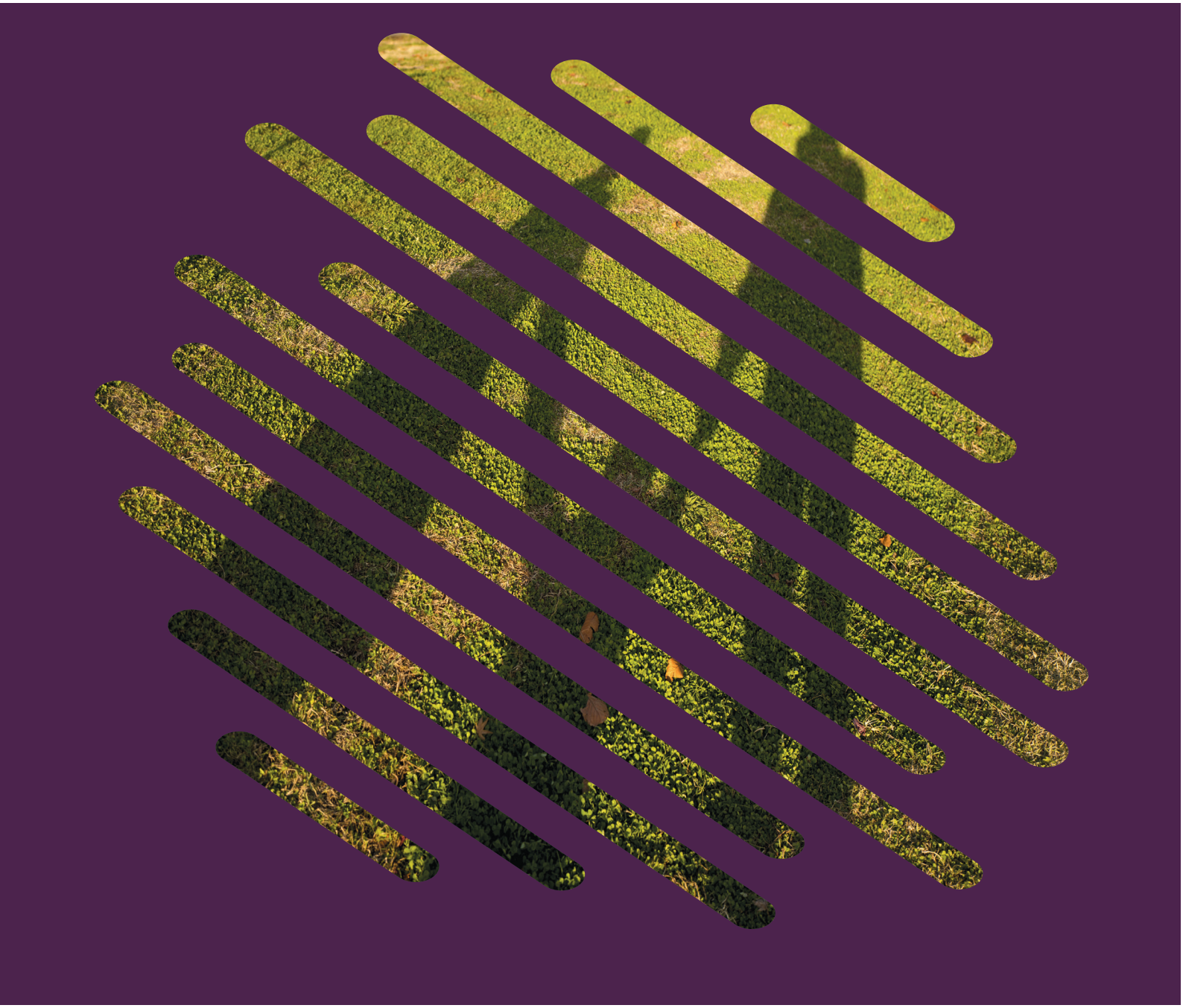
Measuring the Quality of Life of People with Disabilities and Their Families

Scoping Study Final Report

September 2017



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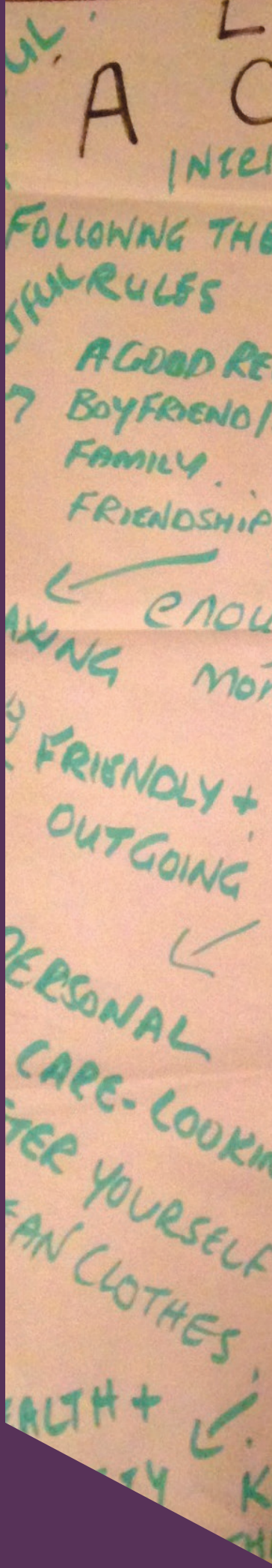


Executive Summary

The Scoping Study was initiated in response to the Programme for Government 2016-2021 indicator, 'Improve the quality of life for people with disabilities and their families'.

The Disability Research Network was approached to assist the Department for Communities in the development of this indicator.

The scoping study included 5 objectives:

(1) To review the international literature on quality of life (QoL) measurements for people with disabilities and their families;

(2) To develop recommendations for key definitions;

(3) To assess existing and emerging data sources for potential use;

(4) To develop recommendations for a preferred option; and

(5) To test the recommended QoL measure.

Following a literature review and consultations with stakeholders, we recommend the following definitions:

• Defining 'disability' as, 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (UN Convention on the Rights of Persons with Disabilities, 2006, Article 1);

• Defining 'quality of life' as, 'Individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relations to salient features of their environment' (World Health Organization, 1997);

21%

of the total population in Northern Ireland reported having a disability

(2011 Census)

• Defining ‘family quality of life’ as, ‘...conditions where the family’s needs are met, and family members enjoy their life together as a family and have a chance to do things which are important to them’ (Park et al., 2003, p. 367)

We recommend using a sample population survey, in addition to oversampling people with disabilities, to compare the quality of life of all residents in Northern Ireland.

• Based on a sample of size 4,050 the estimated cost of conducting a survey incorporating the recommended questions on disability and QoL is £247,500

• Survey data should be collected face-to-face as often as possible and should allow for capturing personal experiences in addition to the standard survey questions. Measures should include both subjective and objective measures of QoL

• It is anticipated that the majority of the disability-specific QoL surveys will be self-reporting, while proxy reporting may be considered in exceptional circumstances in order to capture information from those hardest to reach.

• Any measures used should be brief and appropriate

• The World Health Organization Quality of Life (WHOQOL) – BREF and KIDSCREEN surveys should be used as starting points for developing a measurement tool for use in Northern Ireland. It is important that these are used as baselines with the addition of questions that identify objective indicators of quality of life and explore: qualitative experiences; expectations of quality of life; and suggestions for how it can be improved across all relevant areas of policy and services. Additional questions should include objective indicators of QoL such as: income, housing, education, and employment. It is also recommended that people are asked about their experiences of social inclusion, specifically in political life, and of discrimination. It would also be important to allow people the space to identify or comment on issues which impact on their QoL and to ask them directly what they think should be done to improve their QoL

• Family QoL should be explored through the sample population survey by asking disabled and non-disabled people if someone else in their family has a disability and if they provide care for them and

• Data should be collected on measuring the quality of life of people with disabilities and their families every four years to monitor changes over time.

1. Introduction

This Scoping Study was initiated in the context of the Programme for Government 2016-21 (PfG). Two of the Outcomes in the PfG are: 'We care for others and we help those in need' (Outcome 8) and 'We are a shared society that respects diversity' (Outcome 9). A primary indicator for both of these outcomes has 'Improving the Quality of Life for People with Disabilities and their Families' for which the Department for Communities (DfC) was given responsibility. This raises the complex issue of how to measure (and improve) the quality of life of people with disabilities and their families.

An initial proposal was that the ongoing Labour Force Survey (LFS) may provide data sufficient to monitor this indicator through its measure of 'Average Life Satisfaction Score of People with Disabilities'. Respondents rank how satisfied they currently are with their life from 0-10 (10 being highest satisfaction level). The current measure is derived from the responses given to the life satisfaction question, 'Overall, how satisfied are you with your life nowadays?'.

LFS is a quarterly UK resident population social survey of those aged 16 and over in private households, NHS accommodation and student halls of residence. The LFS facilitates comparison with UK countries and includes questions across a broad spectrum of areas (e.g. economic, education, and health). However, concerns have been raised by stakeholders in relation to the appropriateness of using LFS including that:

- It does not capture responses from key groups including children under 16 years, people in hospitals, and those residing in care homes
- Many people with severe disabilities are likely to be excluded, since proxy interviews (e.g. with designated carers) are not undertaken routinely
- Subgroup analyses by health condition or disability type are not possible due to sample size
- The key health question requires identification of 'health problems' from a pre-defined list which does not correspond with recognised disability groups. This prevents an assessment of the impact of interventions for these groups and
- Life satisfaction is only one aspect of Quality of Life (QoL), is very subjective, and may fluctuate.

It was concluded that an independent scoping study commissioned by the Department for Communities was needed to explore the measurement of the quality of life of people with disabilities and their families. The scoping study need to consider the possible options including, but not limited to, the LFS for this indicator.

It should also be noted that the terms ‘disabled people’ and ‘people with disabilities’ are used interchangeably in this study to reflect differences in opinion on the preferred terminology within the broad disability community.

1.1 Aim & objectives

The main aim of the scoping study is to inform how the quality of life of disabled people and their families should be measured. In order to achieve this the scoping study has a number of more specific objectives:

Objective 1

To undertake a comprehensive review of the international literature on quality of life measurements for people with disabilities and their families

Objective 2

To develop recommendations pertaining to key definitions that underpin the indicator, including ‘quality of life’ and what constitutes a ‘family’

Objective 3

To assess all existing and emerging data sources for potential use within the indicator

Objective 4

To develop recommendations to include a preferred option for measuring quality of life for people with disabilities and their families

The quality of life measurement must facilitate assessment at the population and performance level, cover all age groups including children and be applicable for all disabilities

Objective 5

Test the recommended quality of life measure at the performance level by applying the measure to emerging projects being carried out as part of the delivery plan for this indicator

1.2 Principles for the scoping study

In order to inform the conduct and focus of the scoping study a number of principles were agreed:

We will treat each person, involved with and participating in the study, equally and will respect the inherent dignity and independence of everyone	We will approach development on a co-design, co-development/ co-implementation basis along with people with disabilities and their families and will not impose change on them	We will reuse suitable and appropriate datasets and other information sources, concentrating on plugging any gaps rather than repeating work that has already been done
When considering how the quality of life for people with disabilities can be improved, the focus will be on narrowing the gap between the differential experience of people who are disabled compared to those who are not	We will consider how the quality of life can be improved for carers and family members, including extended family members	Information will be provided in accessible formats and technologies appropriate to different kinds of disabilities
We will accept and facilitate the use of sign languages, Braille and other accessible means of communication of their choice by persons with disabilities	We will take all reasonable steps to overcome communication barriers faced by persons with disabilities to enable them to provide direct input to consultations and only should these prove ineffective to use a reliable proxy	We will involve, where possible, traditionally hard-to-reach participants such as children under 16 and people in rural areas

2. Methodology

Key Points

- A Rapid Evidence Assessment (REA) was used to identify the relevant literature.
- The data from the REA were used to inform our preliminary recommendations.
- Interviews and focus groups with stakeholders were held.
- Potential measures and data sources currently available were critically assessed.
- The preferred measures were piloted with the Department for Communities' Pathfinder projects.

The methodology for the first two objectives was a Rapid Evidence Assessment (REA) (Ganann et al., 2010). REAs provide an established methodology for using systematic review methods to identify and critically analyse the available literature and research evidence on legal, policy and practice issues. They permit a rigorous, open, and effective means of evaluating what is known and are particularly suited to projects which have a limited timescale (additional information on the REA methodology is available in Appendix 1). The data extracted from the REA were then critically analysed to inform the definition of the key terms and the consideration of the available measures of quality of life.

The methodology for Objective 3 was to identify and critically appraise current sources of administrative and survey data in Northern Ireland. It also included consideration of other non-routinely collected data, for example, the census and the Northern Ireland Survey of Activity Limitations and Disability (NISALD). This appraisal considered the relevance of the data to the measurement of the QoL of disabled people and their families, its scope in terms of representativeness of the population/disabilities/ages and the possibility of combining data from a range of sources.

In order to inform Objectives 1-3, a series of interviews and focus groups with key stakeholders were held to develop and inform the option appraisal. Ethical approval was obtained through the School of Social Sciences, Education and Social Work's Research Ethics Committee at Queen's University Belfast. Stakeholders were identified through the Steering Group and the Disability Research Network, and included representatives from key disability groups, (physical disabilities, sensory disabilities, learning disabilities, psychosocial disabilities and other disabilities).

The methodology for objectives 4 and 5 was to develop the criteria by which the range of potential measures and data collection methods could be assessed. The terms of reference for the study had specified that all of the options needed to allow measurement of QoL at both the population and performance levels.

The QoL measure had to be brief and appropriate for: all age groups including children; family members and carers; all disability types; those with profound multiple disabilities; and proxy assessments where applicable (proxy assessments must be shown to be reliable and valid).

The final objective was to pilot the preferred measures with the Department for Communities' pathfinder projects (pilot disability services) to explore any issues with the use of these measures.

The scoping study was conducted between December 2016 and March 2017.

3. Definitions

Our team explored three key definitions, ‘disability’, ‘quality of life’, and ‘family quality of life’. The findings on each will be discussed in this section.

3.1 Defining ‘disability’

UNCRPD, Article 1

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective particpation in society on an equal basis with others.

As the population in Northern Ireland continues to age and the prevalence of chronic health conditions and impairments increase, disability needs to be considered in policy decisions. So while disability may be difficult to define, it is essential for policy development and implementation. This section will explore dominant concepts and definitions of disability before, ultimately, suggesting a preferred approach to defining disability.

Theorising 'Disability'

The medical model of disability viewed the lack of opportunity for social participation as a problem that belonged to the individual and focused on the impaired body as the primary barrier. The model was perpetuated by research that was dominated by healthcare professionals which led to an increased power differential between the professional (who knows best) and the disabled person (who should do as they are told). In this way, disabled people were treated as subjects of study rather than as individuals with personal experiences and abilities worthy of equal involvement.

The civil rights movements of the 1960s inspired many people with disabilities and by the 1970s the disability rights movement (DRM) was in full swing. The DRM challenged the medical model (and the isolationist approach) by introducing the social model of disability. The social model aimed to change the way that people viewed disability by taking the focus away from the individual impairment and instead focusing on the social and physical barriers that restricted people with disabilities from participating within their local communities. In the social model, disability is seen as a series of artificially constructed obstructions resulting from the physical and attitudinal environment which are possible to remove. The social model was the foundation for the DRM and is also heralded as the human rights approach to addressing disability issues (Oliver, 1990; Barnes & Mercer, 1997).

The most recently proposed model for understanding disability aims to address the issues and concerns raised by the social model (such as the physical and attitudinal barriers that limit equal citizenship) and also recognises that the individual's impairment plays a role in their lived experience and identity. The socio-medical model argues that both the individual and society must make changes in order to facilitate inclusion, by recognising three key components: (1) disability is not a homogeneous category and appropriate support needs will vary.; (2) there may be limitations to the changes that are achievable within society; and (3) full inclusion may not be desirable or obtainable for everyone (Turmusami, 2003). It tackles the inequalities caused by different types of impairments and acknowledges the potential for multiple forms of discrimination as the result of different parts of an individual's identity. It also promotes partnership working between professionals and people with disabilities to develop a more inclusive society.

In addition to considering the relationship between impairment and disability, it is also useful to consider a life course approach to understanding disability. While literature on life course has traditionally failed to recognise disability, the concept has a great deal to offer. As Mark Priestley suggested:

> Thinking about disability in terms of generational categories (e.g. childhood, youth, adulthood or old age) helps us to understand more clearly how disability and impairment are produced, how they are socially constructed, and how they are regulated in significantly different ways across the life course (Priestley, 2003, p. 23).

Recognising that disability is experienced differently as a result of not only impairment and environment, but also age, is important when developing strategies aimed at improving the quality of life of people with disabilities and their families.

Definitions of 'Disability'

The first internationally accepted definition of disability was introduced by the World Health Organisation in 1981. The definition identified the distinctions between impairment, disability and handicap (all three of which were common terms of the time) and defined each term:

> 'Impairment' refers to any loss or abnormality of psychological, physiological or anatomical structure or function. 'Disability' is any restriction or lack – resulting from an impairment – of ability to perform an activity in the manner or within the range considered normal for human beings. Finally, 'handicap' denotes any disadvantage to an individual resulting from an impairment or disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual (Wood, 1981).

The definition proposed by the WHO has been widely criticised for placing too much emphasis on the person's inability to conform to social norms and their broken or inadequate body (Oliver, 1990; Hansen, 2002) while understating the responsibilities of society to enable people to participate.

In 2001, the WHO proposed another definition known as the International Classification of Functioning, Disability and Health (ICF) which was endorsed by all 191 Member States. Whereas the previous definition was intended for fieldwork only, the new ICF was to be used in member states as the international standard on health and disability. A significant difference of the ICF was its acknowledgement of degrees of health and wellbeing which fluctuate throughout an individual's life. This recognised that disability was therefore not a minority issue but rather something that anyone could experience. It considered all health conditions as equal and acknowledged the social issues that had been ignored in the previous WHO definition (WHO, 2001). The ICF recognised that a disability could be the result of an impairment, an activity limitation, or a participation restriction and defined each as the following:

> An impairment is defined as a 'significant' deviation or loss in body function or structure… There are broadly three types of impairments: sensory impairments, which include difficulty hearing or seeing; physical impairments, which include difficulty with moving, climbing, reaching and other body functions; and mental impairments, which include difficulties in learning, remembering, concentrating, or performing other mental functions…. An activity impairment is defined as a difficulty an individual may have in executing common daily activities….A participation restriction is defined as an inability to fully engage in a major age-appropriate social activity (Stapletone, Protik & Stone, 2008, pp. 7-8).

This definition provided a more comprehensive understanding of disability as it related to both impairment and social barriers, and helped foster a better understanding of the associated social and medical issues. Other organisations followed in a similar fashion, and the International Labour Organization proposed a new definition of disability the following year:

> A disability is the social outcome of a physical or mental impairment only because of a handicap in the context of a given society, often because this society does not respect the needs and the rights of its citizens living with an impairment (ILO, 2002, p. 5).

The changing nature of the understanding of disability has been largely due to the calls of many people with disabilities for a less medical focus and more of a responsibility on others to deliver social change. Today, the most widely accepted definition of disability comes from the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which states that:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (UN Convention on the Rights of Persons with Disabilities, 2006, Article 1).

It is important to note that this definition of disability should be considered alongside the recognition that 'disability is an evolving concept', as stated in the UNCRPD preamble. This approach to defining 'disability' allows for adaptations over time and in different socio-economic settings. The Handbook for Parliamentarians on the CRPD and its Optional Protocol also states, 'Implicit in this indication is the understanding that States may broaden the range of persons protected to include, for example, persons with short-term disabilities' (UN, 2007, p.13). This way of defining 'disability' has been adopted by many countries' domestic policies, as they begin the process of aligning their own policies to the UNCRPD.

As of December 2016, 172 countries have ratified the Convention, requiring them to adopt the objectives into domestic policies and legislation (UN Enable). The UK ratified in 2009 and the Northern Ireland Disability Strategy introduced in 2012 were largely based in the principles of the UNCRPD. The UK will also be examined by the UN Committee on the Rights of Persons with Disabilities later this year, and have recently been asked to provide additional information about 'initiatives adapting current models to the human rights model regarding the understanding of the evolving concept of disability' (UN, 2017, p. 1). This request implies that it will not be satisfactory to continue with the definitions previously used in UK policy and legislation.

The most significant definition of disability provided in UK legislation can be found in the Disability Discrimination Act (1995). It states, '…a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'. A similar version of this definition (with only minor revisions in presentation and pronoun usage) also appears in the Equality Act (2010) which applies to Great Britain. This definition, while arguably the best known, has been criticised for its foundation in the medical model of disability.

Conclusion

Disability rights activists and the broader international human rights institutions advocate for the adoption of the UNCRPD in its entirety, therefore including the definition proposed in Article 1. The definition, which specifically acknowledges that the presence of multiple barriers may limit the full and equal participation of people with disabilities within society, is supported by many organisations and individuals with disabilities living in Northern Ireland. People have indicated that they like not only the recognition of barriers, but also the broader recognition of types of disabilities and the promotion of full and effective participation on an equal basis with others.

3.2 Defining ‘quality of life’

World Health Organization

Individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relations to salient features of their environment.

The purpose of this section is to draw attention to the different debates surrounding the concept of Quality of Life (QoL), how it has been defined and measured and how this important concept has been applied to disabled people and their families.

Conceptualising Quality of Life

Post (2014) claims that the root of QoL goes back to the definition of health put forward by the World Health Organization (WHO), in which health was defined as the 'state of complete physical, mental and social well-being' (p. 168). There is no consensus as to how to define or conceptualise QoL and this is unlikely to change in the future. Nevertheless, there have been many attempts to define QoL (see Post, 2014, pp. 170-171) and models put forward (see Felce & Perry, 1995).

Since its inception, there appears to be confusion around what QoL is and how best to measure it. This is further complicated as the background of professionals may impact on what they view as important or relevant to QoL. Beginning in the mid to late 1900s, QoL has been used by a variety of disciplines for a variety of purposes. In medicine and nursing, for example, QoL has often been used as a measure of the quality of health care intervention received by a patient.

A major focus in the literature is the difference between QoL and health related quality of life (HRQOL), the latter being a term that emerged in the 1980s. While originally defined as a 'subset' of QoL. Post (2014) points out that QoL and HRQOL have historically experienced conceptual slippage whereby the terms 'health,' 'perceived health,' 'health status,' 'HRQOL,' and 'QoL' are treated as synonymous by many researchers and clinicians (p. 170).

In the literature, discussion also occurs around objective and subjective understandings of QoL. Some argue that QoL can only be measured through subjective measures of 'well-being' as perceived by the individual. This is in contrast to a more objective understanding supported by many professionals and researchers. This blurriness of QoL is compounded by a common practice whereby researchers often fail to conceptually define QoL, identify targeted domains of QoL, or provide a rationale for selecting the QoL instrument they choose (Post, 2014).

The WHO definition of QoL (1997) is the most frequently cited within the literature, which defines QoL as:

> [I]ndividual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relations to salient features of their environment (p. 1) .

Conclusion

In order to compensate for the lack of standardised understandings of QoL, researchers must clearly articulate their use of QoL conceptually and provide a rationale for why they have chosen the preferred measure. The research team recommends using the World Health Organization's definition of quality of life as it is the most widely used in the international literature. They also recommend incorporating both objective and subjective measures of wellbeing and QoL that extend beyond health-related indicators.

3.3 Defining 'family quality of life'

Park et al. (2003)

...conditions where the family's needs are met, and family members enjoy their life together as a family and have a chance to do things which are important to them

Families of Disabled People

Defining ‘family’ for people with disabilities is a complex task (see Appendix 2). In recent decades, there have been dramatic changes related to the diversity in family forms for all families, including those of the disabled. Sociodemographic factors such as age, gender, marital status, the type of disability, as well as the timing of the onset of the disability, may affect the composition of family members most important in the lives of people with disabilities. To identify families of people with disabilities, several strategies are recommended based on the themes in family and disability research. First, individuals that live in the same household and identify as having a familial relationship to the person with a disability should be included. Most often these circumstances apply to parents, partner, children, and/or siblings. It is important to emphasise that due to the growing complexity of family forms these roles may not be defined by blood relations or by legal status. Cohabiting relationships, same-sex partners, and adoption are among many possible variations of families that divert from a ‘traditional’ nuclear family definition. Allowing the definition of family to be fluid around familial relationships rather than ancestral or legality determined status will provide a more accurate and socio-contextual view of the family’s needs.

Second, family members who do not live in the household but nevertheless are actively exchanging emotional and practical support should be included. Capturing these family members as part of a larger familial network may be more challenging than just identifying immediate members of the household, but doing so could provide a more complete picture of the family lives of disabled people. These extended family members could be best defined by caretaking roles they provide including both emotional and practical support as well as direct interactions with a disabled family member. This can be most accurately identified by allowing individuals to define their own family members. For instance, individuals whom researchers and policy makers might identify as caregivers might not self-identify as such. Thus, parents caring for adult disabled children could perceive those interactions not as adult care but as an extension of parenting, siblings of a disabled family member visiting over the weekends could perceive their visit not as care but as family interaction, or spouses may not view their day to day assistance as official care. These family conceptions of interactions are often about relational care rather than a dependency dichotomy of care giver and receiver (Knox & Bigby, 2007).

QOL and Disabled People and Their Families

The family quality of life (FQOL) is a recent conceptualisation to provide a holistic and strength based approach to measure the wellbeing of families with a disabled member (Samuel et al., 2011). It was designed to cover a broad range of domains that affect the quality of life for families of people with disabilities across a wide array of contexts. It aims to determine how these varied families are faring and provide a measure to examine the effectiveness of interventions (Samuel et al., 2011). Recent studies applying this framework have, for instance, found that older parents of adult children with a disability have positive attitudes toward their lifelong experiences in

caregiving in multiple domains of satisfaction including leisure/life enjoyment and family relations, but older parents had concerns over the future in regard to health and future care roles of siblings (Jokinen & Brown, 2005). In another study based in China, housing quality was identified as an important context that was strongly associated with family quality of life outcomes of families with children with intellectual disabilities (Hu et al., 2011). Another study found that service adequacy and quality of family-professional partnership was related to FQOL (Summers et al., 2007). These examples highlight how FQOL can be used to measure outcomes from a wide range of family contexts and could be useful in measuring the effectiveness of interventions. A limitation of the approach is that the measurements developed to conceptualise FQOL have been developed only in the last couple decades. As Jokinen and Brown (2005) note, this relatively new field emerged from a 'need for a positive theoretical and conceptual framework within which to understand and develop family-centered approaches to support' (p. 789).

Werner et al. (2009) explain that a commonly accepted definition of FQOL was developed by the Beach Center on Family and Disability (published by Park et al., 2003), as the 'conditions where the family's needs are met, and family members enjoy their life together as a family and have a chance to do things which are important to them' (p. 502). Nevertheless, there appear to be two dominant frameworks/instruments used to explore QoL of disabled people and their families: the Beach Center FQOL Scale and the FQOLS/FQOLS-2006. While these instruments have similarities, they also have important differences that must be considered when determining what framework/instrument is most appropriate to adopt. These tools will be explored further in section 4.3.

Conclusion

Family is ultimately defined in terms of relationships of family members to one another. These relationships consist not only of blood relations, but emotional and social bonds with and toward one other. In this broader context, the family includes not only members of an immediate household, but extended kinship and social networks of caring and of mutual responsibility. One of the most crucial aspects of family is the provision of care, the demands of which can change over the life course and depending on a variety of circumstances.

In keeping with the international literature in this area, the research team recommends using the Beach Center definition of family quality of life (cited at Park et al., 2003).

4. Measuring Quality of Life

4.1 Measuring the quality of life of adults

Key Points

- Both objective and subjective measures are important.
- The most common domains in QoL assessments are physical wellbeing, material wellbeing, interpersonal relations and social inclusion, personal development, self-determination, emotional wellbeing, rights, environment, family relationships, recreation and leisure activities, and safety/security.
- Subjective quality of life may, or may not, be closely associated with services provided.
- There are a wide range of measurements used to assess QoL.
- It is important to involve those whose QoL you wish to measure in the development and design of the relevant measure.

The concepts relevant to measuring the quality of life of disabled people and their families are complex, contested and evolving. This section focuses on the literature related to measuring the quality of life of disabled adults and their families. In general, different approaches have been developed to assess the quality of life of adults and children. In this section, the focus is on adults , while the following section will address the specific issues for children.

Brown et al. (2013, p. 316) considered why measuring quality of life is challenging and suggest that, in addition to there being no universally accepted definition, it can also be perceived from many different perspectives and raises some fundamental questions such as:

- What constitutes a good, and an exquisite, life?
- Do people share views on what constitutes a good life?
- Are some aspects of life more important than others in determining quality of life?
- Are there aspects of life that can be said to universally contribute to, or detract from, life quality?
- To what degree should people's own perceptions determine how we consider their quality of life?
- How do social and cultural factors influence quality of life? And [most importantly for this report]
- What are the best ways to measure quality of life?.

As the previous sections have argued, both objective and subjective aspects of quality of life are important, especially if the purpose is to inform policy and/or service development.

Verdugo et al. (2005) have recommended that the measurement of QoL should include:

- the range of relevant domains
- both objective and subjective measures
- multivariate designs to explore relationships between personal and environmental factors and QoL
- a systemic perspective that acknowledges factors at the micro and macro levels
- the involvement of those whose QoL you are assessing in the design and implementation of the assessment.

Verdugo et al. (2005) also summarised the most common domains in QoL assessments as: Physical wellbeing; material wellbeing; interpersonal relations and social inclusion; personal development; self-determination; emotional wellbeing; rights; environmen;, family relationships; recreation and leisure activities; and safety/security.

Most common domains in assessing quality of life

A further initial point to acknowledge is that subjective quality of life may, or may not, be closely associated with the quality of services provided. Albrecht and Devlieger (1999, p. 977) discuss what has been referred to as 'the disability paradox' which is 'Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these individuals seem to live an undesirable daily existence?'. There is a range of possible explanations for this, one set are referred to as response shift phenomena which involve: '(1) a change in the respondent's internal standards of measurement (i.e. recalibration), (2) a change in the respondent's values (i.e. reprioritization), or (3) a redefinition of the construct by the respondent (i.e. reconceptualization)' (Schwartz et al., 2007).

A further complexity is referred to as the Easterlin paradox (1974, 1995) which suggests that, in developed countries, although at the individual level people may report a relationship between increased income and happiness this does not appear to be reflected in national level data over time. More recently, the Spirit Level has demonstrated that once countries have moved beyond high levels of absolute poverty, then relative and/or perceived inequality becomes of central importance rather than the overall wealth of the country (Wilkinson & Pickett, 2010). In other words, an important aspect of quality of life is how our circumstances compare with the people around us (Kapteyn et al, 2013).

A related example is the study by Brickman et al. (1978) which compared the results of a six-point happiness scale between 29 people severely incapacitated

by accidents, 22 lottery winners, and 22 controls. They reported there was no significant difference between the lottery winners and controls, and although those who had been in accidents rated themselves as less happy, they still rated themselves above the average. There is further evidence, for example Edgerton's (1996) review of a number of longitudinal studies, that satisfaction is relatively stable over time. It may be temporarily affected by major life events (positive and negative), but tends to return to a level which may be influenced by a range of other variables, such as personality, as well as context.

On the other hand, although third party estimates may be lower and satisfaction may be relatively stable, the available evidence from the Labour Force Survey, on life satisfaction does suggest, at the population level, the ratings of disabled people are consistently lower than those without disabilities: 6.96 vs 8.02 in 2013/13; 7.24 vs 8.13 in 2014/15; and 7.14 vs 8.14 in 2015/16 (NISRA, 2017).

Van Campen and van Santvoort (2012) examined the gap between the disabled and non-disabled population's subjective well-being across Europe using data from the European Social Survey. This provided data from 40,605 people including 2,846 with disabilities. They found that although there is a gap across all European countries, it was smaller in the Northern countries than in Eastern Europe. They suggest that differences within countries are related more to differences in personal resources, vitality (mental health) and social support rather than disability, socio-economic status or participation in work.

It has already been argued that quality of life is, or should be, a broader concept than health-related quality of life. As will become clear in this section, health related quality of life is the dominant focus of standardised measures in this area but, although health is a necessary component of quality of life it is insufficient to provide a measure across all the other domains of life that may be important. This means that if the most appropriate tool/s do focus on health, additional questions may need to be added to ensure a more comprehensive measure of QoL is provided.

This scoping study aimed to identify how quality of life can be measured across all ages and all disabilities. Ideally one measure could be identified or developed to do this but, from the literature, most measures have been designed for specific forms of disabilities and for children, adults, or specific age bands.

Literature included in the Rapid Evidence Assessment

Following the search of literature on measuring disabled adults' and their families' quality of life, we included: 22 research articles which explored the use of QoL measures; 6 articles which reviewed QoL measures; 3 articles which explored the qualitative views of disabled people on the measurement of QoL; and a range of possible data sources in the Northern Ireland context.

Of the 22 articles directly addressing the measurement of QoL for adults there are a wide range of measures used and a combination data collection methods. These are summarised in Appendix 3.

Review articles

The Rapid Evidence Assessment searches identified six review articles which provided analysis of a wide range of possible measures. Moons et al. (2006) reinforce that there is still no consensus on the definition or measurement of quality of life. They identify six different conceptualisations which have contributed to the variety in approaches and measures: (1) normal life; (2) social utility; (3) happiness/affect; (4) satisfaction with life; (5) achievement of personal goals; and (6) natural capabilities. They conclude that satisfaction with life is the most appropriate approach as:

> Conceptualising quality of life as satisfaction with life clearly distinguishes quality of life and health. Satisfaction with life refers to a subjective appraisal of one person's life. Overall satisfaction with life can be considered to be an indicator of quality of life because one indicates how satisfied one is with one's life as a whole (p. 898).

Bowling (2014) provides a comprehensive review of measures of quality of life, although the focus is on older people. She reports that a lack of agreement on concepts or measures of social care and QoL outcomes has meant that investigators have tended to place a 'heavy emphasis on health status, physical and mental functioning' (p. iii). Bowling also identifies the criteria to be considered when assessing a QoL measure. These include:

- Development of a clear conceptual basis underpinning the measure
- Rigour in the research methods used to develop and assess the measure
- Engagement with diverse range of people in the target group from the outset to ensure social significance, as well as policy and practice relevance
- Use of adequate and generalizable sample sizes, coverage and types for testing, and provision of population norms
- Use of gold-standard psychometric testing
- Convincing trade-off between scale length and levels of psychometric acceptability (p. 12).

Brown et al. (2013) provide a concise analysis of objective and subjective measures:

> Objective measures (those able to be observed and independently verified) tend to satisfy reliability criteria, but they represent some problems for quality of life measurement if used alone. For example, spending at least one hour a week with at least two friends maybe a good objective indicator that a person is socially active with friends, but such activity may vary among people in importance and quality…Subjective measures, sometimes referred to as perceptual measures, have a credibility that emerges from the fact that they represent how an individual, and only the individual, perceives other people, things, issues, and situations. But subjective measures are also problematic if used alone…they are impossible to verify…are fluid…[and] may be compromised by a human tendency to see things in a similar way over time and by a tendency to make the best of things unless circumstances are dire (p. 319).

They also address the specific question of 'How can quality of life indicators for individuals and families inform policy and practice?' They suggest that QoL frameworks, rooted in psychological theories, may not be the best for 'understanding and evaluating the effectiveness of policies and practices' (p. 323). They propose the Capabilities Framework (Nussbaum, 2011; Sen, 2001) as an alternative which focuses more on how well policy is achieving social justice for all.

Coram Voice (2015) have also completed a literature review on measuring well-being and identified three broad approaches: (1) evaluative (which usually requires people to assess their life satisfaction on a scale); (2) experience (which focuses on the emotional quality of their lives, such as happiness, sadness, anxiety and energy); and (3) eudemonic (which focuses more on their assessment of their internal world such as self-efficacy, relationships, sense of purpose, achievement and autonomy).

Townsend-White et al.'s (2012) systematic review of QoL measures focused on people with intellectual disabilities and challenging behaviours found 24 measures and identified six as sufficiently psychometrically sound. They acknowledge that although there is no consensus about the best measure/s there is more agreement about the core QoL domains: emotional well-being; interpersonal relationships; material well-being; personal development; physical well-being; self-determination; social inclusion and rights.

Van Beurden (2011) provides a specific critical review of the literature on the Beach Quality of Life Scale which aims to assess the QoL of families. She found that the Family Quality of Life Scale is psychometrically sound, but there is a need to explore the relationship between individual QoL and family QoL and how that relationship can be measured and defined.

Qualitative research involving disabled adults in developing QoL measures

It is important to involve those whose quality of life you wish to measure in the development and design of the relevant measure (Verdugo et al., 2005) . From the Rapid Evidence Assessment searches, three articles were selected which focused on this process. As mentioned earlier, Albrecht and Devlieger (1999) explored the 'disability paradox' and discussed the ongoing difficulties of how disabled people may be negatively perceived by others. To do so they used semi-structured interviews to collect qualitative date from 153 people with disabilities. They found that 54.3% of people with 'serious disabilities' in the study reported that they had an 'excellent or good quality of life' compared with 80-85% of people without disabilities who reported they were satisfied or very satisfied with their QoL (p. 981). Their analysis suggested that:

> High quality of life does not seem to be explained by denial of the consequences of disability…Rather, respondents explain their well-being in terms of acknowledging their impairment; being in control of their minds and bodies; being able to perform expected roles; having a `can do' approach to life; finding a purpose, meaning, and harmony in life; having a spiritual foundation and outlook; constructing and living in a reciprocal social world, including emotional give and take; and, feeling satisfied when comparing one's self to one's capabilities and the conditions of others in similar situations." (p. 984)

Connell et al. (2014) also used a systematic review and qualitative methods, focusing on QoL in mental health, to explore whether we are asking the right questions. They interviewed 19 people, who had a broad range of mental health problems, and identified seven domains important to quality of life: well-being and ill-being; relationships and a sense of belonging; activity; self-perception; autonomy; hope and hopelessness; and physical health. They make the important point that those with more severe difficulties were more likely to talk about what decreased quality of life than what added to it. Connell et al. (2014) conclude that the development of further measures is needed since existing generic QoL measures do not address many of the domains (p. 20).

Using a range of creative methods to facilitate discussion and data collection, Scott et al. (2014) explored what makes for 'a good life' with 12 young adults with Down's Syndrome. Identifying four main themes (relationships, community participation, independence, and hopes for the future), Scott et al reported a general consensus among participants that they had a 'good life' and a desire for the same life opportunities as their peers in terms of autonomous behaviour, independent living, and the recognition of their status as young adults (p. 1296).

Conclusion

Measuring the quality of life of adults with disabilities is multi-dimensional and must go beyond health-related quality of life measurement tools. The most common domains in assessing QoL are: physical wellbeing; material wellbeing; interpersonal relations and social inclusion; personal development; self-determination; emotional wellbeing; rights; environment; family; relationships; recreation and leisure activities; and safety/security.

We recommend that the breadth of issues that contribute to a 'good life' be considered in the development of a suitable measurement tool and that both subjective and objective measures are included. The development of any potential QoL measurement tools should also include the participation of the people whose QoL the tools intend to measure.

4.2 Measuring the quality of life of children & young people

Key Points

- There is no single, global instrument recommended for measuring the QoL of disabled children & young people.
- Many of the QoL measures that are available have a narrow focus on health-related QoL for older children and young people with chronic health conditions.
- Qualitative work should be undertaken with children and young people with a range of impairment types and across age ranges.
- Less attention is paid to measuring QoL of younger children (under 8) despite evidence showing that children as young as 4 can self-report.
- Parents as proxies have differing views of their child's QoL but can be useful when used in addition to child self-reports.
- More participatory approaches to obtaining self-reports are required.

Quality of life is a complex concept defined and measured in different ways, depending on each study's purpose or focus. With regard to children and young people, quality of life is also a term that is used interchangeably with other related concepts, such as 'wellbeing' (Thompson & Aked, 2009). The World Health Organisation defines quality of life as:

> Individuals' perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (1997, p. 1).

Rather than a narrow focus on functional domains, measures of quality of life should be broad ranging taking full account of the range of domains relevant to quality of life.

This section of the Rapid Evidence Assessment will provide a synthesis of literature on measures of QoL for disabled children and young people including: the types of measures used to collect data on disabled children and young people's quality of life; the extent of literature available on this topic; and the messages from this body of literature on how best to measure quality of life for disabled children and young people.

Measuring quality of life for children and young people

The literature on quality of life for children and young people takes two broad approaches. Firstly, objective, standardised measures usually administered by survey to measure proxy indicators of QoL such as, household income or mortality rates. Secondly, subjective self-reported indicators often using scaled questions to measure the extent of happiness, satisfaction or positive/negative feelings across domains associated with of quality of life, such as, family and social relationships, schooling, resilience or health (e.g., UNICEF, 2007).

Subjective, self-reports of QoL are often treated with caution as there is potential for differing interpretations of questions/concepts, for responses to be based on the child/young person's frame of reference in terms of individual experience and circumstances, and for concerns about unreliability, particularly for young children or disabled children and young people. However, subjective self-report approaches have also been increasingly accepted as authentic sources of data on children and young people's quality of life as they are a direct reflection of children and young people's feelings and experiences (Thompson & Aked, 2009).

Increasing attention has also been paid to the involvement of children and young people in the design of measures of quality of life and capturing children and young people's views on what well-being means to them and what is important to their quality of life (Hicks et al., 2011).

There is an emphasis in the literature on the need to use a multi-dimensional definition of QoL including objective measures (e.g. income and wealth), subjective indicators of

children's own sense of quality of life, and consultation with children and young people to ensure measures are appropriate (Hicks et al., 2011, p. 9).

Whilst there is a wide range of research examining children and young people's quality of life, few of these studies make reference to disabled children and young people. For example, the Good Childhood Report (The Children's Society, 2016) provides an overview of children's well-being in the UK but does not report findings specific to disabled children (although it does report on the mental health of children and young people based on the 25 item Strengths and Difficulties Questionnaire).

Some studies on the quality of life of children and young people have included those with health or disability related needs but, unfortunately, have not produced disaggregated data on this sub-population. For example, the national study on the quality of life of 1,265 children and young people aged 8-11 and 12-17 in Ireland used the KIDSCREEN tool. Overall, 17% of respondents indicated they had chronic health problems; however, more detailed findings of this sub-population are not reported.

Across the range of child and youth quality of life literature, authors repeatedly note the under-representation of disabled children and young people in surveys of children and young people's wellbeing (Hicks et al., 2011; Selwyn & Riley, 2015). There are a range of potential reasons for their exclusion from national studies of child and youth well-being and quality of life studies including their absence from schools used to access survey samples, lack of identification of disability among the population surveyed (thereby not excluded but not clearly identified as a sub-group within the child and youth population) or concerns about their incapacity to reliably complete quality of life survey instruments.

Many of the objective and subjective measures of quality life usually administered by survey method are not accessible for disabled children and young people, particularly those with a cognitive impairment. Some disabled children and young people may have difficulty understanding the typical terminology used or timeframes (e.g. how often?) and scales used (on a scale of 0-10). As a result, studies often rely on parents/carers or professionals as proxies for the child despite concerns about bias and differences in perspectives. Increasingly, there is an emphasis on finding alternative and more accessible ways to ascertain disabled children and young people's self-reports on their quality of life.

Literature included in the Rapid Evidence Assessment

In our search for literature on disabled children and young people's quality of life, we found 4 systematic reviews and 25 articles/reports using various measures of quality of life for disabled children and young people. Of the articles/reports measuring quality of life for disabled children and young people, 19 of these articles/reports used a range of self-report or proxy quality of life measures in studies with disabled children and young people (see Appendix 4) and five were based on qualitative research with disabled children and young people or their parents aimed at seeking their views on the appropriateness or development of

The majority of the studies use KIDSCREEN, a self-report standardised health related quality of life instrument for children and young people developed as part of a European project involving 13 countries (Ravens-Sieberer et al., 2001; 2005). Several studies also use the DISABKIDS instrument which was also developed as part of a European project aimed at enhancing the quality of life and the independence of children with chronic health conditions and their families (Peterson et al., 2005). See 4.5 for analysis of these measurement tools.

The following common trends can also be identified in the review of the literature cited in the appendix:

- Most self-report measures focus on school age children and young people (often those aged 8 years and above) with less attention paid to younger children

- There is a disproportionate focus on health related quality of life and children and young people with chronic health conditions, with more limited attention given to other domains of quality of life

- Some studies are specific to a particular impairment type (e.g. cerebal palsy) or health condition. Several refer to disabled children and young people more generally in a purposive effort not to identify impairment types within the sample population, based on a commitment to the social model

- A continuing reliance on parents as proxies is concerning given evidence of differing views of parents and children and the risk that parents' own quality of life biases their assessment of their child's quality of life (Eiser & Jenney, 2007). However, proxy reports can be useful when used in addition to child self-reports to access multiple perspectives.

Systematic reviews

The four systematic reviews of quality of life measures focused mainly on health-related quality of life: two focused on health-related quality of life measurement (Morris et al., 2014; Solans et al., 2008); one addressed a range of quality of life measures for children with cerebal palsy (Carlon et al., 2010); and one focused on quality of life of young children with heart conditions from early infancy (Jardine et al., 2014). These systematic reviews helpfully appraise a range of quality of life measures, however, they have a narrow focus on disease or health conditions.

Solans et al. (2008) reviewed 30 generic and 64 disease-specific (mostly asthma, cancer and epilepsy) health related quality of life instruments for children and young people up to 19 years old based on a review of literature from 2001-2006. Of the disease-specific instruments, 43.7% were exclusively child self-reports, 26.6% were parent only reports and 29.6% were both child and proxy reports (p. 745). Most commonly measured concepts were emotional well-being, social functioning, physical function, symptoms and treatment. The majority of instruments met accepted standards of internal consistency and validity although few provided data on test-retest reliability or structural validity (p. 758). The review concluded that health related quality of life instruments are multi-dimensional but should also explore health inequalities and population subgroups by gender, socio-economic status and capture a greater range of

diseases/conditions. Although the authors found that child self-report was increasing, there was still a reliance on parent/proxy reports, particularly for younger children, despite evidence of differences in child and parent scores. The authors called for more participatory approaches to obtaining self-reports from children and young people.

Carlon et al. (2010) conducted a systematic review of quality of life measures for school-aged children with cerebal palsy, including: the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) (Narayanan, 2006), CP QOL-Child (Waters et al., 2007), DISABKIDS (Baars et al., 2005; Peterson et al., 2005; Schmidt et al., 2006) and PedsQL 3.0 CP Module (Varni et al., 2006). Three of these measures were developed based on interviews with parents of children with cerebal palsy and relevant professionals (CP QOL-Child, CPCHILD and DISABKIDS). The CP QOL-Child and DISABKIDS measures were also developed in consultation with children with cerebal palsy. All measures had a parent proxy version and three also had a child self-report version for those aged 8 years and over (CP QOL-Child, DISABKIDS and PedsQL 3.0). Following assessment of quality, validity and reliability, the authors concluded that CPCHILD and the CP QOL-Child demonstrated the strongest psychometric properties and considered the DISABKIDS and PedsQL 3.0 as being moderately constructed.

Jardine et al. (2014) conducted a systematic review of self-reported quality of life measures of young children with heart conditions from early infancy. The Pediatric Quality of Life Inventory was most commonly used. The authors found differences in child and parent perceptions of quality of life and also found that children as young as 4 years could self-report if questionnaires with simplified response scales or interviews were used, highlighting the importance of obtaining children's own views on their quality of life. Overall, the authors noted a lack of published studies on self-report quality of life for younger children, including proxy reports and found variation in approaches to analysis and sampling and low sample sizes for studies involving children under 12 years old.

Morris et al. (2014) conducted a systematic review of patient reported outcome measures (including health-related quality of life) for children with a chronic condition or neurodisability. Of the quality of life measures reviewed, the most studied instruments were KIDSCREEN and PedsQL. PedsQL has three versions, according to age (infancy to adolescence), for self-report and proxy responses, mainly assessing functioning. The authors found no evidence of qualitative research to inform the development of the PedsQL instrument and mixed reports of its validity. For self-report measures for children aged 8 years and over, the authors found stronger evidence of structural validity of KIDSCREEN in general populations and those with cerebal palsy. Similarly, evaluations of the psychometric properties of DISABKIDS are positive. Overall, Morris et al. (2014) found discrepancies in child and parent proxy reports of quality of life, particularly in relation to emotional and social domains. They also highlighted that, as some instruments measure functionality whilst others, such as KIDSCREEN, predominantly assess children's feelings about their health, the choice of instrument should be consistent with a given study's purpose.

Qualitative research involving disabled children in developing quality of life measures

As noted earlier, KIDSCREEN and DISABKIDS were developed based on consultations with children and young people with chronic health conditions and their parents. Our review also identified five key articles/reports focused on qualitative research with disabled children and young people or their parents aimed at seeking their views on the appropriateness or development of quality of life measures which are useful examples representative of the wider literature on involving disabled children and young people in the development of quality of life measures (Ikeda et al., 2016; Young et al., 2007; Morris et al., 2014; and Redmond et al., 2016).

The findings from the literature highlight the importance of involving disabled children and young people in the appraisal, development and testing of quality of life measures.

There are a number of key points to consider:

- the need to adapt questions and approach to the communication needs and real life contexts of disabled children and young people
- the importance of clear wording, visual presentation and varied response options
- the need to capture the priorities disabled children and young people report to be missing from existing instruments
- the differing perspectives of disabled children/young people and those of their parents as proxies
- the acceptability of negatively worded questions
- the varying interpretations disabled children and young people may apply to key concepts, especially family and community
- the inter-relationship of domains covered in quality of life instruments and
- the importance of cognitive interviewing to test new measures with young people from a wider range of ages and impairment types.

Conclusion

This section of the Rapid Evidence Assessment has provided a summary of the literature on measures of quality of life for disabled children and young people, highlighting the most commonly used quality of life instruments and qualitative approaches to involving disabled children and young people in the appraisal, development and cognitive testing of quality of life measures. It is clear that there is an over-emphasis on health-related quality of life, older children and those with particular types of health conditions/impairments. As a result, we have limited evidence of the effectiveness or quality of life instruments for the full range of disabled children and young people across age and impairment type.

There is an ongoing reliance on proxies despite concerns about the reliability of proxy measures and parental reservations about their ability to accurately report on social and emotional domains of their child's quality of life. There are some examples of studies involving disabled children and young people in the development, completion or testing of quality of life measures. However, there is a need to develop more adapted versions of quality of life instruments and adopt more inclusive, participatory approaches to involving a greater range of disabled children and young people in the development and testing of quality of life measures.

4.3 Measuring quality of life using proxies

Key Points

- There is little consideration of people with complex disabilities in the subjective wellbeing literature.
- All possible supports should be explored before considering proxy responses.
- Proxy reporting tends to rate QoL lower than self-reporting.
- Minimise potential proxy bias by including very clear instructions, including both proxy-patient and proxy-proxy perspectives.
- We recommend focusing on self-reporting within the disability QoL survey as much as possible, while it is expected that the general population survey will include at least some proxy reporting.

A key limitation with the existing data available on subjective well-being is that the current samples do not include sufficient numbers of people with disabilities and those who are unable to respond are excluded. This means that, in addition to insufficient numbers to enable analysis, there is also an important group, people with complex disabilities, who are not represented.

Ideally, all possible supports would be made available to ensure that those who could provide responses directly would be included but, even with high levels of flexible support, there will still be some people who will not be able to respond. In those situations, the options are to exclude or use proxies to estimate the person's quality of life. Rand and Caiels (2015) have completed a review of the issues and challenges of using proxies to assess quality of life. They included 79 articles which reported research with adults and which address the complexities of using proxies. They highlighted four main findings:

- Proxies tend to rate quality of life lower than self-report

- The size and direction of difference between self-reported and proxy-reported QoL are associated with methodology

- There is a higher level of self- to proxy-report agreement when the health status of the self-respondent is either very good or very poor and

- According to Pickard and Knight (2005), there are two ways in which the proxy may answer QoL questions on behalf of another individual: (1) the proxy-patient perspective, where the proxy attempts to reconstruct the individual's internal mental state to answer the question; and, (2) the proxy-proxy perspective, where the proxy answers based on their own judgement influenced by their own values, expectations and assumptions (pp. 1-2).

Rand and Caiels (2015) conclude that there are limitations with using proxies and to minimise potential bias, proxy measures should: include very clear instructions; include both proxy-patient and proxy-proxy perspectives; and acknowledge that the response will be biased.

Balboni et al. (2013) directly compared the use of self-report and the report of others assessments and found that clients always rated their QoL higher than their caregivers. They also found that if the caregiver was clearly told to estimate QoL from the disabled person's perspective the results were closer. This reinforces Rand and Caiels' recommendation about the importance of the instructions provided to the proxy.

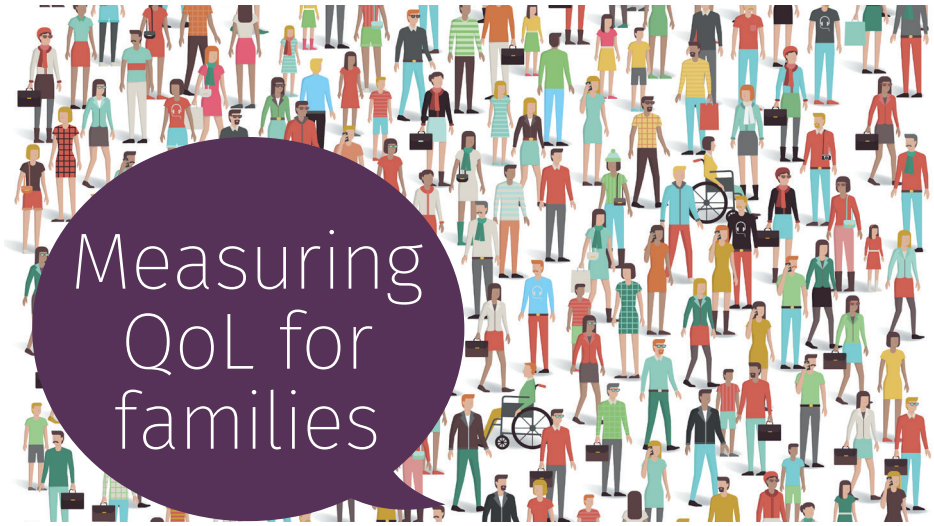
Koch et al. (2015) also explored proxy and self-reported QoL in adults with intellectual disabilities to try and establish why proxies often underestimate the subjective QoL of those with disabilities ,and found that 'proxies tend to consistently underestimate the QoL subjectively experienced by adults with ID'. They also warn that if proxy reports are the only available source of data, they should be 'interpreted with caution' (p. 144).

Conclusion

Recognising the complexities associated with proxy reporting, we recommend the use of self-reporting as much as possible, including the use of face-to-face interviews that may utilise alternative forms of communication. While acknowledging the limitations of proxy measurements, they do warrant careful consideration, as failure to do so would exclude an important subgroup of people with disabilities. It is anticipated that the majority of the disability-specific QoL surveys will be self-reporting, while proxy reporting may be considered in exceptional circumstances in order to capture information from those hardest to reach. It is also expected that much of the general population data captured on disability will come from proxy reporting.

4.4 Measuring quality of life for families

Key Points



- All studies focused on families in which there was a child with a disability.
- The Beach Centre FQOL Scale and the FQOLS/ FQOLS-2006 were the most commonly used tools.
- Nearly half of the studies were concerned with the development of measurement tools while the other half were focused on applying the available tools.
- Measuring FQOL is still in its infancy and more work needs to be done to address its complexities.
- We recommend including questions about the family in a general population survey, in addition to the self-reporting survey.

As the discussion of definitions has highlighted, the concepts related to measuring the quality of life for families are complex, contested and evolving. This section focuses on the literature related to understanding and measuring the quality of life of families that include at least one person with a disability.

Interventions focusing on the entire family, identifying needs and providing resources to the entire family, and focusing on strengths rather than deficits of family members have been shown to be related to higher level of life satisfaction for the whole family (Prilleltensky, 2004). A concern is that these types of interventions can be more expensive and more difficult to implicate compared to interventions targeting solely the disabled family member (Olsen & Parker, 1997).

Until recently, research on families and disability followed a more medical model (Ferguson, 2001) and the shift toward a social model of disability has refocused the narrative to understanding more about the contextual experiences of families of people with disabilities that shape their wellbeing. Along these lines, research on families of disabled people frequently report the joy and happiness that the disabled person has brought to their lives (Stainton & Besser, 1998). However, family members can face structural, environmental, and attitudinal barriers in the process of advocating of their disabled family member that create a 'burden of care.' Families with disabled members are often perceived as 'problem families' in terms of interaction with services and the state, narrowing of social networks, and attitudinal forces of pity or hostility (McLaughlin, 2002). The life course perspective that underlines how the sociocultural context can alter the trajectory of peoples' lives (Elder, 1999). Applying this to disability and family it is essential to understand the resources available and situational context of families navigating disabling barriers. There has been a greater understanding that the amount of resources family have access to can notably affect the familial reaction to disability (Bérubé, 1996; Harry, 1992; Hayden and Heller, 1997; Patterson, 1993; Turnbull & Turnbull, 1990).

One of the primary discussions around measuring QoL for families that include someone with a disability is that of burden of care. Parents of disabled children have been shown to have increased levels of parenting stress and have higher rates of divorce (Hartley et al. 2010). Parents of adults with disabilities have been found to have more limited interactions with friends, lower rates of employment, and diminished savings (Heller and Harris, 2011). Feminist perspectives have concentrated primarily on the gendered component of the burden of care. Generally women are more likely to take the role and identity of care giver due to a myriad of complex sociocultural forces. This may be particularly challenging for the "sandwich generations" of women who may be simultaneously caring for both their young children and aging adults (Spillman & Pezzin, 2000).

Measuring FQOL is a useful way to consider some of the social contexts of living with a disability and, in particular, for families in 'under-resourced areas with diverse family structures and racial/ethnic backgrounds' (Samuel et al., 2017).

Literature included in the Rapid Evidence Assessment

In our search for literature on the quality of life of families with a disability, we found 17 studies. Nearly all of the studies focused on families with a child with a disability (though sometimes the child was over the age of 18). We were unable to locate any studies which focused on families where at least one parent had a disability. The majority of the studies that were not reviews (79%) focused on families that had someone with intellectual or developmental disabilities. Eight of the studies were concerned primarily with the development and validity of the available tools for measuring family quality of life and nine were empirical studies that aimed to measure a particular aspect of QoL for families. See Appendix 5 for additional information on the related studies.

Standardised measures of quality of life for families

Of the 17 articles measuring of quality of life for families with someone with a disability, only two studies included reporting by the person with a disability. The most commonly used mechanisms for measuring FQoL are the Beach Center FQOL Scale and FQOLS.

The Beach Centre FQOL Scale and FQOLS/FQOL-2006

Van Beurden (2011) critically evaluated the Beach Centre Family Quality of Life Scale and came to the conclusion that it was a 'psychometrically sound measure that has the potential to be a useful tool' (p. 4). This assertion was futher confirmation of similar claims made by Hoffman et al's assessment in 2006.

Isaacs et al. (2012) trialled FQOL-2006 in Nigeria, Australia, and Canada to test its domain structure and concluded that the domains 'provide a good basis for service providers to operationalise the FQOL construct across service components, to identify outcome predictors and to assess the impact of services and practices on families' (p. 29).

Perry & Isaacs (2015) recommended the use of the Beach Centre FQOL scale as a valid and efficient measure but the FQOLS-2006 for gathering 'richer, descriptive detail' (p. 587).

This scale would therefore provide a possible measure if the focus was exclusively on family quality of life. However, in the context of a representative sample of the population it could be more efficient to identify all individuals who are in a family with a disabled to provide an indication of family quality of life.

Other findings

In a recent study of FQOL when there is a child with a developmental disability, Brown et al. (2017) suggested that 'there is a need to both identify and provide measures of care and support that would enable families to function at an optimum level within their home and community, so they may experience a quality of life similar to that of families without a child with a disability' (p. 238).

Rillotta et al. (2012) also found that families placed a greater emphasis on the domains of health, family, relationships and financial wellbeing over practical and emotional support from others. Families generally reported being satisfied with their family relationships and neither satisfied nor dissatisfied with their financial wellbeing. A similar study by Bertelli et al. (2011) found that families reported a low level of QoL in support for others and community interaction and a higher level of QoL in family relationships and health of the family. For individuals with intellectual disabilities who self-reported, the highest area of QoL was physical health and the lowest was spiritual health.

Two studies addressed health-related QoL for parents of children with disabilites. Burton et al. (2008) concluded that 'mothers' overall self-rated health is negatively associated with parenting a child with a seroious disability' (p. 1184) but the same does not apply to fathers.

Conclusion

Family QoL measurement is still an emerging concept and there is not yet a great deal of evidence on which to base our conclusions. To date, there are two prominent measurement tools, one shorter (Beach Center) and the other more robust. We are in need of more qualitative assessments, however, in order to gain a better understanding of the family dynamic. The lack of studies considering people with disabilities as carers and the over-reliance on the views of the caregiver and not the person with a disability is also concerning.

In light of the complexities of measuring family quality of life as a concept, we recommend that the survey of QoL include questions aimed at the general population about carers and family members with disabilities, as it was agreed that the tools currently available were better suited for smaller scale academic studies than general population surveys.

4.5 Assessment of Selected Measurement Tools

Key Points

- Following a critical evaluation of the available tools, we recommend using amended verions of the World Health Organization Quality of Life (WHOQOL) - BREF and KIDSCREEN.

- These measurement tools were selected based on their international comparative properties and their suitability for measuring the quality of life of people living in Northern Ireland.

- The tools will also allow for comparative data to be collected by targeting both disabled people specifically, as well as a general population survey.

There are a wide range of tools available which have been designed to measure QoL and directly related concepts. Eighteen specific measurement tools have been selected to provide an overview of the range available. The strengths and limitations of each of them are assessed below.

1. Control Autonomy Self-realization Pleasure (CASP-19) (Hyde et al, 2003)

The CASP-19 has been included primarily as it is the QoL measure already included in the NICOLA survey. It was specifically designed for use with older people and is based on a needs satisfaction model. Each question is scored 0-3 (Often, Sometimes, Not Often and Never). The strengths of the CASP 19 are that it covers the main domains of QoL in a concise and accessible format. Some of the questions are, however, more suitable for older people and so would make its use across all ages problematic.

2. EQ-5D (Euroqol Group, 1990)

This is a very commonly used measure of health related quality of life. The strengths of the EQ-5D are that it is focused and used across many research projects, however, it is straightforwardly designed to be a health related QoL measure.

3. Quality of Life Questionnaire (QOL-Q) (Schalock & Keith, 1993)

This is a 40 item questionnaire which was designed for measuring the QoL of people with intellectual disabilities. It covers four main domains: satisfaction (10 questions); Competence/productivity (10 questions); Employment/independence (10 questions); Social belonging/community integration (10 questions). The QOL-Q explores a wider range of issues but was designed to be used for those with intellectual disabilities. It has been tested as valid for those with physical disabilities (Caballo, Crespo, Jenaro, Verdugo, & Martinez, 2005) and across a range of countries (Latin America, Spain, China, Canada, and the United States) (Schalock et al., 2005) but not at the general disabled and non-disabled population level. There is also a shortened version with has 20 items with 5 questions in each domain.

4. Washington Group on Disability Statistics' disability questions for census & survey use

These questions were based on WHO's International Classification of Functioning, Disability and Health (WHO, 2001) and there is an extended version but it is still very focused on disability and functioning rather than QoL.

5. The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle et al., 1993)

This is a very interesting measure as it allows the person to identify the five domains that are most important to their own quality of life, then asks how things are going in each of the areas (using a bar chart), and then the relative importance of each area to determine a weighting (using a pie chart). The SEIQoL also includes a single overall question. This is a good example of a measure which doesn't impose any assumptions about what is important to people's subjective QoL but it may raise difficulties in terms of comparison at the population level.

6. The Kemp Quality of Life Scale (KQOL) (Kemp & Ettelson, 2001)

There are a number of examples of single question QoL measures. One of the more robust is the KQOL which asks: Taking everything into account, please rate your overall Quality of Life on the following 7 point scale (1-7). It provides the following explanation for the scoring: One (1) means life is very distressing; it's hard to imagine how it could get much worse. Seven (7) means life is great; it's hard to imagine how it could get much better. Four (4) means life is so-so, neither good nor bad. There is an appealing simplicity, clarity and speed to single item measures but the central limitation is that they provide little information about what domains may be relevant to the overall assessment.

7. Office of National Statistics (2016) (Labour Force Survey)

In the UK, data on personal (subjective) well-being have been collected each year since April 2011. It is measured by four questions: 1. Overall, how satisfied are you with your life nowadays?; 2. Overall, to what extent do you feel the things you do in your life are worthwhile?; 3. Overall, how happy did you feel yesterday?; 4. Overall, how anxious did you feel yesterday?. A scale of 0 to 10 is used where 0 is 'not at all' and 10 is 'completely'.

It is acknowledged that 'yesterday' may not be typical but the large sample (165,000 people aged 16 and over in residential households) should average out the differences. In Northern Ireland these questions are asked as part of the Labour Force Survey (LFS). As detailed in the Project Initiation Document the LFS is a quarterly UK resident population social survey of those aged 16 and over in private households, NHS accommodation and student halls of residence. The LFS facilitates comparison with UK countries and includes questions across a broad spectrum of areas (economy, education, health etc). However, concerns have been raised by stakeholders in relation to the appropriateness of using LFS to measure the quality of life of disabled people and their families including:

- The LFS does not capture responses from key groups including children under 16 years, people in hospitals and those residing in care homes

- Many people with severe disabilities are likely to be excluded from the LFS as proxy interviews (e.g. with designated carers) are not carried out as a matter of routine

- Due to restrictions with sample size, subgroup analyses e.g. by health condition or disability type, are not possible

- The key health question included in the LFS invites respondents to identify their 'health problems' from a pre-defined list. The health problems do not correspond with recognised disability groups and therefore prevent an assessment of the impact of interventions for these groups

- Many observers have commented that life satisfaction is only one aspect of Quality of Life (QoL) and that it is very subjective and may fluctuate.

8. 8+1 (EUROSTAT, 2012)

In the focus groups aspect of the scoping study, one of the measures used as an example was the 8+1 (EUROSTAT, 2012). It was introduced as a module on well-being by the European Commission and so all countries in the EU have reported on it. This means there is excellent, cross-country baseline data which can be analysed along with a range of objective indicators (Eurostat, 2016). Data for the subjective well-being module were collected in 2013 but it is not clear if this is an ongoing process and so the usefulness of the baseline data may be diminishing.

9. European Quality of Life Survey (European Foundation for the Improvement of Living and Working Conditions, 2016)

This survey also provides comparative data from across Europe and has been carried out in 2003, 2007, 2012 and 2016. The survey has covered: perceived quality of society, trust in institutions; social tensions; housing; deprivation; family; health and wellbeing; people's levels of happiness; how satisfied they are with their lives; and their participation in society. In 2016 the questions included a specific focus on the quality of public services and life online. The central difficulty is the size of the sample of disabled and non-disabled people in Northern Ireland.

10. European Social Survey (2015)

The ESS has been collecting data on well-being every two years since 2002. The survey includes subjective well-being considerations such as 'life satisfaction' and 'happiness' in its primary questionnaire. More in-depth data is also provided in some 'thematic rotating modules'. The data are collected in addition to a large number of socio-demographic background variables and questions in order to provide researchers and policymakers with robust information to explore Europeans' well-being. Again, the central difficulty is the sample size of disabled and non-disabled people in Northern Ireland.

11. Quality of Life Scale (QOLS) (Burckhardt & Anderson, 2003)

This was also used as an example in the focus groups and is, similar to the WHOQOL-BREF relatively focused. In most versions the Delighted-Terrible scale is used but some of the feedback suggested this language was now dated and a satisfaction scale, as used in the international versions would be more appropriate.

12. INTEGRAL Quality of Life Scale (Verdugo et al., 2007)

This scale was developed for use with people with intellectual disabilities in Spain but has also been validated and used with other groups and across many countries. It is also of interest as it has been mapped to the UNCRPD (Verdugo et al., 2012; Schipper et al., 2015). The objective sub-scale has 29 items (yes/

no) and asks for a professional overview of QoL. The subjective scale has 47 items and uses Likert-type responses (strongly disagree, disagree, agree, strongly agree). The scale can be self-report or completed by interview. This scale is still developing and being tested across a number of countries but it may be important to consider for future data collection.

13. San Martin Scale (Verdugo et al., 2014)

A limitation of the INTERGRAL is that there isn't a proxy version but the San Martin Scale has been developed to resolve that. It is a 95 item scale that assesses the eight integral uality of life domains from the conceptual framework Schalock and Verdugo (2002) have researched and developed.

14. World Health Organization Quality of Life (WHOQOL) – BREF (World Health Organization 2004)

This is a commonly used tool and so would provide ongoing comparison with many other countries and across a wide range of research with specific groups. It is also relatively short although is arguably relatively health and deficit focused.

WHOQOL-BREF is a 26-item version of the WHOQOL-100 assessment. Skevington et al (2004) analysed its psychometric properties using cross-sectional data obtained from a survey of adults carried out in 23 countries. The WHOQOL-BREF self-assessment was completed, together with socio-demographic and health status questions and analyses of internal consistency, item–total correlations, discriminant validity and construct validity through confirmatory factor analysis, indicate that the WHOQOL-BREF has good to excellent psychometric properties of reliability and performs well in preliminary tests of validity.

See Appendix 6 for survey questions.

Consultation participant

15. Beach Center on Disability Family Quality of Life Scale (FQoL) (Hoffman et al., 2006; Park et al,. 2003)

This measure appears to be very well-established and commonly used. Balcells-Balcells (2016, p. 43) reports that it "consists of 25 items responding to five QoL dimensions of the families of children with intellectual disability (Family Interaction, Parenting, Emotional Well-being, Physical and Material Well-Being, Disability-related Support), all of them validated in previous research. The items in this scale have also been formulated to be answered through a 1-5 Likert scale of importance and satisfaction. Cronbach's alpha provides a measure of the reliability of an instrument or how consistently it is measuring what it is intended to measure. A result of 0.7 or more is viewed as acceptable and 0.9 or more is viewed as excellent. (Balcells-Balcells et al., 2011)." The domains the scale covers are: emotional wellbeing; physical material well-being; family interation; parenting; disability-related supports.

16. Family Quality of Life Survey (FQOLS-2006) (Brown et al., 2006)

The Family Quality of Life Survey is comprised of quantitative and qualitative items in each of the nine domains and is most often administered as an interview. The domains are: health of the family; financial well-being; support from others; support from disability-related services; influence of values; careers; leisure and recreation; community interaction. FQOLS-2006 has been used in roughly 20 countries to collect QoL data on disabled people and their families (Cagran et al., 2011). Researchers claim that this survey is useful for a variety of health and social care settings and its ability to be adapted to different situations and life stages is an advantage. It can be a useful research tool in a longitudinal design before and after residential placement or allocation of other services in the transition from school to a day. It has been criticised for its one dimensional focus on the family and would be complemented by the additional of social factors that shape and impact the family.

17. DISABKIDS

The DISABKIDS instruments measure general quality of life and the level of distress caused by a chronic disease and have been developed in consultation with children and young people and their parents. A long version (DCGM-37) as well as a short version (DCGM-12) are available and in both a self-report (child version) and a proxy version. The DISABKIDS chronic generic module (DCGM-37) has 37 Likert-scaled items assigned to six dimensions: independence, emotion, social inclusion, social exclusion, limitation, and treatment. The sub-scales of these six dimensions of the DCGM-37 can be combined to produce a general score for health-related quality of life. Morris et al.'s (2014) systematic review found some evidence to support structural validity across the psychometric properties of DISABKIDS-37 version but limited evidence of validity of the 12 item version.

There are also DISABKIDS condition specific modules for children and young people with different chronic health conditions. The DISABKIDS questionnaire set contains seven disease-specific modules for the following conditions: asthma, arthritis, dermatitis, diabetes, cerebral palsy, cystic fibrosis and epilepsy (Baars

et al., 2005). In addition, there are three questions to self-report on the perceived severity of symptoms from the child perspective. This modular approach allows for shorter and more comprehensive approaches and detailed analysis of quality of life for disease-specific conditions but does not allow for comparison across other groups (Eiser & Jenney, 2007, p. 348).

Finally, there is a DISABKIDS-Smiley version with 12 items aimed at cognitive levels of children between 4 to 7 developmental years but can be used with older children who do not have the reading ability to complete the generic DISABKIDS questionnaire. This instrument uses smiley graphics to on a Likert-like rating scale to represent emotions ranging from very sad to very happy. The items for the questionnaire were derived from focus groups with parents of children between 4 and 7 years. Self-report (child) and proxy versions are available.

18. KIDSCREEN

The KIDSCREEN measure is applicable for healthy and chronically ill children and young people aged 8 to 18 years.There is a 52 item instrument assessing children's views, attitudes and feelings about their perceived health which measures 10 health related quality of life dimensions: Physical wellbeing, psychological wellbeing, moods and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance, and financial resources. There are also three other versions of KIDSCREEN: KIDSCREEN-27 and KIDSCREEN-10 and a proxy measure for parents or carers. The KIDSCREEN-10 Index was developed from the longer KIDSCREEN-27 and requires only a few minutes to complete. Morris et al. (2014) reviewed literature on the psychometric properties of KIDSCREEN instruments in that support the structural validity of these instruments. Whilst KIDSCREEN can provide helpful data on health related quality of life related to preventive health care and treatment, it does not cover other non-health related domains of quality of life.

The psychometric properties of this index are such that the distribution of raw-scores resembles the theoretical expected normal distribution. Thus the index provides a good discriminatory power along the HRQoL-trait-continuum, shows only few ceiling/floor effects, and even raw-scores may provide interval-scaled HRQoL measurement. In addition the good internal consistency reliability (Cronbach's Alpha = .82) and the good test-retest reliability / stability (r = .73; ICC=.72) enables a precise and stable HRQoL measurement. Additional statistical analyses show that the KIDSCREEN-10 Index is able to differentiate between different groups. Children and adolescents with a low score on the family affluence scale (FAS, effect size d=.47), with behavioural problems (SDQ, effect size d=.1.30) and with a high number of psychosomatic complaints (d=1.69) display significantly lower health related quality of life in comparison to the respective comparison group.

See Appendix 7 for survey questions.

Table 1: Assessment of Selected Measurement Tools

	Suitable for general population and all disabilities	Proxy version or designed for proxy	Covers all main Quality of Life domains	Ongoing international comparison possible	Manageable length for a population level survey
Control Autonomy Self-realization Pleasure (CASP-19) (Hyde et al., 2003)	No – specifically designed for older people	no	Control Autonomy Self-realisation and Pleasure	yes	yes - 19 items
EQ-5D (Euroqol Group, 1990)	yes	yes	No – this is specifically for health related QoL	yes	yes - 26 items
Quality of Life Questionnaire (QOL-Q) (Schalock and Keith, 1993)	No – specifically designed for those with intellectual disabilities	yes	Satisfaction, competence, independence and social belonging	yes	yes - 40 items
Washington Group on Disability Statistics' disability questions for census and survey use	no - focused on disability and functioning	yes	No – this is specifically for health related disability and functioning	yes	yes - 6 items
The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle et al. 1993)	yes	no	No – this is only designed for the subjective perspective on QoL	yes	Needs to be completed face to face
Office of National Statistics (2016) (Labour Force Survey)	yes	Not designed for proxy completion	No – the focus is on subjective well-being	yes	yes
Kemp Quality of Life Scale (KQOL) (Kemp and Ettelson, 2001)	yes	yes	no - single question measure	yes	yes - 1 question
INTEGRAL Quality of Life Scale (Verdugo et al., 2007)	No – specifically designed for those with intellectual disabilties	no	yes	Yes, an emerging measure	Probably not – 76 items

8+1 (EUROSTAT, 2012)	yes	no	yes	This is derived from a number of surveys so it's not clear if it would enable ongoing comparison	yes - main QoL is 23 items
European Quality of Life Survey (European Foundation for the Improvement of Living and Working Conditions, 2016)	yes	no	yes	This is also a European survey which focuses on a range of different areas so consistent comparison could be problematic	yes
European Social Survey (2015)	yes	no	Yes – objective indicators and subjective wellbeing	Another European wide survey	yes although this also has different modules
World Health Organization Quality of Life (WHOQOL) – BREF (World Health Organization 2004)	yes	yes	Yes - Physical health, Psychological, Social relations & Environment	Yes – commonly used internationally	yes - 26 items
Quality of Life Scale (QOLS) (Burckhardt and Anderson, 2003)	yes	yes	yes	Yes – although mainly used for those with long-term health conditions	yes - 16 items
San Martin Scale (Verdugo et al., 2014)	No – specifically designed as a proxy measure	yes	yes	Yes, an emerging measure	no - 95 items
Beach Center on Disability Family Quality of Life Scale (FQoL) (Hoffman et al., 2006; Parket al., 2003)	No – specifically designed for measuring QoL for families with children with iID	yes	Yes although focuses on Family Interaction, Parenting, Emotional Well-being, Physical & Material Well-Being, Disability- related Support	yes	yes - 25 items
Family Quality of Life Survey (FQOLS-2006) (Brown et al., 2006)	No – specifically designed for measuring QoL for families with a member with ID	yes	Yes but focuses on health of the family; financial well-being; support from others; support from disability- related services; influence of values; careers; leisure & recreation; community interaction	yes	no - 118 items
DISABKIDS	No – specifically designed for children with disabilities	yes	Yes – although disability focused	yes	yes - 12 items & 37 item versions
KIDSCREEN	No – designed for children but both disabled and non-disabled	yes	yes - although health focused	Yes – very commonly used	Yes – different versions from 10 items to 52

Conclusion

Based on the comparative assessment and recognising the strengths and weaknesses of each tool, we recommend using adapted versions of WHOQOL-BREF and KIDSCREEN. Despite the health-related focus in both, we believe that carefully selected questions representing a broader understanding of QoL can be added to provide richer data.

5. Findings from interviews & focus groups

Key Points

• 73 stakeholders contributed to consultations between February and March 2017.

• People supported taking a multi-dimensional approach to measuring QoL.

• The majority of participants agreed that the government should be measuring the QoL of disabled people and their families.

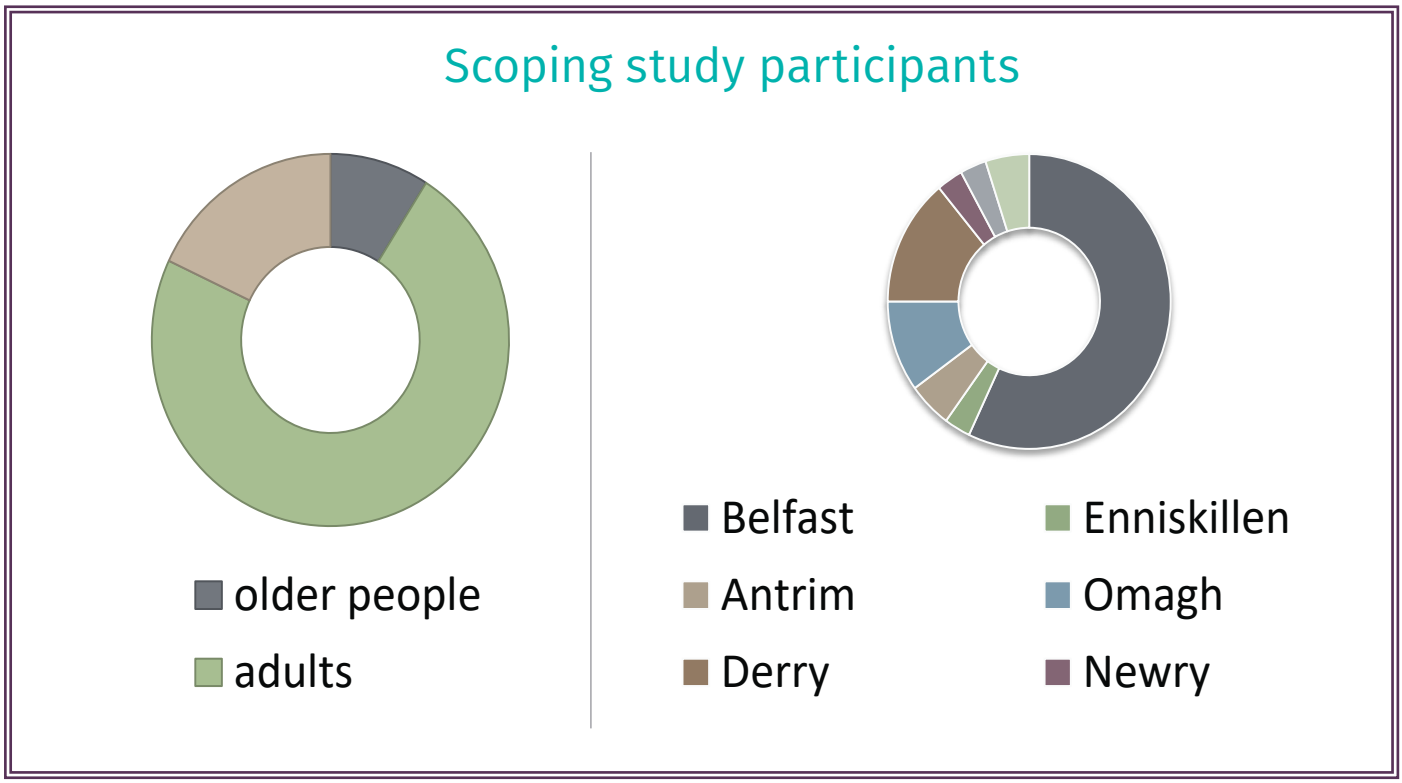
• There was some support for data that could be compared internationally but there was greater interest in being able to compare the data to people without disabilities in Northern Ireland.

• There was general agreement with the proposed definitions.

Interviews and focus groups were conducted between 14 February 2017 and 10 March 2017. Sixteen sessions were held across Northern Ireland and included 73 participants. Groups were organised with a designated focus based on age to encourage discussions around common themes. Participants were recruited through letters of invitation administered by the Department of Communities (30%) and through the Disability Research Network contacts (70%) and were primarily people with disabilities or parents of children with disabilities. They represented different types of disabilities, ages, and support needs.

Table 2: Locations & dates of focus groups & interviews

Date	Location	Focus
14 February	Antrim	Adults with Learning Disabilities
18 February	Derry/Londonderry	Older People
21 February	Newry	Children & Young People
21 February	Newry	Older People
21 February	Omagh	Adults with Learning Disabilities
22 February	Newtownabbey	Adults
23 February	Belfast	Children & Young People (included organisational/group representatives, parents, and young people with learning disability - hosted by Mencap)
23 February	Bangor	Adults
24 February	Derry/Londonderry	Adults (hosted by North West Forum)
24 February	Derry/Londonderry	Adults
25 February	Belfast	Parent/carer
25 February	Belfast	Children & Young People
25 February	Belfast	Older People
25 February	Enniskillen	Adults
9 March	Belfast	Adults (hosted by Disability Action)
10 March	Belfast	Adults (hosted by Action on Hearing Loss)



Limitations of the consultations

Recognising the tight timeline for the project, the research team was pleased with the number of people that were able to participate. We are conscious, however, that there were many people interested but unable to make the necessary arrangements on such short notice. Although there was a variety of different types of disabilities (including all five categories), we were unable to recruit any participants with complex needs that would require proxy reporting. We were also able to engage with only a limited number of children and young people (including siblings of children with disabilities). These are areas to consider for future consultations.

Discussion

Participants were asked a number of questions related to measuring the quality of life for people with disabilities and their families. The following section will provide a summary of the findings. For more comprehensive information on responses given, see the Appendix 8.

What does having a good life mean to you?

This question was introduced and participants were asked to write or draw their response. The following answers were given (presented in order of frequency given):

Adult participants:

family; having friends and a social life; work; getting out (particularly the cinema); health; financial security; sport/active lifestyle; independence; productive life/ contribution to society; romantic relationships/love; holiday/travel; basic needs (food, shelter, etc.); atttitudes of others; transport; access to information (including news and music); education; and equality.

Children and young people:

family; good health; hobbies; pets; friends; games and doing fun things; money; treats; and free time.

How should QoL be measured?

Overall people liked the multidimensional approach to measuring quality of life rather than a focus on one aspect (such as health) which tended to dominate within the international literature.

Many people thought the data collected should be collected and analysed annually and should be comparable with people without disabilities (full population sample). Many others also were interested in having data that were comparable across the UK and possibly Europe as well (although this had less support).

Do you agree with the proposed definitions of 'quality of life', 'family quality of life', and 'disability'?

The majority of the participants agreed with the definition proposed by the WHO but there were concerns about it being too wordy. It was suggested that it would be preferable to simplify the wording but maintain the same concept. They were also satisfied by the definition proposed by the Beach Centre regarding family quality of life. Regarding defining disability, the participants were given three definitions to choose from: (1) the Disability Discrimination Act, (2) the WHO's International Classification of Functioning and Disability, and (3) the UN Convention on the Rights of Persons with Disabilities (CRPD). The preferred definition for disability was the CRPD. The most common reason given was that the participant referred the wording over the others.

Recommendations for measuring the QoL of people with disabilities and their families based on the consultations

- The two things that people stressed were most important in having a good life were family and friends/social life

- There was agreement from participants that any measurement tool would have to consider all aspects of a person's life rather than a single focus (such as health or employment)

- Although people agreed with the definitions proposed, some found them too cumbersome and recommended making them simpler

- It was suggested that the monitoring of quality of life of people with disabilities should use the UNCRPD as its framework

- The monitoring should be based on a full population survey so that people with disabilities can be compared with their non-disabled peers

- It was recommended that this data should be captured as regularly as possible (possibly employing a longitudinal study if possible) and should draw upon both subjective and objective data

- People preferred the development of a new tool but were open to the idea of capturing data through a combination of existing sources

- The preferred method was a survey but with a slight advantage to having it administered face-to-face rather than through the post. Most people agreed that it needed to capture qualitative and quantitative data in order to get a better understanding of the quality of life for people with disabilities and their families

Recommendations for improving future consultations

- More notice would likely improve turnout

- There needed to be a clearer understanding of the purpose and expectations of the event for participants

- First time attendees of consultations need longer sessions to allow for a better introduction of the project, process, and outcomes

- There were some issues with accessibility. Some of the locations were difficult to find (the rooms need to be clearly signposted) and alternative formats were not always available

- Participants were expecting refreshments (at least tea and coffee)

- People tended to be more comfortable speaking on the topic in focus groups rather than interviews (particularly people that were new to the consultation process)

- People that had never participated in a consultation gave very different responses than 'seasoned' responders – this balance is important in gaining a more comprehensive view of the lives of people with disabilities

6. Findings from piloting the measures

Key Points

- Potential measures of QoL were discussed with participants in pathfinder projects (including children and adults with disabilities, parents, and staff.
- The proposed individual measures do not include questions on the person's family, so additional questions are needed.
- 'Social connectedness' measures need to be included in addition to the health-related quality of life.
- Preparation is needed with the participants of any potential measurement tool to ensure they understand the expectations.
- Proxy responses for parents to participate in the survey should be carefully considered.
- Including some indication of people's expectations of their QoL and their view of others' expectations is important for understanding the results of the standardised measures.

When the focus groups were presented with examples of the possible measures, mainly the 8+1, QOLS and KIDSCREEN, there was general agreement that the main relevant domains of QoL were covered. It was, however, suggested that a new approach which addressed the UNCRPD should be adopted. There was also consensus that it needed to be short and accessible. QoL measures based on the UNCRPD are still developing and so the most appropriate of the more established measures, the WHOQOL-BREF and KIDSCREEN, were piloted. This addressed Objective 5 of the scoping study which required the suggested measures to be piloted with some of the DfC's pathfinder projects.

During the pilot with the pathfinder projects, it was possible to consider the measures in more depth. This involved three visits to three of the projects for children and discussion with four members of staff and one parent. In those projects it was possible to pilot the KIDSCREEN-10 with five children, aged 8-11. The proxy version would have been needed for some children.

One of the staff at a Pathfinder project provided the following detailed feedback on the proposed use of KIDSCREEN–10:

"1. Overall, we feel that the questionnaire and the questions asked do not qualify as an appropriate means to collect data from children with severe learning disabilities. (As you have seen in our session… this week, most of the children attending could not comprehend the concepts presented, and certainly would not be able to relate how they feel about these concepts. We appreciate that some children and young people are more able to engage with the proposed questionnaire format.

2. As a means to address the highlighted shortcoming – we feel that you will need to include a proxy measure which places the parent/ primary carer as the medium through which the child's responses to the questionnaire can be collected, (based on their understanding of their own child).

3. A more fundamental point is that Indicator 42 seeks to measure "the Quality of Life for Children with Disabilities and their Families". The proposed tool makes no reference to the quality of life of the family. We feel that this needs to be addressed.

Specifically, we feel that the Quality of Life of Families with a disabled child is hugely dependent on the availability of community based respite support for them and the availability of 'practical support' from within their own community.

Hence we feel that it would be important to include measures which capture this such as:

- As a parent of a disabled child have you felt exhausted?

• Can you access a service in your own community that offers your family respite?

• Can you access payments to support the costs of availing of respite services?

• Have you felt that the barriers to accessing respite services are high?

• Can you access advocacy services to support your rights and the rights of your disabled child from within your community?

• Have you as a parent of a child with disabilities had enough time to spend with you other kids who are not disabled?.

4. We feel that there is a strong bias in the questionnaire towards health, whereas we would like to see the inclusion of a range of 'social connectedness' measures such as:

• Do you feel that you are included in your community?

• Do you have opportunities to attend your local clubs?

• Have you ever been told that you are not allowed to attend a social group?

• Do you go to the same club as your siblings?

• Do you need additional support in order to attend?

• How many Social activities have you attended in the last week?

5. We feel that the social connectedness of the family to its community is very important – often families of children with disabilities feel very isolated. Hence we would like to see the inclusion of measures which capture the 'social connectedness of the 'family':

• Do you feel that you are included in your community?

• Do you have opportunities to attend your local clubs?

• Do you feel that your friends and community make adjustments to include your needs?"

Further issues which arose from the pilots included the importance of preparation for the completion of the measures. For some of the children who piloted the KIDSCREEN they tended to answer yes or no rather than with one of the set responses. It was also highlighted that from some children their responses could be highly influenced by what had been happening immediately before rather than over the last week (as the KIDSCREEN requests).

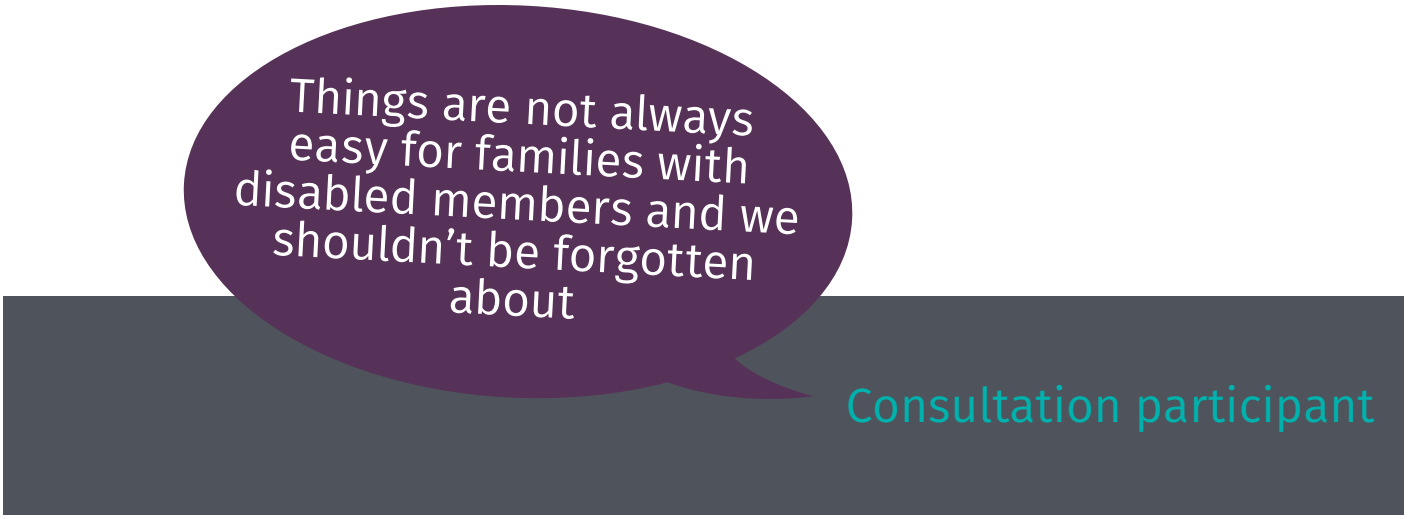
It was also possible to pilot the main proposed measure, the WHOQOL-BREF, with three adults. The responses were positive about the measure but there were some important and useful suggestions about additional questions:

- Have you ever experienced any form of discrimination?
- Have you ever been victim of a hate crime?
- How much do you participate in politics?
- How aware are you of your rights?
- Do you feel any of your rights are infringed?
- How confident do you feel about participating in your community?
- Do you have access to work which is right for you?
- Is information provided to you in an accessible format?

It was also suggested that two questions be added to address the concern that quality of life may be related, to some extent, to people's expectations of life so: What level best describes your expectations of your life?' and 'What level best describes other people's expectations of your life?'.

Conclusion

Following the piloting of the proposed survey tools, we recommend the addition of questions related to social inclusion for both KIDSCREEN and WHOQOL-BREF. While we recognise the limitations of using a health-related quality of life tool in isolation, we feel that the additional questions proposed in the pilot will allow for a more complex understanding of quality of life measurement for people with disabilities and their families.



7. Northern Ireland Context - Existing Data

Key Points

- The Department for Communities has access to a wide range of administrative data which may be useful in developing a sampling frame.

- Current data sources do not collect sufficient information on subjective and objective aspects of quality of life across ages.

- Adding modules to existing surveys may be a useful way to collect data on people with disabilities in general population surveys, however, the lack of a representative sample of people with disabilities is a noteworthy limitation.

- Despite the NISALD survey (2006/07) finding that, 'There is a lack of good quality information on people in Northern Ireland with a disability', little progress has been made to address this.

Administrative data

Administrative datasets are increasingly being used for constructing sampling frames.

The Department for Communities (DfC) holds a wide range of administrative data on social security benefits in Northern Ireland including benefits providing support for sick and disabled people. These benefits include Disability Living Allowance (DLA), a tax-free, non means-tested benefit that provides a cash contribution towards the extra costs for care and mobility needs arising as a result of an impairment or health condition. From June 2016, DLA has been replaced for Working Age claimants by the new benefit, Personal Independence Payment (PIP). Attendance allowance (AA) is a benefit paid to individuals over the age of 65 with care or supervision needs.

Alongside cost savings, the main advantages of deriving a sample frame from disability benefit administrative systems include accuracy and completeness as data are already collected for operational purposes. The data have been collected in a consistent way and capture individuals who may not typically respond to surveys.

However using disability administrative systems would lead to issues of undercoverage as disability benefit applications are assessed on the needs arising from a disability and not everyone with a disability chooses to apply for disability benefit. This coverage gap could be addressed by using a range of other data sources. In addition to holding information pertaining to social security benefits, DfC is also in receipt of HMRC held records in relation to Child Benefits, tax credits, savings and earnings. Given the wide coverage of the NI population, these data sources could collectively be used as a sampling frame for a bespoke disability survey.

Potential sources of data currently collected

In addition to the subjective well-being questions in the Labour Force Survey there are a range of other potential sources of data and/or vehicles for QoL data collection in Northern Ireland. There are two main issues with the existing sources of data: the ongoing surveys don't collect sufficient objective and subjective data relevant to quality of life to enable this outcome to be measured across all ages. The second main issue which is that they don't provide a representative sample of disabled people. The existing surveys, however, may still provide a means of collecting data by including an additional module on QoL which would provide a general population sample but the issue remains that they do not provide a representative sample of disabled people.

Potential vehicles for data collection include:

The **Continuous Household Survey** is designed to provide a regular source of information on a wide range of issues relevant to Northern Ireland. It has been running since 1983, with recent results covering housing characteristics, changing population, tourism, participation in sports, arts and culture and attitudes towards the environment. Based on a systematic random sample of 4,500 addresses drawn each year from the Pointer list of domestic addresses. Data is collected by personal interview using Computer Assisted Personal Interviewing (CAPI), and the interviews are spread equally over the 12 months from April to March.

The **Family Resources Survey** asks about the available funds and living conditions of households, including questions on income, benefits, housing costs, child care costs and savings. Based on a systematic random sample of 3,600 addresses drawn each year from the Pointer list of domestic addresses. Data are collected by personal interview using Computer Assisted Personal Interviewing (CAPI).

The **Labour Force Survey,** as already mentioned, includes the ONS subjective well-being questions. It also asks people in Northern Ireland about employment, unemployment and economic activity. It also covers a wide range of related topics such as income, qualifications, training and disability. It is based on a systematic random sample of 650 addresses is drawn each quarter from the Pointer list of domestic addresses. Everyone aged 16 and over is interviewed about a range of questions.

The **Northern Ireland Health Surve**y asks questions on general health, smoking and drinking, fruit and vegetable consumption, stress, exercise, mobility, and the use of some health services. Based on a systematic random sample of 5,800 addresses drawn each year from the Pointer list of domestic addresses. The questionnaire consists of both a household interview and an individual interview with each person aged 16 and over. Physical measures (height and weight) are taken of those people resident aged 2 and over.

Understanding Society is the UK wide longitudinal household survey which began in 2009. In Northern Ireland it builds on the Northern Ireland Household Panel Survey. Across the UK it collects data on the socio-economic circumstances and attitudes of 100,000 individuals, aged 16 and over in 40,000 UK households (the Northern Ireland part of the sample is 2,500 households). It covers a wide range of issues, for example health, crime, finances, parenting, community participation, work and politics. It would therefore provide data relevant to quality of life but would not provide a sufficiently representative sample of disabled people or children.

Young Persons Behaviour and Attitudes Survey (YPBAS) is a school-based survey conducted among 11-16 year-olds. Those schools that are exclusively for those with ‘special needs’ are not included. The research covers a range

of topics, relevant to the lives of young people today including: Demographics; Family Financial Circumstances; Nutrition; Sexual Experience and Knowledge; Subject Choices; Next Steps; Starting a Business; School; Shared Education; Play and Leisure; Libraries; Museums and Science Centres; Arts; Irish and Ulster Scots; Sport and Physical Activity; Travelling To School; Road Safety; Police Ombudsman; Breastfeeding; Flu Vaccine; Organ Donation; Sun Protection; Social Support; Smoking; Alcohol; Health and Wellbeing; Solvents and Drugs; Firework Safety; Personal Safety; Medicines; Attitudes towards Sexual Violence; Attitudes towards Domestic Violence; Long Term Conditions; More About your Views. Five rounds of the survey have now taken place: in 2000, 2003, 2007, 2010 and 2013.

The **Northern Ireland Schools Census** (from 1990 to present) is conducted annually in October. It contains data from approximately 1,200 schools, 400 pre-schools and individual level records for over 300,000 pupils each year. Example variables include: date of birth, religion, ethnicity, year group, free school meal entitlement, special educational needs status, home language. The Schools Census data covers school level data for each pre, nursery hospital and independent school and pupil level data for each special, primary and secondary school in Northern Ireland. It is completed at School level though rather than with each pupil.

Northern Ireland Life and Times Survey is annual survey monitoring the attitudes of people aged 18 years and over in Northern Ireland to a wide range of social and political issues. NILT began in 1998, and follows on from the Northern Ireland Social Attitudes (NISA) Survey, which ran from 1989-1996. NILT has a modular format, and so each year's survey includes four modules reflecting key social policy issues. In 2015 1202 face-to-face interviews with adults aged 18 years or over. The main interview was carried out using CAPI and the respondent was then asked to complete a self-completion questionnaire. A systematic random sample of addresses selected from the Postcode Address File.

Young Life and Times Survey (YLT) Survey is the sister survey to NILT but is specially designed to monitor attitudes among young people in Northern Ireland to social and political issues. Founded in its present format in 2003, YLT records the attitudes of 16 year olds.

Kids' Life and Times Survey (KLT) has been monitoring the attitudes of children in P7 (10-11 year olds) to issues that affect them since 2008.

NICOLA is a longitudinl survey of the health, lifestyles and financial situations of 8,500 people (aged 50 and over) as they grow older monitoring how their circumstances change over a 10 year period. Closely follows the comprehensive approach taken by ELSA (English Longitudinal Study of Ageing) and TILDA (The Irish Longitudinal Study of Ageing). Study participants will be invited for interview every 2 years and a Heath Assessment every 4 years. They will be followed up for a period of at least 10 years.

There have also been some one-off surveys which may also help inform consideration of the most effective approaches. Borooah (2006) reports on data from the Poverty and Social Exclusion in Northern Ireland Project which surveyed 3000 people and included consideration of objective (for example income, marital status) and subjective factors (satisfaction with one's standard of living (SoL), money worries, experience of poverty) that may contribute to happiness. Borooah (2006) concluded that 'income was the major source of satisfaction with one's SoL. In turn, satisfaction with one's SoL was an important course of happiness but it was not the most important source. The two most important sources of happiness were: an absence of health problems, particularly mental health problems; and freedom from financial worries' (p. 459).

The Northern Ireland Survey of people with Activity Limitations and Disabilities was an in-depth survey conducted in 2006/07. It involved more than 4,000 interviews and found that '18% of all people living in private households in Northern Ireland have some degree of disability. The prevalence rate for adults is 21% and 6% for children' (NISRA, 2007, p.6). The review which lead to that survey had found 'There is a lack of good quality information on people in Northern Ireland with a disability, especially in terms of their multiple identities and their experiences across a range of social and economic contexts such as education, employment, transport and claiming of benefits' (p. 8).

Another example from Northern Ireland was the work of McDaid et al (2016) who used data from the Northern Ireland Health and Wellbeing Survey (NIHSWS) 2005 and the Survey of Lifestyle, Attitudes and Nutrition (SLAN) 2007 to compare the effect of multiple chronic conditions on self-rated health, disability and quality of life among the older populations of Northern Ireland and the Republic of Ireland. In that study QoL was determined by the question 'How would you rate your quality of life?' and the possible options were 'very poor', 'poor', 'neither good nor poor', 'good', or 'very good'. They reported that people with three or more chronic conditions were at extremely high risk of disability (80-90%). The majority of these also rated their health as poor, while nearly half rated their QoL as poor or very poor. (McDaid et al 2016, p.4)

Conclusion

There is not a current survey that has been conducted which would allow for the collection of data covering the span of ages and disabilities needed to meet the objectives of the indicator. We recommend adding modules to existing surveys where appropriate to gather data, but that this should not be the primary means of data collection on measuring the quality of life of people with disabilities and their families.

8. Option Appraisal

Key Points

The criteria for considering the options included:

- Provides data on all ages
- Provides data on all disabilities
- Includes data from proxies
- Allows measurement at performance & population levels and
- QoL measure is brief and appropriate.

The original objectives of the Scoping Study included:

Objective 4: To outline suitable, robust and statistically valid options for measuring QoL in the context of PfG Indicator 42. All options will allow measurement of QoL at both the population and performance levels.

The QoL measure will be brief and appropriate for:

- All age groups including children
- All disability types
- Those with profound multiple disabilities and
- Proxy assessments where applicable (proxy assessments must be shown to be reliable and valid).

Objective 5: To recommend a preferred QoL measurement and subject to gaining approval from the steering group, pilot this measure to emerging projects being carried out as part of the delivery plan for this indicator. Differences in self-assessment and proxy-assessment for severe disability cases and for children with disabilities will be assessed.

The Rapid Evidence Assessment and the data collected from the focus groups have generated a number of options that would enable the measurement of QoL across ages and disabilities, including for those where proxy assessments are needed. An initial question in the option appraisal however is where the original objectives still apply in the context of the revised Delivery Plan. The options are therefore set out based on a number of premises which include the available resources, the focus of data collection, and the purpose of data collection. The criteria used to analyse the options included: (1) coverage; (2) purpose; (3) cost; (4) feasibility; (5) frequency; and (6) sample size.

Option 1 is to use the data from the ONS' four subjective well-being questions, currently collected in the Labour Force Survey. This option is based on the premises that resources are very limited and that the original focus on subjective quality of life remains the same. However, the existing sample and data would be inadequate. In order for this to be used to indicate changes in the quality of life of disabled people and their families the sample would need to be boosted or supplemented to include sufficient numbers of disabled people. It would also be important to ensure that there were sufficient, relevant objective data collected and that it was possible to disaggregate the types of disabilities identified. To address the quality of life of families, either everyone could be asked if they care for someone with a disability and their individual QoL could be aggregated, or there could be a separate survey of families.

The strengths of Option 1 are that the ONS' questions are asked across a number of surveys and so would allow comparison across the UK countries. It would also require the lowest level of additional resources to collect the data, however, a boosted sample, and possibly a separate survey of families, would still be needed. The central limitation of this option is that the measure of QoL, the four subjective well-being questions, provide very little detail of any of the wide range of domains and variables that are relevant to QoL. The findings would therefore provide very little guidance on what the issues are and what the policy and/or service responses could be. Option 1 would also not enable measurement of family QoL. In Options 2-5 it would be possible to identify all those who are in a family with a disabled person and also if they are providing care for that disabled person.

Option 2 is to add a module on QoL to existing surveys in Northern Ireland. The premises for this option are that resources remain very limited and that the focus remains on the more conventional definition of QoL as primarily about life satisfaction. The Rapid Evidence Assessment concluded that the measures that had been developed for adults were not transferable to children and so different measures would be used for children and adults.

The most commonly used measure for children that is suitable for non-disabled and disabled children is the KIDSCREEN and the shortest available version has 10 items. There is also a proxy version of KIDSCREEN available. The KIDSCREEN is designed for children aged 8-18 and the most likely existing survey vehicle is the Young Persons Behaviour and Attitudes Survey which is for those aged 11-16 year-olds and does not include special schools. Arguably the KIDSCREEN is relatively health and deficit focused.

For adults there are a wide range of options for both vehicle and measure. For those aged 50 and over the NICOLA survey provides an excellent opportunity to collect data along with a wide range of objective and subjective data which would provide an in-depth and detailed analysis. Ideally the measure selected would allow direct comparison with adults aged 18-49 and so an additional measure, as well as the CASP-19, which is already included could be used. The most focused would appear to be the WHOQOL-BREF, which would allow considerable international comparison and the QOLS, which is slightly shorter and would still allow some comparison with ongoing research. The available vehicles for adults would not appear to have sufficient sample sizes in Northern Ireland to achieve a representative sample of disabled people and so a boosted sample or separate survey would be needed.

Option 3 retains the premises for this option that the focus remains on the more conventional definition of QoL as primarily about life satisfaction. This options acknowledges the complexities of attempting to boost existing samples and/or adding modules across a range of existing surveys and so would involve a new survey specifically focused on QoL that would enable the inclusion of measures with a greater number of items, such as the longer version/s of KIDSREEN. This would also enable the inclusion of a selected range of objective measures which would allow the exploration of a range of hypotheses. A separate survey would allow the Department for Communities more flexibility about when, how and how often the survey was

Option 4 is based on the premises that, internationally the UNCRPD is increasingly central in disability policy and this will be reflected in policy developments in Northern Ireland. The impact of the UNCRPD on the measurement of QoL of disabled people has also been merging over recent years. Karr (2011) applied QoL and self-determination (SD) to the implementation of the UNCRPD in Nepal, Zambia, and the United States. She concluded that, 'although there were various demographic differences among the three countries, and country was correlated with QOL, country was not a significant predictor of QOL. The following variables cut across country differences to predict QOL: SD, employment, and previous advocacy experience' (p. 80).

Verdugo et al. (2012, p. 1040) have also argued that the measurement of QoL, if understood as a multi-dimensional concept broader than satisfaction with life, can be directly related to the Articles of the UNCRPD. They set out the relationship between the eight domains of QoL they have previously identified and the UNCRPD articles:

Table 3: Links to the UNCRPD

Domains of QoL	QoL Indicators	UNCRPD articles (directly linked to QoL indicators)	UNCRPD articles (indirectly linked to QoL indicators)
Personal development	Education status; personal skills; adaptive behaviour	Art. 24	Art. 27
Self- determination	Choices/decisions; autonomy; personal control; personal goals	Arts. 14; 19; 21	Atr. 9; Art. 12
Interpersonal relations	Social networks; friendships; social activities; relationships	Art. 23	Art. 30
Social Inclusion	Community Integration/ participation; Community roles; supports	Arts. 8; 9; 18; 20; 27; 29; 30	Arts. 19; 21; 24
Rights	Human (response, dignity, equality); Legal (legal access & due process)	Arts. 5; 6; 7; 10; 11; 12; 13; 15; 22	Arts. 14; 16; 16; 21
Emotional wellbeing	Safety & security; Positive experiences; Contentment; Lack of Stress	Art. 16; Art. 17	Art. 23; Art 25
Physical wellbeing	Health & nutrition status; recreation; leisure	Arts. 16; 25; 26	Art. 17
Material wellbeing	Financial status; employment status; housing status; possessions	Art. 28	

This approach would be a better response to the revised Delivery Plan's focus on promoting:

- A greater sense of belonging to their communities, where they feel valued and respected as others are and have more opportunities to participate in community life. This includes action to: raise awareness and change attitudes towards disability & improve participation in public and community life.

- A greater sense of influence over their own lives, so that they are more engaged in decisions which impact on them, with their lives and aspirations shaping services, rather than services shaping their lives and limiting their aspirations. This included actions to: address the needs of children and young people including improving transitions; improve independent living and the provision of suitable homes; improve access to information and better data collection.

This option would involve the use of Verdugo et al.'s measures, such as the INTEGRAL Quality of Life measure and the San Martin Scale (for proxies) as these address all of the domains set out in the table above. It could also be an opportunity to explore the application of these scales with disabled children. These measures of QoL, based on the UNCRPD, are still developing and are maybe not yet suitable for a population level survey. The approach could, however, inform the additional questions added to the more established standardised measures. Option 4 would involve trying to add a module to a combination of existing surveys so would encounter the same difficulties as Option 2 as there does not appear to be a combination that would cover all ages.

Option 5 would involve using the emerging QoL measures based on the UNCRPD in a specifically designed survey to measure the QoL of disabled people, non-disabled people and their families in Northern Ireland. This would resolve the lack of coverage of all ages by existing relevant surveys but would not address the concern that those measures are still developing and may not yet be suitable for a population level survey.

The recommended option is Option 3. A new survey should be developed which would use well established standardised measures of QoL (WHOQOL-BREF and KIDSCREEN) but would add important objective indicators of QoL, additional questions to ensure other important aspects of QoL are covered; and allow people to add some qualitative comments about the key issues for them and how they could be addressed.

Table 4: Option Appraisal

	Provides data on all ages	Provides data on all disabilities	Includes data from proxies	Allows measurement at performance & population levels	QoL measure is brief & appropriate
Option 1 - use data collected from the Labour Force Survey	no	no	no	no	no
Option 2 - add a module on QoL to existing surveys	no - doesn't appear to be an existing combination of surveys that would cover all ages	yes - if sufficiently boosted	yes	yes	yes
Option 3 - develop a new survey based on QoL	yes	yes	yes	yes	yes
Option 4 - use a longer measure which fully reflects the UNCRPD as a module in existing surveys	no - doesn't appear to be an existing combination of surveys that would cover all ages	yes - if sufficiently boosted	yes	yes	not yet
Option 5 - use a longer measure based on the UNCRPD in a bespoke survey	yes	yes	yes	yes	not yet

Table 5 provides an indication of the costs involved for Option 3. It is recommended that this should be a face-to-face survey but costs are provided for other methods of data collection. It should also be noted that disability populations are based on percentages from the NISALD (2006/07) survey and that each disabled population would need to be stratified by broad primary disability type.

Based on a sample size of 4,050, the estimated cost of the survey is £247,500.

Calculations of sample size and costings were contributed by Perceptive Insight, an independent Belfast-based company serving the market and social research needs of public and private sector organisations across Northern Ireland, the Republic of Ireland and Great Britain.

Table 5: Survey Estimate Costings

	Total population	Sample	Method	Est cost 20 min survey	Est cost 40 min survey
General Older People (65+)	291,800	450	Phone Face-to-face Mixed	13,500 27,000 23,625	27,000 54,000 47,250
General Working age (16-64)	1,174,600	450	Phone Face-to-face Mixed	13,500 27,000 23,625	27,000 54,000 47,250
General Children (0-15)	385,200	450	Face-to-face	31,500	63,000
Carers	222,192	450	Phone Face-to-face Mixed	13,500 27,000 23,625	27,000 54,000 47,250
Disabled population	401,088	2,250	Face-to-face	135,000	270,000
Total (face-to-face)		**4,050**		**247,500**	**495,000**

The telephone costs for the general population sample are higher than for the disabled population sample. This is based on the assumption that the DfC could provide a sampling frame (or list) of the disabled population, but for the general population it would be necessary to buy random digit dialling telephone numbers to make the calls. It is also likely that more calls would be required to meet the demographic quotas so that the survey is representative.

The estimated sample size required is 4,050 in total. This would provide sufficient numbers for the planned sub-group analyses. The general population sample would be 1,350, 450 from each of the three age groups. The disabled population would also be stratified by age and disability type so the disabled population sample would be 2,250, 450 from each of the five main disability categories (physical disability, sensory disability, learning disability, mental health and other). A sample of 450 carers is also included.

A 20 minute interview would allow data to be collected on QoL but this survey presents an excellent opportunity to inform other key policy areas so costings are also included for a 40 minute interview which would enable a wider range of data to be collected.

Based on the 2011 Census it is estimated that 12% of the general population are providing unpaid care. It is recommended that everyone (both general population and disabled population) is asked if they care for a family member with a disability. There may be an underrepresentation of carers in the disabled population, so it may be necessary to boost the sample of carers from the relevant Social Security dataset.

9. Recommendations

The research team make the following recommendations:

Defining key terms

Defining Disability

'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (UN Convention on the Rights of Persons with Disabilities, 2006, preamble [E] & Article 1).

Defining Quality of Life

'Individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships personal beliefs and their relations to salient features of their environment' (World Health Organization, 1997).

Defining Family Quality of Life

'…conditions where the family's needs are met, and family members enjoy their life together as a family and have a chance to do things which are important to them' (Park et al., 2003).

Developing a QoL Measurement Tool

A sample population survey is recommended (in addition to oversampling people with disabilities) in order to compare the quality of life of all residents in Northern Ireland. Subjective and objective measures should be used and qualitative data should be gathered in addition to quantitative. We recommend the use of face-to-face interviews for the administration of this survey. It is anticipated that the majority of the people with disabilities selected to participate will self-report, though proxies need to be carefully considered in order to consider those that may be hardest to reach.

The research team has suggested using adapted versions of the WHOQOL-BREF and KIDSCREEN as starting points for developing a measurement tool for Northern Ireland. It is important to note that these surveys are primarily used for collecting data on health-related quality of life and that we recommend that additional questions are added to capture the complexities of a 'good life'. The new questions should reflect social inclusion as well as include questions about family quality of life. Instead of having a separate survey to collect data on family QoL it is recommended that everyone is asked if there is someone, or someone else, in their family who has a disability and if they provide care for them.

The addition of new questions also presents the opportunity to collect data that are of particular relevance to Northern Ireland, without compromising on the potential of international comparative data (as both KIDSCREEN and WHOQOL-BREF are widely used). The additional questions will also allow the space to capture more qualitative data to support our understanding of the quality of life of people living in Northern Ireland.

An important additional question will be to identify the relevant type of disability or disabilities. Although it would be ideal to collect detailed information on this, it may be necessary, for pragmatic reasons, to have relatively broad categories. The UNCRPD definition should be provided and then people asked if, based on that definition, they have a disability. It is also recommended that this definition be used across all relevant policies.

Additional questions should include objective indicators of QoL such as: income, housing, education, employment, if a family member has a disability and if you provide care for them. It is also recommended that people are asked about their experiences of social inclusion, specifically in political life and of discrimination. Even a basic measure (such as a 5 point Likert scale) of people's level of expectations of QoL and what they think others' expectations of their QoL are, would provide important context for interpreting the findings. It would also be important to allow people the space to identify or comment on issues which impact on their QoL and to ask them directly what they think should be done to improve their QoL.

The involvement of disabled people and advocacy groups in this scoping study has been of central importance to addressing its objectives. It is also recommended that there should be a high level of involvement in the next stages of the process which would be to further pilot and refine the recommended approach before proceeding with the national survey.

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Appendix 1

Rapid Evidence Assessment (REA)

The key features of the REA methodology are summarised below:

Searching

Searching is the process of locating evidence that might be relevant to the review questions. Working closely with the Scoping Study's Steering Group, targeted and focussed strategies for the REA were developed. The following databases were then searched: Medline; Embase; SocIndex; EconLit; Psychinfo; Centre for Reviews and Dissemination; and the Cochrane Library. Key websites were also explored to identify reports and official documents relevant to QoL measurements for people with disabilities and their families. The most relevant studies published in English from the past ten years (since 2006) and key documents identified from before then were included.

Search Strategies

Specific search strategies were developed and used for each of the main aspects of these objectives and then used across the databases. In addition to the date and language parameters, examples of the search terms for each area included:

(Quality of Life OR well-being OR happiness OR life satisfaction OR welfare) AND (disabilit* OR disable*) AND (measure* OR scale OR assess*)

(Quality of Life OR well-being OR happiness OR life satisfaction OR welfare) AND (disabilit* OR disable*) AND (measure* OR scale OR assess*) AND (family* OR carer OR caregiver OR relative OR parent)

(Quality of Life OR well-being OR happiness OR life satisfaction OR welfare) AND (disabilit* OR disable*) AND (measure* OR scale OR assess*) AND (prox* OR child*);•

Screening

Screening was conducted to determine which of the studies were most relevant to the study. Studies were included if they directly addressed the measurement of quality of life for people with disabilities and their families, and more specifically for children and proxy assessment measures. As the PfG requires a measure that can be used across all types of disabilities, at both the population level and intervention level, studies that focus on measures for specific disabilities were excluded unless they contained elements that can be applied across disabilities. The types of designs included: articles that discuss and/or compare relevant measures; before-and-after studies assessing quality of life; observational studies; qualitative studies reporting views of service users, carers and professionals; systematic reviews; and narrative reviews.

Quality assessment

Each included publication was assessed by two of the research team for quality and relevance to the review.

Data extraction

A comprehensive data extraction approach to capture all necessary data, including study context, population, psychometric properties, and effectiveness findings were used.

Data synthesis

Data synthesis is the process by which we identified the key issues and drew conclusions across the body of evidence reviewed.

Appendix 2

Defining Family Quality of Life

Definitions of 'family' vary but usually encompass at least one of the following components: consanguine relations; legal kinship; living arrangements; and/or emotional bonds. What constitutes a family is culturally shaped with a wide range of variations found across time and place. Defining the family has become increasingly complex in the modern era in advanced industrial societies. Since the mid-1900s, there has been a growing diversity of family forms related to increases in non-marital fertility, cohabitation, divorce, and remarriage (Lesthaeghe, 2010).

In understanding the unique circumstance of families of people with disabilities, applying a life course perspective and a social model of disability is especially useful. The life course perspective emphasises the importance of identifying stages of development across the life course and how lives of family members are linked within and across generations (Elder, 1999). Reflecting themes within disability research, we will consider family contexts across three stages of the life course: childhood, youth and emerging adulthood, and mid-life to older adulthood. We will also consider how the lives of family members are interdependently linked through a network of shared relationships.

Defining the family using a life course approach

The majority of research on families and disabilities has concentrated on parents with young children with disabilities (McLaughlin, 2012); however, recent research increasingly considers families at multiple life stages. It is well established in the literature that social networks play a vital role in wellbeing and that family members make up a central part of those expanded networks, including and especially in families with members who are disabled (Allen, Ciambrone, Welch, 2000).

Children

The social model emphasises the need to consider guardians and their experiences as a key component of improving the quality of life for children with disabilities as well as their families. For example the Family Fund, which supports the families of disabled children in Northern Ireland, defines the family for their determination of services as "A person who has parental responsibility for the disabled child, and who that child lives with for the majority of the time" (McCrea, personal communication, 24 January 2017).

Important family members in the lives of disabled children often reside outside the home. Grandparents, usually the maternal grandmother, are often actively involved family members in the lives of disabled grandchildren (Findler, 2000; Mitchell 2007). Grandparent involvement has been identified as particularly useful for providing both emotional and practical support to parents of disabled children (Mitchell 2007) and that grandparents are also increasingly providing direct custodial care.

Emerging adults and adult children

Transitioning into adulthood can have significant meaning and bring about significant changes in family relationships. Parents have reported concern for their children transitioning into adult services as they are often not as well managed or comprehensive as children's services (Swain & Thirlaway, 1994). Balancing the need to provide ample support for the emerging adult while allowing for autonomy and adult

identity can make the transition challenging for families. Additionally, while social norms support the concept of parents caring for children, the caregiving role can become more complex when an adult child still requires support (Knox & Bigby, 2007). Also important to note is that family involvement may not always be conducive to individual wellbeing. For instance, family support can be seen as inhibiting individual autonomy and independence (Tucker & Johnson 1989) and may also be related to having more contained social networks outside the family (Allen, Ciambrone & Welch, 2000).

Mid-life and older adults

Partners and parents, followed by children and siblings, are generally identified as the primary care providers for adult family members with disabilities (Grosser & Vine, 1991). This is somewhat contingent on living arrangements, the nature of the disability, age and the gender of the family members. Many adults with developmental disabilities or mental illness live with their parents. Disabled people who live with parents are more likely to have smaller social networks consisting primarily of family members (Krauss & Erickson 1988; Krauss et al, 1992). Those that live with a partner are more likely to have other family members in their social network than those living alone but these relatives can be geographically dispersed (Allen, Ciambrone & Welch, 2000). Disabled adults who require assistance from their children or spouse can also find the changing nature of the relationships challenging (Priestley, 2003).

Families play a key role in assisting disabled people as they age but this can become more difficult as the caregivers themselves age. Aging parents can be dealing with their own aging as well as their adult children (Jokinen & Brown, 2005). Aging disabled people may be providing care to their older parents (Priestley, 2003). Depending on the type of disability, many disabled adults outlive their parents (Jokinen & Brown, 2005). Future planning of care is a recurrent theme in determining how support and care should be maintained as disabled people age and as their primary carers are no longer able to provide the same level of support (Seltzer et al, 2005). Those with congenital disabilities are less likely to have ever-married or have children; in such cases, siblings often become primary caregivers especially when parents are no longer able (Seltzer et al, 2005). Adults with later onset disabilities, however, are frequently supported by their spouses. Disabilities occurring in mid adulthood create new and generally unplanned demands on spouses of the disabled, particularly for men who were not expecting to take on a caregiving role.

Older disabled family members who are parents frequently encounter difficulties obtaining effective services to aid in their parenting and have reported fear over having their parenting skills questioned and scrutinised (McLaughlin, 2001). The literature on parents with disabilities draws on themes of competence and autonomy. Young children acting as caregivers for their disabled parents has emerged as an area of literature needing more attention. One area of concern in this regard is the assumption that children are ‘parenting’ their parents regardless of the parenting skills and autonomy of the disabled parent (Barker & Maralani, 1997). This desire for disabled parents to keep their children has led to encouraging more non-stigmatising forms of support for disabled parents, particularly in regards to providing enhanced childcare support and promoting coping strategies for disabled parents (Barker & Maralani, 1997).

Appendix 3

Supporting literature on measures of quality of life for disabled adults

Author	Focus	Participants	QoL Instrument/s	Reporting
Balboni et al. (2013)	Assessment of the QoL of adults with intellectual disability (ID)	176 adults with ID (aged 18-70) in Italy	Personal outcomes scale	self-report, proxy & third party
Barker et al. (2009)	Comparison of QoL of people with spinal cord injury & their non-disabled peers	270 adults with spinal cord injury in Australia	WHOQOL-BREF; Functional Independence Measure; Community Integration Measure	Telephone interview
Binder & Broekel (2012)	Measuring 'conversion efficiency' (converting individual resources into wellbeing)	154,300 observations	British Household Panel Survey, 1991-2006; GHQ-12; Subjective assessment of health (1 question, excellent to poor); Objective assessment (hospital use, GP visits & accidents)	Face-to-face interview
Boyce (2010)	Adjusting for personality in subjective wellbeing	93,016 individual-year observations from 17,210 individuals	German Socio-Economic Panel Survey; Self-reported measure	Self-report
Gomez et al. (2015)	Develop a set of QoL indicators for measuring QoL of adults with severe disabilities	12 experts	118 items proposed - 8 domains selected	Delphi panel of experts from the field of ID
Groessl et al. (2007)	Health-related QoL in older adults at risk for disability	424 older adults at risk for disability	Quality of Wellbeing Scale Self-Administration (measure of health-related QoL)	Self-report
Hensel (2000)	Comparison of quality of & satisfaction with life between people with an ID & those without	31 people with ID & 31 without	ComQoL	Face-to-face interviews
Howley (2016)	The extent to which people are willing to pay for improvements (using life satisfaction data)	British survey (sample size of 50,000)	Understanding Society Survey, 2009-2011 (1 question, completely dissatisfied to completely satisfied)	Face-to-face interviews
Kapteyn et al. (2013)	Comparability between subjective QoL in the US & Netherlands	2,250 Dutch households & 1,113 American resondents	RAND American Life Panel; CentERpanel for the Netherlands	Internet surveys

Author	Focus	Participants	QoL Instrument/s	Reporting
Karr (2011)	Applying QoL & self-determination to UNCRPD	Disabled people interested in advocacy from Nepal, Zambia & U.S.	QOL-Q (for people with ID); AIR (to measure self-determination); Human Rights Survey (developed for study)	Self-report survey
Koch et al. (2015)	Explored possible reasons why proxies often underestimate QoL	adults with ID	WHO QoL - 100; WHOQOL-BREF	Face-to-face interview & proxy questionnaire
Knott et al. (2016)	Use of vignettes to identify differential item functioning re: health or QoL		EuroQoL's EQ-5D	Patient Reported Outcome Measure (PROM)
de Leon & Freedman (2015)	Review of measures of disability, physical functions & cognitive abilities of adults		National Health & Aging Trends Study; Health & Retirement Study; Aging, Demographic & Memory Study; Panel Study of Income Dynamics; Survey of Income & Program Participation; Medical Expenditure Panel Survey; American Community Survey; WHO-ICF; Washington Group on Disability Statistics; WHO- Disability Assessment Schedule	Recommends survey to be completed face-to-face by all adults in household
Lucas-Carrasco & Salvador-Carulla (2012)	Psychometric properties of SWLS	adults with ID in Spain	Satisfaction with Life Scale; WHOQOL-BREF	Face-to-face interviews
Morisse et al. (2013)	Explorative study of QoL of people with ID & mental health problems	adults with ID & mental health problems in Belgium	Schalock et al.'s (2005) Eight domains	Focus groups with carers
Nota et al. (2005)	Examined relationship between personal characteristics, self-determination, social abilities & living situations	people with ID in Italy	Evaluation of Self- determination instrument; Evaluation of QoL Instrument; Social Ability Evaluation Scale	Proxy (health & social work professionals)
Pierce & Hanks (2006)	Life satisfaction after traumatic brain injury (TBI)	180 adults with TBI in Denver, Colorado	Satisfaction with Life Scale	Face-to-face interviews
Sanchez et al. (2006)	Predicting QoL in adults with severe mental illness	194 adults with severe mental illness in America	Personal factors; Environmental factors; Mental health; WHO Disability Assessment	Self-report

Author	Focus	Participants	QoL Instrument/s	Reporting
Siebans et al. (2015)	Single-item QoL Meausre	Older people with disabilities in California	Kemp QoL Scale (KQOL)	Secondary analysis (data originally collected by face-to-face interviews)
Sines et al. (2012)	Evaluating QoL in adults resettled from hospital to supported living	39 adults with profound ID	Comprehensive QoL Scale; QoL Questionnaire; The Mood, Interest & Pleasure Questionnaire; Choice & Independence measure	Proxy (primary carer)
Verbunt et al. (2008)	Disability & QoL	111 adults with Fibromyalgia in the Netherlands	Health-related QoL - SF36	Face-to-face assessment
Verdugo et al. (2014)	Measuring QoL	1,770 people with intellectual & multiple disabilities in Spain	San Martin scale	Self-report & third party

Appendix 4

Supporting literature on measures of quality of life for disabled children & young people

Author	Focus	Participants	QoL Instrument/s	Reporting
Gomez et al. (2016)	Development of a new scale for measurement of QoL in children with ID	1,060 Children & young people (CYP) with Intellectual Disabilities (ID) (aged 4-21)	KidsLife scale	self-report & proxy
Colver & SPARCLE Group (2006)	European study examining relationship of participation &QoL to impairment & environment	children with cerebral palsy (CP) (aged 8-12) sampled from total population databses in 9 European regions	KIDSCREEN; Strengths & Difficulties Questionnaire; Child Health Questionnaire	self-report & proxy
Baars et al. (2005)	European DISABKIDS project examining Health-related QoL	CYP (aged 8-16) with chronic medical conditions and their families	Caregiver Priorities & Child Health Index of Life with Disabilities (CPCHILD)	proxy
Kelly et al. (2016)	Explored subjective wellbeing of disabled adolescents	Group of young disabled people in Northern Ireland	Photographs of things that make you happy; interview	face-to-face interview
Narayanan et al. (2006)	Development and validation of a disease-specific measure of health status & well-being	77 primary caregivers of Children with CP (aged 5-18)	Caregiver Priorities & Child Health Index of Life with Disabilities (CPCHILD)	proxy
McDougall et al. (2013)	Applying ICF Framework to study changes in QoL	34 Youth with Chronic Conditions (aged 11-17)	Students' Life Satisfaction Scale (SLSS) and the Brief Multidimensional Students' Life Satisfaction Scale (BMSLSS)	self-report & parents
Emerson et al. (2008)	Wellbeing & aspirations	adolescents & young adults with a long-term health condition, disability or impairment (aged 15-29) in Australia	Household Income & Labour Dynamics in Australia (HILDA) panel survey instruments; life satisfaction; mental health subscale of SF-36; Pearlin Mastery Scale (self-efficacy)	self-report
McDougall et al. (2010)	Importance of self-determination to perceived QoL	Youth & young adults with chronic conditions & disabilities (aged 17-29)	Life Satisfaction Index-Adolescents; Arc's Self-Determination Scale	Self-report

Author	Focus	Participants	QoL Instrument/s	Reporting
Hubert- Dibon et al (2010)	Health-related QoL in adolescents with specific language impairment (aged 8-18)	paretns of 67 children with SLI & 67 unaffected children	KIDSCREEN	Proxy
Rosenbaum et al (2007)	Health-related QoL	203 adolescents with CP (aged 13-20)	QoL Instrument for People with Developmental Disabilities	self-reporting & proxy
Law et al (2014)	Health-related QoL	427 parents of children with a physical disability (aged 6-14)	Child Health Questionnaire Parent Forum 50; Impact on Family Scale; Strengths & Difficulties Questionnaire; Craig Hospital Inventory of Environmental Factors; Activities Scale for Kids; Children's Assessment of Participation & Enjoyment	self-reporting & proxy
Mezgebe et a. (2015)	QoL comparison	children with epilepsy (345); 'typical' children (5,950) & children with CP (489) (aged 8-12)	KIDSCREEN	self-reporting & proxy
Sylvester et al (2013)	QoL	91 disabled children & young people (aged 5-18)	KIDSCREEN	self-report
Nolan et al (2014)	Parent & paediatric hospital professional perceptions of health-related QoL for children with severe disabilities (aged 5-18) when not hospitalised	115 parents of children with severe disabilities (aged 5-18) & medical care staff in Utah	KIDSCREEN	Proxy
Razafimahefa-Raoelinaa et al (2016)	Assess QoL in children with cochlear implants	32 CYP with cochlear implants (aged 6-17)	KIDSCREEN	self-report & proxy
Biggs & Carter (2015)	QoL for transition age youth with autism & ID	389 transition-age youth with autism or ID	KIDSCREEN	proxy
Peterson et al (2005)	Develop health-related QoL instrument for CYP with chronic health conditions	CYP with chronic health conditions (aged 8-12 & 13-16)	DISABKIDS; Child Health Questionnaire	self-report & proxy

Author	Focus	Participants	QoL Instrument/s	Reporting
Schmidt et al (2006)	Cross-cultural validity of DISABKIDS generic QoL instrument for children with chronic diseases	CYP with chronic diseases (aged 8-16)	DISABKIDS	self-reporting & proxy
Waters et al (2007)	Psychometric properties of the QoL Questionnaire for children with CP	CYP with CP (self-reporting aged 9-12) & parents of children with CP (aged 4-12)	CP QOL-Child; child Health Questionnaire; KIDSCREEN	self-reporting & proxy
Varni et al.(2006)	PedsQL in pediatric CP	Children with CP (aged 5-18) & parents of children with CP (aged 2-18)	Pediatric QoL Inventory (PedsQL) - generic core scales & CP module	self-reporting & proxy
Ikeda et al. (2016)	Develop Pediatric QoL Inventory Young Child Self-report in children with ASD & ID & adapted measure of QoL based on their feedback	10 children in focus groups; (FG) 8 children in interviews (Int); 14 parents in Int & FG; 3 teachers in FG	Pediatric QoL Inventory Young Child Self-report	self-report
Young et al. (2007)	Examined what disabled children & their parents thought was most important in their lives	28 children with CP (aged 8-13); 35 parents	KIDSCREEN	self-report
Morris et al. (2014)	Views on how to capture patient care outcomes for children & their families	50 CYP with neurodisability in FG; 4 CYP in Int (aged 8-25); 47 unrelarted parents in FG & 6 in int.	'Talking Mat' approach used to enage CYP with profound communication impairments; Children's Outcome Measurement Study (CHUMS)	self-report
Redmond et al. (2016)	Australian Child Wellbeing Project on what disabled CYP considered important for a 'good life'	9 disabled CYP (8-14); interview with 1 disabled child in Australia	Developed wellbeing survey & piloted in schools	Self-report

Appendix 5

Supporting literature on measures of quality of life for families

Author	Focus	Participants	QoL Instrument/s
Davis & Gavisia-Payne (2009)	Impact of child, family & professional support characteristics on QoL of families	64 Parents of children with a developmental delay or disability (aged 3-5) in Melbourne	Beach Centre FQOL
Vonneilich, Lüdecke & Kofahl (2015)	Burden of care on parental health- related QoL	Parent of a child with a disability or chronic condition	Original survey; health-related QoL SF-12; Impact on Family Scale
Burton, Lethbridge & Phipps (2008)	Parental health of a child with a disability or chronic condition	Parental health of a child with a disability or chronic condition	Statistics Canada National Longitudinal Survey of Children and Youth
Ferrer, Vilaseca & Bersabe (2016)	Impact of parents' positive perceptions on FQoL	861 parents of child (aged 1-70) with ID	Positive Contributions Scale & Spanish Family quality of life scale
Balcells- Balcells et al (2015)	Identify better indexes to measure QoL	202 families of child (age 0-6) with ID	Beach Center FQOL; Service inventory; Beach Center Family-Professional Partnership
Hoffman, et al 2006	Develop scale to assess FQOL	488 families of children with disabilities	FQOL
Isaacs, et al (2012)	Test the structure of the FQoLS-2006 survey	402 Family members of someone with ID	FQoLS-2006
Perry & Isaacs (2015)	Validity of the FQoLS-2006	62 Parent and children (age 5-17) with ID or ASD in Canada	FQOLS-2006; Beach Center FQOL
Samuel, et al (2016)	Validity of FQOLS-2006	65 Family caregivers of children with developmental disabilities	FQOLS-2006; Beach Center FQOL
Dardas & Ahmad (2013)	Identify predictors of QoL for parents of children with ASD	184 Parents of children (age 2-12) with ASD	WHOQOL-BREF; PSI-SF
Bertelli et al (2011)	Relationship between QoL scores of individuals with ID and members of their families	27 Adults with ID & their parents in Italy	FQOLS-2006; interviews
Van Beurden (2011)	Critical evaluation of FQOL Scale	[literture review]	FQOLS
Gardiner & Iarocci (2012)	Review of studies on FQOL among families of children with ASD	[literature review]	Beach Center FQOL; FQOLS-2006
Samuel, Rillotta & Brown (2012)	Changing trends in family support and FQOL	[literture review]	FQOLS

Appendix 6

World Health Organization Quality of Life (WHOQOL)-BREF

The focus is on the last four weeks and each is rated on a 1-5 scale.

1. How would you rate your quality of life?

2. How satisfied are you with your health?

3. To what extent do you feel that physical pain prevents you from doing what you need to do?

4. How much do you need any medical treatment to function in your daily life?

5. How much do you enjoy life?

6. To what extent do you feel your life to be meaningful?

7. How well are you able to concentrate?

8. How safe do you feel in your daily life?

9. How healthy is your physical environment?

10. Do you have enough energy for everyday life?

11. Are you able to accept your bodily appearance?

12. Have you enough money to meet your needs?

13. How available to you is the information that you need in your day-to-day life?

14. To what extent do you have the opportunity for leisure activities?

15. How well are you able to get around?

16. How satisfied are you with your sleep?

17. How satisfied are you with your ability to perform your daily living activities?

18. How satisfied are you with your capacity for work?

19. How satisfied are you with yourself?

20. How satisfied are you with your personal relationships?

21. How satisfied are you with your sex life?

22. How satisfied are you with the support you get from your friends?

23. How satisfied are you with the conditions of your living place?

24. How satisfied are you with your access to health services?

25. How satisfied are you with your transport?

26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?

Do you have any comments about the assessment?

Appendix 7

KIDSCREEN-10

About Your Health

1. Have you felt fit and well? not at all slightly moderately very extremely

2. Have you felt full of energy? never seldom quite often very often always

3. Have you felt sad? never seldom quite often very often always

4. Have you felt lonely? never seldom quite often very often always

5. Have you had enough time for yourself? never seldom quite often very often always

6. Have you been able to do the things that you want to do in your free time?

never seldom quite often very often always

7. Have your parent(s) treated you fairly? never seldom quite often very often always

8. Have you had fun with your friends? never seldom quite often very often always

9. Have you got on well at school? not at all slightly moderately very extremely

10. Have you been able to pay attention? never seldom quite often very often always

In general, how would you say your health is? excellent very good good fair poor

Appendix 8

Responses from the consultation events

1. What does having a good life mean to you? (lists provided by participants)

- Family; work; qualifications – achieving; participating in social/sport events; community; voluntary work

- Family; travel; finances; social life; hobbies/activities; healthHealth; Fundamentals of life (food, etc.); friends; shelter; family contact; mobility; senses to read, etc.; independence; ability to work; freedom to follow faith; expression of values

- It's good for me to have good friends

- Health; safety; rights

- Being healthy; not being poor; enjoying school; getting on well with friends and family; enjoying work; lots of free time; doing well in school

- Shopping (sweets, clothes, games for playstation); spending time with my family; live in Ballymena; live on my own but have staff to support me; playing pool; swimming; walking; football; PlayStation; going out for dinner

- Going to socialise in a social club with friends; going to the cinema weekly; doing shopping once a week; getting out of Muckamore Abbey Hospital and going out of the community; going to a coffee shop with my friend; playing pool with friends; going walking around the hospital; going to the Patients' Council meetings

- Working for money; family; shopping; going out (discos, parties, out for dinner, cinema); being able to be yourself; being happy; being able to see my son; get out of hospital (too noisy); independence; have a job; have money; place of my own; support from friends, staff, family; hobbies and things to do; basketball/swimming/sports

- Not having any health worries either for me or my children; not having family problems that can't be resolved; having choices to do what I want to do; meaningful activities; paid employment; access to information/news/current events; my dogs (I get regular exercise through my dogs)

- Money; the same opportunities as other people

- Getting out of the house; hobbies; socialisation

- Family; independence; job

- Independence; need to be productive; need to be needed/valued; good health; companionship/friendship; capability

- Travel and finances
- Equality and love
- Financial stability; human contact (social, friends), accessible healthcare (both physical and mental); housing; family
- Basic needs/life essentials being met (food, shelter, etc.)
- The right to speak for ourselves and be heard; cash
- Family; being able to get out and about with family; transport
- Romantic relationships; good family relationships; positivity; friendships & social life; self-care and cleanliness; financial security; healthcare and physical activities; having confidence; relaxation; daytime activities such as work or study; general happiness; having choices and opportunities in life; a god support worker; intelligence; eating out; day trips; access to media (news and music)
- Travel – being able to go out and not just sitting at home; work; holiday; go out and enjoy life; food
- Family; health; being happy
- Making my brother happy all the time; no arguments; lots of free time; my family to always be happy; always to be loved by my friends; going to school

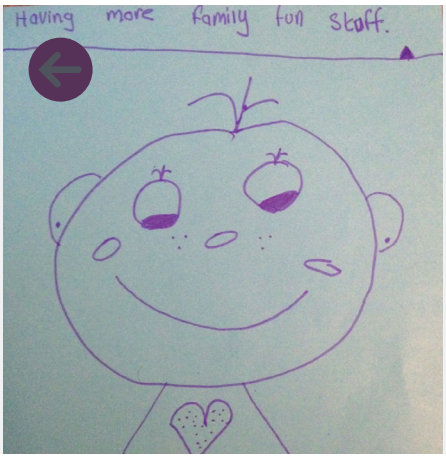
2. What is the most important thing you want us to say about measuring the quality of life of people with disabilities?

- Sort the benefits system, using the right professionals in assessment not outsourced to private firms!
- That older people with disabilities are offered the same opportunities as anyone else (they currently are not)
- I have a right to a good life
- Getting the right place to live
- I want a family for the future
- To realise that things are not always easy for families with disabled members – and we shouldn't be forgotten about
- Improve GP services

- Things that make me happy: having a job so I can have my own money to spend; being able to socialise with friends in my community; having hobbies that I can take part in
- You need to see the human being behind the disability and treat them in the way that you would want to be treated!
- Creating a sense of ‘wantedness’ and respect; The government can implement this in all layers of society from day to day life to healthcare, education, etc.
- Being with family and friends
- Making infrastructure and social activity more accessible (e.g. for big events there should be designated slots for those with mobility problems or learning difficulties)
- You need to see the human being behind the disability and treat them in the way that you would want to be treated!
- More theme parks and more parks and to ensure that school playgrounds are safe
- Music & playing cards
- Holistic approach to individual well-being – stop separating services
- Having more more family fun stuff
- Listen to us often and again and again
- Listen to us – focus groups/ advisory groups
- The effects of financial difficulty on emotional state and general well-being
- We need a Commissioner for people with disabilities.

Children & young people's reponses to 'what makes me happy'

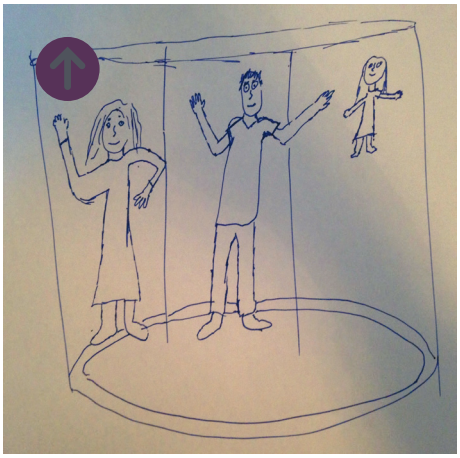
'Family makes me happy'



Eating together

Going to the cinema

Having fun together



The European Quality of Life 8+1 Survey

The European 8+1 Framework was introduced as a way to think about the interrelatedness of different parts of a person's life that contribute to overall life satisfaction. The categories that are used in the survey include: productive or main activity (including employment); material living conditions; health; education; leisure and social interactions; economic and physical safety; governance and basic rights; and natural living environments. Participants were asked to think about the categories and if they thought this was a helpful way of thinking about quality of life. Most participants agreed with the framework or suggested slight readjustments, such as strengthening the section on 'basic rights' to a more specific reference to human rights and the Convention on the Rights of People with Disabilities or splitting 'economic and physical safety' into two distinct categories. Some groups proposed developing their own lists. A group of adults with learning disabilities decided upon:

- Leisure;
- training/education/learning;
- human rights (including independence, housing, support, feeling safe, family, and having relationships);
- health/fitness (this makes you feel good and like yourself);
- Employment (this is not only about working but also about making social connections; it should be the choice of the individual and it should be meaningful);
- finance; transport; and environment.

Should the government measure the things that are important in people's lives? How can they do this?

Participants were asked 'why should it be measured?' and the following answers were given:

- not everyone has been capable of saving for their future;
- the government has a responsibility to monitor well-being but there's no point in holding the information if they aren't going to do anything about it;
- for people who can't get what they need, the government may need to intervene;

- if the questions aren't being asked, then there's no measurement;
- If you don't measure, then you can't identify improvements;
- to discover if you are happy or not, and if you're not, it should trigger a reaction or change;
- A person's well-being is very much about society and the contentment of society. If people struggle and are going for protests and are unhappy with things, it's very destructive to both the individuals and the families.

Some of the suggestions for how the quality of life should be measured were:

- Surveys
- Ask people
- A combination of objective and subjective assessments
- A children-friendly survey using smiley faces
- Use basic language in any survey
- Different agencies/departments need to communicate and work together better
- Face-to-face surveys would be best
- Qualitative surveys with representative samples… there needs to be more qualitative surveys like this one
- Both qualitative and quantitative data collection
- I don't think a survey on a scale of one to five for questions will tell you anything. People will get bored of it and just respond with 'three'
- People were not aware of other surveys administered in Northern Ireland such as NICOLA or Life & Times Survey
- Looking at evidence that already exists makes sense, but it must go beyond the labour force survey