbour's two children come to understand their autism better. Through these one-to-one interactions Tommy went on to write a book on autism to help others – an endeavour he is very proud of.

> *Well one day I was giving some friends of ours whose kids have autism some advice, my mum decided I should write a book. I thought it was a genius idea. So I got to work and created an early draft. I dealt with any possible contingent I could think of, you name it. Emotions, fears, dreams, hopes, all of it. It is currently being typed up by a friend.*

Similarly for Owen, when his teacher asked him to speak to a younger boy in his school to help him make sense of his feelings. This made Owen happy, to think that his experience could help another boy in a similar situation.

Referring back to the *What Works for Wellbeing* initiative discussed above, which aims to gather the best evidence of what works to enhance well-being and bring it to those areas and organisations that can use it to best effect, it is worth considering areas that as yet may not be fully realised. Peer coaching, if appropriately channelled, might make an important contribution.

Summary of Chapter 7

- SWB is enhanced by self-determination, choice and autonomy and having a purpose in life.
- Young people who were most dissatisfied with their lives had limited opportunities in most of these core dimensions.
- SWB is an ongoing process and not an independent outcome.
- There is good reason to believe that informal peer coaching may increase psychological health and well-being.
- Given the appropriate status, recognition and certification, there may be potential for formal peer coaching to complement a traditional model of integrated care.

Chapter 8: Conclusions and key messages

This study set out to understand how adolescents with disabilities experience well-being - a multi-dimensional concept that includes subjective, social, physical and psychological dimensions (Bowling, 2013). SWB is assessed by asking individuals their opinion on how they feel about their own well-being in terms of their satisfaction with life overall, how they experience everyday life (positive and negative emotions) and whether they believe their life is meaningful. SWB was the focus of this study, which means that our assessment of well-being is based on the perspectives of individuals, and not on objective measures.

Well-being was examined through the lived experiences of 37 young people with a range of physical and mental impairments. An important objective was to draw out the main components that constituted SWB, and identify the main drivers which promoted this. An associated objective was to highlight the obstacles which prevented young people from experiencing contentment and satisfaction with their lives, and propose recommendations to address these barriers.

The study was not without difficulty but the difficulties were not insurmountable. Among the main challenges were communication difficulties. A combination of methods and approaches were used to overcome this barrier. It took time and effort, some interviews were better than others, but every young person who participated in this study contributed to its findings, and enhanced our knowledge on the well-being of adolescents with disability.

What constitutes good subjective well-being?

What is most important in the lives of adolescents with disability differs little from that of their non-disabled peers – positive family relationships, good friendships, social interaction and participation. High significance was attributed to family time spent together, knowing that family was there for you, and for the emotional support that family provided. What set the adolescents in this study apart from their non-disabled peers was their high reliance on family for instrumental support, for example, attending to personal care needs and arranging transportation. Likewise, family played a highly significant role in facilitating opportunities for young people to take part in community activities and engage socially with their peers. It is very important to bear this in mind when considering the self-reported assessments of life satisfaction, as contentment is very much dependent on the ability of the family to maintain the high degree of support required.

Existing research suggests that families with a disabled child face extra costs up to three times greater than that of families with no disabled child (Children's Society, 2011), placing obvious demands on household income. Lack of adequate income and financial worries are well known stressors on family

relationships (Kempson, 1996; Orr, et al., 2006; Green, 2007). Research also suggests that parents of children with intellectual disability often suffer from higher stress levels and greater rates of relationship breakdown (Hodapp and Krasner, 1995). Parental depression and family difficulties are known risk factors for depression in children and the impact is reported to be more severe for children with an intellectual disability (Hatton and Emerson, 2004).

It would be sensible, therefore, to ensure that families of children with disability are helped to manage the known risk factors associated with family stability. Stressors that would be immediately amenable to intervention include enabling families with a disabled child or adolescent to achieve the same standard of living as other families. Radical changes to the UK tax and benefit system introduced by the UK coalition government in 2010 under welfare reform saw a huge reduction in public spending (Browne, 2010). Some of the largest cuts in expenditure came from a ceiling on benefit increases; freezes in child benefits and tax credits; cuts to housing benefits and cuts to disability benefits (Hood and Phillips, 2015). It is reported that cuts in recent years have impacted disproportionately on disabled people (Edwards, 2011; Wood, 2012). Moreover, forecasts of public spending on disability benefits in 2018–2019 project them to be at their lowest level since the late 1960s (Banks et al., 2015).

Furthermore, the structure of the benefit system has changed, making eligibility to receive benefits more restrictive. The severity and number of sanctions has also increased for those claimants failing to meet the new harsher conditions (Hood and Phillips, 2015). This often has wider (and hidden) implications for more people than the sole claimant because eligibility to certain benefits can act as a trigger for the payment of additional premiums or benefits like, for example, carers allowance where a carer can only receive support if the person they are looking after continues to receive benefits. Recent work by Reed and Portes (2014) examined the cumulative impact of various UK policy changes between 2010 and 2015 and concluded that:

> The impacts of tax and welfare reforms are more negative for families containing at least one disabled person, particularly a disabled child, and that these negative impacts are particularly strong for low income families. (2014: vii)

The right to an adequate standard of living for children and young adults with disabilities in enshrined in law under Article 27 of the UNCRC and Article 28 of the UNCRPD. The significance of this right is recognised in many of the key policy documents discussed in chapter two.

Key Message One
Welfare reform will impact disproportionately on disabled young people and their families. An assessment of the impact needs to be undertaken and measures put in place to protect children and young people and their families from poverty.

Existing research shows that young disabled people value activities that help them maintain existing friendships and develop new ones, and the findings of this study validate that view. Two-thirds of adolescents reported taking part in some sort of social activity that gave them the opportunity to meet other young people. Activities were typically characterised as formal (such as Gateway club, Special Olympics) and/or affiliated to a charity or church group. Facilities commonly were situated outside of the local neighbourhood. Reference to young people accessing local play and leisure facilities such as parks, leisure centres or youth clubs was highly exceptional. One exception was the cinema, where there was mention of visits, but these usually entailed a family outing to see a film. Such organised facilities provided an important space for meeting people with similar experiences, and for almost two-thirds of participants, this was rated as very valuable. As Ed explained when he talked about belonging to a club for people with particular impairments:

> *See I've got to meet a whole lot of people in my position so I have, and it's good to see them so it is…It's made me fit in, to be able to fit in to a group, because they're all like the same disability as me.*

Similarly, Clare, who just recently joined a young carers group, said she has met more friends than she ever would have in normal circumstances. With one friend in particular, Clare said they '*just clicked like that*' because they understand each other:

> *There's a girl there and her mum is the same as my mum and I thought there is nobody in the world the same as my mum. The doctors told me my ma wouldn't get better and like, she is just going to get worse. And she says 'my mum is on 33 tablets a day' and I'm like 'so is my ma'. It's just like I'm not the only young person who is going through this stuff.*

Despite the significant reliance placed on them, these formal facilities are heavily dependent on continued funding. In light of current budgetary constraints, their future existence could be described as precarious. This is exemplified in Bobby's case where he cannot access a club for young people with learning disability because it is oversubscribed and they do not have funding to pay extra staff. Bobby is currently on a waiting list to join the club.

Key Message Two
Opportunities for social participation are a key factor in contributing to increased well-being for adolescents and their families. This needs to be given the recognition it deserves and supported accordingly. Cuts in funding to, or lack of investment in, existing services are counterproductive.

Not every participant had the opportunity to avail of formal clubs and societies, or indeed wanted to. Their social participation was mainly contained to contact with school friends – many of whom lived a distance away from their home. This meant that few opportunities existed for meeting up with friends after school or at weekends. For young adolescents still at school, the summer holidays presented a time when the lack of social interaction was felt even more acutely. The summer break is especially problematic in Northern Ireland as summer holidays typically last for approximately nine weeks – at least three weeks longer than other regions in the UK (Daly and Kelly, 2015).

Where youth clubs or summer schemes were available in local neighbourhoods, young people in this study generally felt excluded from them. This was mainly because they did not know the other young people attending, and were worried they would not fit in. Physical factors included concerns about the availability of extra supports required for some young people to participate. For the few participants we spoke to who had given a local summer scheme a try in the past, the schemes were considered '*too noisy'* or '*too busy'* or '*too crazy'*. Their unstructured nature was a particular problem for young people (like George and Martin) whose main impairment was associated closely with a need for structure and continuity, such as autism. Barriers to participation like this could be easily forecast, and controlled for in advance, if there was sufficient participation of children like George and Martin in community planning processes.

The lack of opportunity to participate in typical leisure activities, together with the segregated nature of the formal clubs and societies, intensifies the invisibility of young disabled people in mainstream society.

How PPI sits with young people with disabilities is a moot point because, as this research shows, active and meaningful involvement requires the will and dedication to provide the resources capable of overcoming communication barriers in a way that suits all young people. Questions also remain as to the degree of awareness of processes like PPI among those young people with little experience of participatory procedures and practices, but whose views and experiences could only enrich existing inclusionary structures.

Key Message Three
At the core of PPI is the active and meaningful involvement of service users, carers and the public as a key component of quality health and social care provision (DHSSPS, 2007). A high level of commitment to overcome communication barriers in a way that suits all young people is required to fulfil this obligation.

Under Article 4 of the UNCRC (Leisure, play and culture) State parties are required to take all appropriate measures to implement children's economic, social and cultural rights to the maximum extent of their available resources. Article 31 recognises the right for children to relax and play, and to join in a wide range of cultural, artistic and other recreational activities (http://www.unicef.org/crc/files/Rights_overview.pdf), and Article 30 of the UNCRPD requires States to guarantee a right to participation in cultural life, recreation, leisure and sport.

Key Message Four
Meaningful participation of adolescents with disabilities in the planning and design stages of planned community play and leisure activities is a prerequisite for improved social inclusion.

Our analysis revealed a lack of references by the participants to mainstream social and leisure pursuits, or engagement in art and culture activities. The perceived psychological and physical barriers, as expressed by young people (whether genuine or not), indicate a lack of opportunity to access such facilities. As such, this represents a shortfall in the delivery of young and older adolescents' rights relative to the key requirements of the UNCRC and UNCRPD.

All of DCAL's supported initiatives under their Promoting Equality, Tackling Poverty and Social Exclusion Agenda aim to tackle barriers to full participation in society and improve the lives of those most in need. Some good examples of initiatives include 'Soundbeam', which delivered outreach workshops to enable people with disabilities to participate in music therapy workshops, using soundbeam and vibracoustic equipment. However, there is no specific budget or grant scheme in

relation to the overarching agenda[9]. Ultimately that leaves any initiative vulnerable to short-termism and sends out the message that this is an area that merits limited support. Yet, analysis of longitudinal data shows how engaging with the arts promotes better health and well-being and also has financial benefit:

> "Those engaging with the arts as an audience member were 5.4% more likely to report good health. The second analysis, which took life satisfaction as an indicator of subjective wellbeing, noted that, after adjusting for a range of potential confounders, arts engagement was found to be associated with higher wellbeing. This is valued at £1,084 per person per year, or £90 per person per month." (Gordon-Nesbitt, 2015: 53)

Key Message Five
Wider engagement in arts and culture is associated with enhanced physical health and subjective well-being. Increased investment in arts and culture would prove value for money in terms of positive social and financial outcomes.

The stated aim of The Northern Ireland Curriculum is to '*empower young people to develop their potential and to make informed and responsible choices and decisions throughout their lives'.* Objectives are that the '*learning opportunities provided through the Northern Ireland Curriculum should help young people to develop as individuals, contributors to society, contributors to the economy and environment' (http://www.nicurriculum.org.uk).*

Through the curriculum, provision is made at different stages for learning in religious education, language and literacy, mathematics and numeracy, science and technology, the arts, the environment and society, personal development and mutual understanding (PDMU), learning for life and work (LLW) and physical education. References to human rights education, as part of the statutory curriculum, is accompanied by non-statutory guidance. A review of recent reforms within the Northern Ireland educational system, undertaken through a human rights lens, noted a lack of guidance on the teaching of human rights at primary and post primary level (Lundy et al., 2012b: 27).

Our analysis proposes that there is scope for improving personal development and enhancing well-being through raising awareness of individuals as rights holders. However, it was noticeable that the only participants to make any reference to human rights instruments such as the UNCRC, were those

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associated with a Participation Project concerned with facilitating the involvement of young people with complex communication and learning difficulties. The non-statutory basis for the delivery of human rights education through the Northern Ireland curriculum can only encourage inconsistent practice. This is an area that could be addressed without too much difficulty by including a statutory requirement to include human rights education across the statutory curriculum.

Key Message Six
The teaching of Human rights instruments, particularly the UNCRC and the UNCRPD, as a statutory requirement across the Northern Ireland curriculum has the potential to increase the well-being of all children and young people. It is reasonable to assume that exposure from a young age to a rights based society will encourage greater acceptance of others as rights holders.

Factors which contributed to experiencing positive emotions, such as happiness, pride and confidence, were strongly associated with personal achievements and an acknowledgement of doing well, or improving, having a positive attitude, a sense of independence and good communication with others. Good psychological well-being was characterised by having aspirations, choice, autonomy, self-determination and a sense of meeting one's potential. The interaction of all these factors together influenced happiness, contentment and satisfaction – in other words good SWB.

This finding was corroborated in two ways: by the lack of references to these experiences by young people who were unhappy or discontent and/or by the way particular negative experiences depleted the effect of positive experiences. Here, bullying, disrespect, dependence, lack of choice and an overprotectiveness towards parents stand out as significant stressors for declining overall well-being, particularly psychological well-being.

Key Message Seven
There is a lack of understanding of disablist bullying generally and the intermittent guidance in relation to disablist bullying as part of initial teacher training requires attention.

Key Message Eight
Any new legislation on bullying in schools needs to be clear and consistent on the classification of 'bullying incidents' which may take a more subtle form like secondary bullying or incidents that take place outside of school premises like cyber-bullying.

Bullying and disrespect are encouraged by negative stereotypical attitudes and ignorance. However, they are more structural in nature and therefore more easily within our power to address.

Key Message Nine
Awareness-raising of the capabilities and contribution of disabled adolescents is covered under Article 8 of the UNCRPD. Awareness-raising programmes should include measures which address the negative stereotypes of people with disabilities made by the general public, the media, government officials and departmental publications. Evaluation of these programmes is necessary in order to judge how these statutory duties are being fulfilled.

For the majority of participants in this study, aspirations to live an independent life and exercise choice over a wide range of issues that affect their lives, were vital components of good psychological functioning. Uncertainty about future independence set in motion a chain of negative feelings like worry, sadness and fear. This ambiguity surrounding dependence/independence was a key component of the extra layer of anxiety associated with overprotectiveness towards parents and exacerbated feelings of guilt. Negative self-conscious emotions, like guilt, have been associated with a wide range of mental and physical health outcomes and, as a result, they are of increasing interest within health

research (Tuner-Cobb et al. 2014). For people who desire it, independent living is supported under Article 19 of the UNCRPD. It is intuitive that support systems and resources that facilitate independent living arrangements would also promote improved mental health and well-being. Yet, young disabled people's knowledge of supported living options remain limited and opportunities to avail of such supports severely restricted due to lack of provision (Kelly, 2013).

Key Message Ten
For those who aspire to it, living independently, or with support, can be a route to autonomy and self-determination – principal components of good SWB. A strong and visible commitment by government to Article 19 of the UNCRPD (independent living, choice and control) would relieve uncertainty, anxiety and stress about the future for young people with disabilities.

Contentment with life, the emotions we experience and how we cope with them, together with a good emotional state, equate to good well-being. If we are serious about improving the well-being of young adults with a disability, society needs to ensure that the opportunities for living a happy and fulfilling life are available to them, and the conditions which deplete their well-being are addressed.

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APPENDIX A

Level 1 Information Sheet

Feeling Good?

Young person's information leaflet

Who I am?

Hello, my name is Grace.

I work in a big school in Belfast and we would like your help with some work we are doing.

Before you decide to help, we would like you to read this leaflet, and also watch the video we made. You can see the video from this link:

www.qub.ac.uk/research-centres/InstituteofChildCareResearch/Video/WiLDA

What do I want to know?

We want to visit you and find out about what sort of things make you happy and what sort of things make you sad.

What will happen?

We would like you to take photographs of things that make you happy or sad.

Then we would like to visit you to see what photos you have taken and talk about them.

If it's OK with you we will tape record what you say so we can remember it all.

Where would we meet?

We could come to your house after school or at the weekend.

Would you like to meet us?

It's OK to say no!

If you have any questions, you or your mum or dad can ring me on 02890973483 or email me at g.p.kelly@qub.ac.uk.

Bye for now, Grace.

Level 1 – Consent form

Feeling Good?

Research project at Queen's University Belfast

Young person's agreement form

Did you look at the leaflet we sent you or did you watch the DVD?

☺Yes ☹No

Do you want to ask me anything?

☺Yes ☹No

Is it OK if I record what you say on my tape recorder?

☺Yes ☹No

Do you understand that you can choose?

☺Yes ☹No

Are you happy to take part?

☺Yes ☹No

Level 2 - Information Sheet

Feeling Good?

Young person's information leaflet

Who I am?

I am Grace.

I work at Queen's University Belfast and we are doing a research project with some young people in your area.

We would like you to take part in our research. Before you decide to take part, we would like you read this leaflet about the project, and also watch the video from the link below.

www.qub.ac.uk/research-centres/InstituteofChildCareResearch/Video/WiLDA

What do we want to know?

We want to visit you and find out about what you like to do. What makes you happy? What makes you sad? What stops you from doing what you like?

What would we like you to do?

We would like you to take photographs of things that make you happy or sad. Then we would like to visit you to see what photos you have taken and talk about them.

We will ask you some questions but there are no right or wrong answers.

If it's OK with you we will tape record what you say so we can remember it all. What you tell us is just between us, but if you said that someone was hurting you or someone else, we might have to tell someone.

If you would like to see us, you can choose who is there with you while we talk; on your own, with your mum, dad, brother, sister, a friend or a teacher.

Where would we meet?

We could come to your house after school or at the weekend, or somewhere else that suits you.

Do you have to take part?

You don't have to take part, or if there is any part of the project you don't want to do, that's OK.

If you have any questions, you or your mum or dad can ring me on 02890973483 or email me at g.p.kelly@qub.ac.uk.

If you do not want to take part, that's ok. You don't need to do anything.

If you think you might like to take part, then ask your mum or dad to ring or email me.

Bye for now, Grace.

Level 2 – Consent form

Feeling Good?

Research project at Queen's University Belfast

Young person's agreement form

	Please circle	
Have you read the information leaflet or did you watch the DVD?	☺ Yes	☹ No
Have you had the chance to ask questions and talk about the project?	☺ Yes	☹ No
Do you feel happy with the answers you have been given?	☺ Yes	☹ No
Do you understand that it is your choice to take part in the project?	☺ Yes	☹ No
Do you understand that, if you agree, what you say will be recorded on a tape recorder?	☺ Yes	☹ No
Do you understand that you can stop taking part in the project any time you want?	☺ Yes	☹ No

Do you understand that what you say is between you and me but if you said that you or someone else was being hurt in any way then I might have to tell someone? ☺ ☹ Yes No

Are you happy to take part in the project? ☺ ☹ Yes No

Name: _____

Signed: _____

Researcher: _____

Date: _____

Level 3 - Information Sheet (Level 3)

Feeling Good?

Information sheet for young people

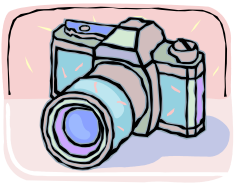
Hi, my name is Grace and I work at Queen's University Belfast. I work on a research project about the wellbeing of young people. We are interested in what makes you feel happy and sad. We are hoping to talk to about 40 young people aged between 11 and 19. We would like to invite you to take part in the study, and would like you to read this information sheet or watch the video we made before you decide whether or not to take part. You can see the video from this link:

www.qub.ac.uk/research-centres/InstituteofChildCareResearch/Video/WiLDA

Information about the research

What would you have to do?

Sometimes young people like to do some sort of activity when they take part in research as it makes it more interesting! We are asking young people if they would like to take photographs of what makes them happy or sad, and then we could talk about them in the interview. However if you would prefer not to take photographs, we can just ask you some questions, and you can just talk to us – it's up to you. If you decide at any time that you do not want to do something or take part in the research, that's perfectly OK.



Where would you meet us?

We could come to your house when your mum or dad are there, or we could meet you at your school or somewhere else – it's up to you.

How long would it take?

The first time we meet we will just talk about what's involved in the project and you can ask questions about it. This may only take between 30 minutes to 1 hour. Then, if you want, you can start to take

photographs of the things you want to talk about in the interview. When you've finished that, we'll come back and we can spend about 1 hour talking about your photographs. We can take less time or more time than this if we need to – it's up to you.

Will taking part in the study be kept confidential?

Yes. You will at no time be named in any reporting of the findings of the study and all the information you provide will be confidential (hidden from anyone else). What you say is between us, but if you said that you or someone else was being hurt in any way then we might have to tell someone to keep you or others safe.

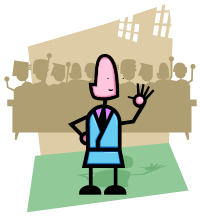
We would like to record the interview to help us remember what you have said, but the information will be deleted from the tape immediately after it is typed into the computer. Your name will not be linked to the information, and at no time will this information be provided to any other party in a way that could identify you. The information you give us will be stored on computer at Queen's University Belfast, and can only be accessed with a password. We will hold onto the information in this way for five years, and then it will be deleted. Sometimes researchers like to use the photographs young people have taken as they provide a very powerful message. If we wanted to use any of your photographs we would ask your permission first.

What are the possible benefits of taking part?

Although there may be no direct benefits to you personally, it will give you the opportunity to share your views and raise awareness of the importance of being asked your opinion.

What will happen to the results of the study?

The results of this study will be presented at meetings with groups such as



the Children and Young People's Strategic Partnership on Disability. We will also present the findings at university conferences and publish in academic journals. We will provide a summary document for adults and young people, in a variety a formats including Braille and large print. We will also present findings in a DVD with subtitles and signing. Remember at no time will you be named in any of these publications or presentations.

Are there any disadvantages?

Taking part in the research will take up some of your time but we will meet with you at a time and place that suits you best, and you can always have an adult with you if you want.

Who is organising and funding the research?

The research is being carried out by the Institute of Child Care Research, School of Sociology, Social Policy and Social Work at Queen's University Belfast. The project is funded by the Research and Development Office of the Public Health Agency for Northern Ireland, and has been approved by a local ethics committee.

Further information

If you have any further questions, please do not hesitate to contact us for more information:

Grace Kelly

Tel: 02890973483

Email g.p.kelly@qub.ac.uk

Level 3 – consent form

Feeling Good?

Research project at Queen's University Belfast

Young person's agreement form

	Please put your initials in the box below	
Have you read the information leaflet or did you watch the video?	Yes	No
Have you had the chance to ask questions and talk about the project?	Yes	No
Do you feel happy with the answers you have been given?	Yes	No
Do you understand that it is your choice to take part in the project?	Yes	No

	Yes	No
Do you understand that, if you agree, what you say will be recorded on a tape recorder?		
Do you understand that you can stop taking part in the project any time you want?		
Do you understand that what you say is between you and me but if you said that you or someone else was being hurt in any way then I might have to tell someone?		
Are you happy to take part in the project?		

Name: _____

Signed: _____

Researcher: _____

Date: _____

Level 4 - Information Sheet

Feeling Good?

Information sheet for young people

Hi, my name is Grace and I work at Queen's University Belfast. I work on a research project about the wellbeing of young people. We are interested in what makes you feel happy and sad. We are hoping to talk to about 40 young people aged between 11 and 19. We would like to invite you to take part in the study, and would like you to read this information sheet or watch the video we made before you decide whether or not to take part. You can see the video from this link: www.qub.ac.uk/research-centres/InstituteofChildCareResearch/Video/WiLDA

Information about the research

What would you have to do?

Sometimes young people like to do some sort of activity when they take part in research as it makes it more interesting! We are asking young people if they would like to take photographs of what makes them happy or sad, and then we could talk about them in the interview. However if you would prefer not to take photographs, we can ask you some questions about what makes you happy or sad and you can just talk to us – it's up to you. If you decide at any time that you do not want to do something or take part in the research, that's perfectly OK.

Where would you meet us?

We could come to your house, or meet you at your school or somewhere else – it's up to you. You can choose to have an adult with you while we talk.

How long would it take?

The first time we meet we will just talk about what's involved in the project and you can ask questions about it. This will only take between 30 minutes to 1 hour. Then, if you want, you can start to take photographs of the things you want to talk about in the interview. When you've finished that, we'll come back and we can spend about 1 hour talking about your photographs. We can take less time or more time than this if we need to – it's up to you.

Will taking part in the study be kept confidential?

Yes. You will at no time be named in any reporting of the findings of the study and all the information you provide will be kept confidential. What you say is between us, but if you said that you or someone else was being hurt in any way then we might have to tell someone to keep you or others safe.

We would like to record the interview to help us remember what you have said, but the information will be deleted from the tape immediately after it is typed into the computer at Queen's University Belfast. Your name will not be linked to the information, and at no time will this information be provided to any other person in a way that could identify you. The information you give us will be stored on computer at Queen's University Belfast, and can only be accessed with a password. We will hold onto the information in this way for five years, and then it will be deleted. After we have gathered the photographs from all the young people, we will pick some to help us explain what we have learnt from your stories. If we wanted to use any of your photographs we would ask your permission first.

What is good about taking part?

Although there may be no real benefits to you personally, it will give you the opportunity to share your views and raise awareness of the importance of being asked your opinion.

What will happen to the results of the study?

The results of this study will be presented at meetings with groups such as the Children and Young People's Strategic Partnerships on Disability.We will also present the findings at university conferences and publish in academic journals. We will provide a summary document for adults and young people, in a variety a formats including Braille and large print. We will also present findings in a DVD with subtitles and signing. Remember at no time will you be named in any of these publications or presentations.

Are there any disadvantages?

Taking part in the research will take up some of your time but we will meet with you at a time and place that suits you best.

Who is organising and funding the research?

The research is being carried out by the Institute of Child Care Research, School of Sociology, Social Policy and Social Work at Queen's University Belfast. The project is funded by the Research and Development Office of the Public Health Agency for Northern Ireland, and has been approved by a local ethics committee.

Further information

If you have any further questions, please do not hesitate to contact us for more information:

Grace Kelly

Tel: 02890973483

Email g.p.kelly@qub.ac.uk

Consent form aged 16+

Feeling Good?

Consent form for young people

I confirm that I have read and understand the information sheet for the above research project being carried out by Queen's University Belfast. I have had the opportunity to consider the information and ask questions about the research. My questions have been answered satisfactorily. I understand that:

Please put your initials in the box below

1. My participation is voluntary and that I am free to withdraw at any time without giving a reason. ☐
2. Any information I provide will be dealt with in the confidential manner described in the information leaflet. This information will be stored confidentially in Queen's University Belfast. ☐
3. If I agree, the interview will be tape recorded, and these tapes will only be available to the research team and will be destroyed once anonymised information has been transcribed. ☐
4. At times, direct quotations from interviews or photographs may be used in publications or presentations of the findings, but I will not be personally identifiable if something I say is used. ☐
5. I agree to take part in the above study. ☐

Name of young person:	Signature:	Date:
_____	_____	_____
Name of researcher:	Signature:	Date:
_____	_____	_____

APPENDIX B

Information Sheet for parents

Feeling Good?

Information sheet for parents

This leaflet provides information about a research project currently being carried out by the Institute of Child Care Research at Queen's University, Belfast. The project is funded by the Research and Development Office of the Public Health Agency for Northern Ireland, and has been approved by a local ethics committee.

Information about the research

We want to provide professionals who provide services for disabled young people and their families with a better picture of the sorts of services families really need and want. We have been funded to carry out a research project which asks young people about their emotional wellbeing. This area was highlighted as a main concern by the 6th Sense group – a group of disabled young people based in the Southern Health and Social Care Trust.

Who is taking part?

We are hoping to talk to about 40 Young people aged between 11 and 19. We do not want to leave anyone out of the project because they have learning disabilities or because they do not use speech to communicate – we will try our best to find ways to include everyone.

What the research project involves

If you and your child are interested in finding out about the study, one of the research team will visit you at your home, or somewhere else that suits you, at a time that suits you. We have a video about the project with subtitles which you can watch from the following link:

www.qub.ac.uk/research-centres/InstituteofChildCareResearch/Video/WiLDA

We can answer any questions you or your child might have about the research. We are asking the young people if they would like to take photographs of what makes them happy or sad. If your child is happy to do this, we would leave a camera with them at this first meeting. We

would meet again a week or two later (or longer if needed), to talk with your child about their photographs. This discussion may take about an hour, but we can take less time or more time than this if your child wants to. If your child would rather not take photographs, they can still be involved in the project. We can do something else or just talk, whatever your child decides. If you or your child decide at any time that you do not want to do something or take part in the research, that's perfectly OK.

We find it helpful to tape record these discussions so we can remember everything, but we would not do this if you or your child would prefer us not to.

How long would it take?

The first time we meet we will just talk about what's involved in the project and you can ask questions about it. This will only take between 30 minutes to 1 hour. Then, if you want, you can start to take photographs of the things you want to talk about in the interview. When you've finished that, we'll come back and we can spend about 1 hour talking about your photographs. We can take less time or more time than this if we need to – it's up to you.

What will happen with the findings?

We will write a report on the findings of the study and make sure it is given to practitioners and people who work in government departments. We will present the results at meetings with groups such as the Children and Young People's Strategic Partnership. We will also present the findings at university conferences and publish in academic journals. We will provide a summary document for adults and young people, in a variety a formats including Braille and large print. We will also present findings in a DVD with subtitles and signing.

Will taking part in the study be kept confidential?

Yes. You, your child or anyone else will at no time be named in any reporting of the findings of the study and all the information you provide will be kept confidential. What your child says is between us, but if they were to disclose that they or someone else was being hurt in any way then we might have to tell someone.

We would like to record the interview to help us remember what was said, but the information will be deleted from the tape immediately after it is typed into our computer at Queen's University Belfast. You or your child's name will not be linked to the information, and at no time will this information be provided to any other person in a way that could identify you or your child. The information will be stored on our computer at Queen's University Belfast, and can only be accessed with a password. We will hold onto the information in this way for five years, and then it will be deleted.

After we have gathered the photographs from all the young people, we will pick some to help us explain what we have learnt from their stories. If we wanted to use any of your child's photographs we would ask permission from you both first.

What is good about taking part?

Although there may be no real benefits to you or your child personally, it will give you the opportunity to share your views and raise awareness of the importance of being asked your opinion.

Are there any disadvantages?

Taking part in the research will take up some of your time but we will meet with you at a time and place that suits you best. We will cover any childcare or transport costs you and/or your child have through taking part in this project.

Further information

If you have any further questions, please do not hesitate to contact us for more information:

Grace Kelly

Tel: 02890973483

Email g.p.kelly@qub.ac.uk

Consent form for parents

Feeling Good?

Consent form for parents

I confirm that I have read and understand the information sheet for the above research project being carried out by Queen's University Belfast. I have had the opportunity to consider the information and ask questions about the research. My questions have been answered satisfactorily. I understand that:

Please put your initials in the box below

1. My child's participation is voluntary and that I am free to withdraw my consent at any time without giving a reason. ☐

2. Any information we provide will be dealt with in the confidential manner described in the information leaflet. This information will be stored confidentially in Queen's University Belfast. ☐

3. If I agree, the interview will be tape recorded, and these tapes will only be available to the research team and will be destroyed once anonymised information has been transcribed. ☐

4. At times, direct quotations from interviews or photographs may be used in publications or presentations of the findings, but my child will not be personally identifiable if something they say is used. ☐

I give consent for my child to take part in the above study. ☐

Name of young person:	Signature:	Date:

Name of researcher:	Signature:	Date:

Name of parent:	Signature:	Date: