

# STUDY ON INNOVATIVE FRAMEWORKS FOR MEASURING THE QUALITY OF SERVICES FOR PERSONS WITH DISABILITIES



**EASPD**

# Innovative Frameworks for measuring the Quality of services for Persons with Disabilities



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## Executive Summary

The aim of the project was to develop a framework to measure the quality of services for persons with disabilities which would be outcomes focused, centred on the quality-of-life concept, and aligned with the UN Convention on the Rights of Persons with Disabilities. The second task was to formulate a proposal for the development of a framework as such. A literature review and expert consultancy were utilised to gain a picture on the models of service quality used and to identify a potential framework and set of associated indicators.

One of the most common concepts of service quality has been Donabedian's Structures-Process-Outcomes model. For defining "outcomes", the concept and principles of "Quality of Life" have been widely applied. Quality of Life has been conceptualised as: being made up of the same elements for all people; as having both our needs met and the opportunity to pursue life enrichment in the same settings as others as having both objective and subjective elements, as based on individual needs, choices and control and as a "multidimensional construct influenced by personal and environment factors."

The Framework set out in this report is based on the eight Quality of Life domains originally put forward by Schalock et al. (2002) and aims to give services a clear vision of what they should be working towards helping people achieve, at the same time as ensuring they focus on each person in a person-centred way and understand the factors that influence Quality of Life. For each Quality of Life domain, two sets of indicators have been developed – one focuses on capturing people's subjective experiences and what they would *say* if experiencing a good quality of life. The second is a list of objective indicators that identify what one would *see or hear* during observation, talking to staff or managers or reviewing paperwork. This list of objective indicators was considered particularly important by those consulted and is also highlighted in the report as important for a number of methodological reasons. In particular if the aim is to capture the Quality of Life and lived experiences of all people who use services, not just those who can fill in a survey or complete an interview. Following Donabedian's original model, outcome indicators for staff and families have also been included.

The second part of the proposed framework takes account of what is known about the processes or working practices associated with positive Quality of Life outcomes for those who use services – for example, the attitudes of staff, the skills they have and the environment in which support is being provided. In the third section, the framework focuses on what is needed at different levels to ensure that those providing support have the skills, motivation and resources they need to successfully support people to experience a good quality of life.



These two elements are essential if the final framework is to be useful for service development and improvement.

For the further development of the proposed framework, three practical steps are suggested. Firstly, the current framework and indicators need to be piloted with a group of different types of service providers in a number of countries with different welfare /social care systems. Secondly, a comprehensive measurement toolkit that could be used to gain the specific information needed to judge the quality of a service against the domains and indicators, would need to be developed. This component would identify existing measures, map how well these covers the domains and indicators of the framework and any gaps and then develop and consult on new measures. The third element is to field test and conduct cognitive testing for the framework and associated toolkit with the involvement of individuals with disabilities, families, staff, service providers and potentially other stakeholders such as municipalities or local/regional authorities.



## Introduction

In March 2021, the European Commission published the new European Strategy on the Rights of Persons with Disabilities 2021-2030. This strategy included the aim of developing a European Framework for Social Services of Excellence for Persons with Disabilities by 2024. And, this aim was the initiative for the development of this report.

The aims and objective of the study were:

1. To provide an overview of frameworks used for conceptualizing and measuring the quality of services for persons with disabilities and to identify a list of indicators of service quality, with a particular focus on those which are:

- outcomes-based,
- focused on the quality-of-life concept
- aligned with the UN Convention on the Rights of Persons with Disabilities.

2. To present an evidenced-based proposal of how a framework for measuring service quality can be developed as part of the upcoming initiative for a European Framework for Social Services of Excellence.

The report will begin with an overview of some of the theoretical concepts, definitions and methodological issues related to defining and measuring service quality. The aim is not to present a comprehensive account of the state of knowledge but to provide enough background to allow the reader to understand the concepts and issues that have shaped the framework and the proposed list of indicators presented in the report. We acknowledge at this early stage that the Quality of Life framework we have used is only one possible way of thinking about outcomes and only one of many different ways of conceptualising service quality and quality of life.

## Defining and measuring service quality

### Theoretical approaches

There have been many different approaches to defining and measuring quality in health and social care services. However, one of the models most commonly used to conceptualise service quality has been the **Structures-Process-Outcomes model put forward by Donabedian** in 1966 and expanded in 1980.

Although initially conceptualised as applying to health services, this model has become widely used in relation to social care services and is still hailed today as relevant and a useful way to



approach service quality and improvement (e.g., NHS England and NHS Improvement, 2021; Berwick and Fox, 2016).

Donabedian suggested that the **quality of services should be judged by the outcomes they produce and identifies three groups whose outcomes should be considered: those who use services, their families and the staff that support them.** Whilst looking at outcomes was considered paramount, Donabedian highlighted that it was also important to look at:

- the **“processes”** (sometimes referred to as the “transactions between patients and providers throughout the delivery” of healthcare/or other services – in the context of social care this is usually conceptualised as the type of support provided, as the way the support is provided) and
- the **“structures”** (sometimes called “inputs”, e.g., the physical and organisational characteristics of the service/organisation including the resources available in terms of staffing, facilities, equipment, expertise, etc.) in place in a service, primarily as it has already been identified that certain processes and structures are more likely to deliver better outcomes for those supported.

Consistent with the suggestion by Schalock (2001; Schalock et al., 2008), we will use “right-to-left thinking”, starting with considering the outcomes experienced by people who use services and then exploring the importance of processes and structures in the context of disability social care services.

### Outcomes and the importance of quality of life

Just as there has been discussion over how quality should be conceptualised and measured, there has also been much debate as to **how outcomes of services should be conceptualised and measured.** One of the most commonly used ways of defining “outcomes” has been using the concept of “Quality of Life”. “Quality of Life” first began to be used in the field of positive psychology and in research around social indicators in the 1960s and 1970s. The first use in a medical context is attributed to Elkington in 1966 (cited in Katschnig, 2006).

The concept began to be important and conceptualised as a measure of the “outcome” of healthcare in the late 1970s and early 1980s. There was a particular focus on quality of life in populations where the usual outcomes of health care (e.g., cure) was not applicable – e.g., the elderly, those with terminal illness (Armstrong and Caldwell, 2004). Armstrong and Caldwell noted that it was the vagueness of the concept of quality of life that allowed it to be “invoked as a common goal” across different programmes and services. Although some of the 1970s debates in which quality of life had proven to be important were now less discussed, the use of quality of life “as the key referent for judging medical success...” has continued.



They went on to describe, how at the time of writing, quality of life has become “empirically grounded in standardized instruments that try and capture the true voice of the patient. But eliciting patients’ views is only one – and a more recent – way of thinking about quality of life and one that equates its measurement procedures with its purpose. The alternative is to see the concept as being grounded in an important socio-political rhetoric that enables an appeal to quality of life as the arbiter of medical goals and clinical success...” (page 369).

In mental health, quality of life also became a relatively prominent way of conceptualising outcome of services and treatment programmes. And during the 1970s to early 1990s, many measures of quality of life focused more specifically on this population, began to be developed (Katschnig, 2006; Lehman, 1996) and continue to be developed today (van Krugten, et al., 2021).

Less commonly explored in research has been the quality of life of people with physical disabilities, although what does exist tends to focus on subjective elements of quality of life such as life satisfaction, what predicts subjective quality of life and impact of interventions on quality of life (e.g., Kinney and Coyle, 1992; de Almeida et al. 2019). Interventions, where quality of life has been used as an outcome measure, have included programmes such as involvement in sports or the processes of deinstitutionalisation.

However, the conceptualisation and measurement of quality of life is perhaps most researched in the field of intellectual and developmental disabilities (IDD), where quality of life became important in at least two interconnected ways. Firstly, in the 1980s it became an important way of measuring the impact of deinstitutionalisation and was used, primarily by the proponents of deinstitutionalisation, to demonstrate that people with intellectual disability were better off in community-based settings (For reviews of the literature see: Emerson and Hatton, 1994; Young et al., 1998; Kim, Larson and Lakin, 2001; Beadle-Brown et al., 2007; Kozma et al., 2009; McCarron et al. 2019). In many of the earlier studies, the concept of quality of life was still, as had been true in the medical research, relatively vague or specifically focused on subjective measures such as satisfaction and happiness. In the later studies, the Schalock et al. Quality of Life Framework described below was more prominent.

Secondly, in the field of intellectual disability, quality of life became identified as both a “sensitising notion” and, over time, “an integrative framework for service delivery and evaluation” (Schalock and Verdugo, 2014). It was seen as a way of alerting providers to the need to support people in the community rather than in institutions and also as a way of integrating these changes in service provision with wider societal changes - for example, the greater perceived importance of subjective well-being as a measure of health and social care quality, anti-discrimination legislation, the rise of the advocacy movement and the concept of



involvement of people with disabilities in all aspects of society and their services. Schalock and Verdugo go on to state that the concept of Quality of Life can also serve as a “change agent” and will have the “greatest impact when it serves as a guiding principle in the transformation of human service organizations”.

### *Defining Quality of Life*

In terms of how Quality of Life (QOL) has been and is currently defined, there are many papers and books that can take interested people through this. We will provide a very brief account here, drawing primarily on the international consensus on QOL in intellectual and developmental disability (Schalock et al., 2002) and on Schalock and Verdugo (2014). However, we would encourage the interested reader to explore Schalock and Verdugo (2002) and Schalock and Verdugo (2014) for more in depth consideration of the concept (Schalock and Verdugo 2002). To set the context, this section will briefly present some of the keyways that quality of life has been conceptualised over time, prior to the publication of the Schalock et al., 2002 framework.

As indicated above, many of the early conceptualisations of quality of life, primarily focused on what were called “subjective” elements of Quality of Life and thus measurement primarily focused on emotional well-being, happiness, satisfaction, etc. However, there was substantial debate about only considering subjective elements of Quality of Life and a stronger focus on objective life conditions developed. Felce and Perry (1995 and Felce, 1997) proposed a new model for conceptualising Quality of Life built on previous models and responded to some of the debates being had at the time. Felce and Perry (1995) described three essential components of Quality of Life that interact - objective life conditions on different life domains, subjective feelings of wellbeing on these domains, and personal values and aspirations regarding these domains. They suggested six domains of QOL and highlighted that each element can be influenced by variables such as age, as well as social, economic and political variables.

At a similar time, the World Health Organisation (WHO quality of life assessment group – WHOQOL, 1995) was also working on the conceptualisation of quality of life although primarily focused on health-related quality of life. The WHOQOL group defined QOL as “individuals’ perceptions 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 health, psychological state, level of independence, social relationships, personal beliefs and their relations to salient features of their environment” (page 1405).



The five life dimensions identified were material, physical, emotional, and social well-being and productivity.

In contrast, in the 1990s in Scandinavia, a different approach was developed. The principle of “normalization” as proposed by Benk-Mikkelsen’s in the 1960s had become the central policy guideline for the disability sector across Scandinavia (as well as having more international influence too). Some years later, but with the same philosophical message, the Scandinavian Social Indicators Movement arrived on the international agenda. Rather than focus on subjective indicators as “quality of life” was conceptualised as being, the focus was on “objective living conditions”. The contextual assumption was that social policy efforts were to be made to create conditions for all citizens to live a good life. From this perspective, persons with disabilities were to be regarded as citizens with the right to living conditions similar to the general population (see Tøssebro 2021). This implied entitlements for certain housing standards with space, equipment and connected with community service models “that allow a life as normal as possible”.

These are some (but by no means all) of the developments in the conceptualisation of QOL and service-related outcomes that led up to the production of the international consensus on Quality of Life led by Schalock et al. (2002) and summarised in Schalock and Verdugo (2014). This is the conceptualisation that we will draw on heavily in this report, although we recognise that there are other frameworks of quality of life that we could have chosen to use – the ICF framework which developed from the original WHOQOL group work in the 1990s is one such example.

However, the ICF framework is more commonly used with reference to health-related quality of life and is also focused at a much wider systems or societal level more generally. Whilst it is important to acknowledge the interactions between wider societal aspects and individual quality of life, we felt that, in the context of monitoring the quality of *social care* services, it is important to have a framework which makes it clear how services can positively influence people’s outcomes and reduce the likelihood that services will attribute poorer quality of life outcomes to societal or impairment related factors.

Schalock and Verdugo (2014) identify five conceptualisation principles of quality of life:

1. Quality of Life is made up of the same factors and relationships for all people (i.e., for those with and those without disabilities),
2. Quality of Life happens with we both have our needs met and have the opportunity to pursue life enrichment in the same life settings as others,



3. Quality of Life has both subjective and objective elements but is primarily concerned with the views and perceptions of the individual on their life,
4. Quality of Life is based on individual needs, choices and control,
5. Quality of Life is a “multidimensional construct influenced by personal and environment factors.”

The principles for how Quality of Life should be applied in practice are also summarised by Schalock and Verdugo (2014) include the following: application should enhance a person’s well-being, should take into account the individuals cultural and ethnic background, should involve collaboration for change at the personal, program, community and national levels; should increase opportunities and control in relation to activities, interventions and environments, and should play a prominent role in research and evaluation of factors that predict a “life of quality” and of interventions designed to have positive effects.

Although the original QOL conceptualisation pre-dates the publication of the United Nations Convention of Persons with Disabilities (UNCRPD), **it is generally agreed that the values that underpin the QOL framework align with the UNCRPD.** The Quality of Life domains map unto many of the Articles both as an overarching concept – people should have access to the same opportunities and experiences as people without disabilities – and in that many of the Articles of the UNCRPD can be mapped to specific Quality of Life domains (Verdugo et al, 2012).

The most commonly used set of domains, based on the 2002 consensus paper, are set out in Table 1 below. Also presented are some examples of the indicators within each domain and our mapping to the UNCRPD articles, drawing on that of Verdugo et al (2012).

*Table 1* The Quality of Life domains with exemplar indicators and the relevant UNCRPD Articles indicated.

Domain	Examples of indicators	Relevant (directly or indirectly) UNCRPD Articles
<b>Rights</b>	Human Rights – e.g., respect, dignity, equality, privacy, family life, freedom from harm Legal or civil rights – e.g., citizenship, access, due process, voting	5, 6, 7, 10, 11, 12, 13, 14, 15, 16, 18, 21, 22
<b>Self-determination</b>	Choices/decisions, autonomy, personal control, and personal goals	9, 12, 14, 19, 21
<b>Interpersonal relationships</b>	Access to family; positive interactions with others; Intimate and personal relationships;	23, 30



Domain	Examples of indicators	Relevant (directly or indirectly) UNCRPD Articles
	friendship; participating in social activities and events.	
<b>Social inclusion</b>	Community presence/integration (living in ordinary housing dispersed in the community, accessing the same facilities and range of activities as people without disabilities) and participation in activities in the community Community roles and contributions	8, 9, 18, 19, 20, 21, 24, 27, 29, 30
<b>Personal development</b>	Access to education Skill development Meaningful occupation and demonstrating competence	24, 26, 27
<b>Material well-being</b>	Financial status Employment status Housing Status Possessions	27, 28
<b>Physical well-being</b>	Health status, nutrition; recreation and activity; physical safety from abuse and basic physical needs met.	11, 16, 17, 23, 25, 26, 30
<b>Emotional well-being</b>	Safety and security; happiness and contentment; positive experiences and self-esteem; Lack of stress.	15, 16, 17, 25, 26

It is acknowledged that later presentation of the eight domains has sometimes varied from the original 2002 description, particular with regard to the domains of social inclusion and interpersonal relationships. We have chosen to keep the domains of Interpersonal Relationships and Social Inclusion, rather than use the domain of Participation which can be found 1) in Verdugo et al (2012) instead of social inclusion and 2) in Schalock and Verdugo (2014) instead of Interpersonal relationships. We will use the concept of participation in a different way in this research as will be explained later.

Another strength of the Quality of Life domains above is that although there can be within and between culture differences in terms of indicators of quality of life, **in general these eight**



**domains have been found to be valid concepts in a range of different countries and cultures** (e.g., Schalock et al. 2005).

**It is important to note that the Quality of Life domains outlined above can be conceived as inter-connected and not as standing in isolation.** For example, emotional well-being in terms of happiness, positive experiences or self-esteem will be influenced by a number of other domains, in particular the domain of personal development – i.e., having the opportunity to try new things, succeed and develop skills or even just show your current skills and competence through participation in a range of activities and roles. This latter point then also connects to social inclusion and being able to participate in activities where other people will see you use your skills. This in turn is likely to result in greater respect and acceptance from others in society and strengthen your rights and promote freedom from discrimination, which in turn may have potential benefits for social inclusion and interpersonal relationships.

#### Quality of Life for all – an inclusive framework

Finally, although there are a number of scholars and practitioners in the Quality of Life field who would argue that Quality of Life is more appropriately used as a measure *of individual or personal outcomes*, we would argue strongly that **such a framework is as much needed and useful now as a sensitising notion and an integrative framework for the organisation and delivery of services as it was in the 1980s.**

Despite a paucity of research on the quality of people’s lives more generally and the impact social care services currently have, even on their living arrangements and whether they spend their days in any meaningful way (Šiška et al., 2017; Šiška and Beadle-Brown, 2020), **what research there is has found that people with disabilities experience poorer outcomes in a number of domains:** for example, they are less likely to have paid employment, more likely to be living in poverty or in inadequate or appropriate housing and more likely to experience social exclusion more generally (Williams et al., 2008; Independent living survey, 2016<sup>1</sup> Satsangi et al., 2018; Devine et al., 2021). **This is especially true for people with intellectual and developmental disabilities** who in almost all countries are the least likely to be realising their rights under the UNCPRD - being most likely to be still living in congregate, segregated settings and least likely to be experiencing active citizenship (Šiška et al., 2017; 2018; Šiška and Beadle-Brown, 2020). **They generally have little choice over where they live, who they live with and who supports them** (Inclusive research Network, 2010; Stancliffe et al., 2011,

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<sup>1</sup> <https://in-control.org.uk/wp-content/uploads/2018/01/independent-living-survey-2016-v3.pdf>



Šiška et al (2018), Bigby et al. 2017, Pallisera et al., 2021). **They also continue to experience violations of their human rights**, even in countries that were leaders in the first wave of deinstitutionalisation (Murphy and Bantry-White, 2021; Care Quality Commission, 2020) and **often have lives marked by isolation and disengagement, even when living in community-based settings** (e.g., Beadle-Brown et al., 2015).

Although the UNCRPD has been a powerful tool for campaigning at different levels, it has been potentially less influential in services for people with intellectual and developmental disabilities, especially in some countries. In the first wave of deinstitutionalisation, the concepts of normalisation, valued social roles and an ordinary life provided a values-base that services were able to operationalise relatively clearly, although the concepts themselves were sometimes misunderstood and have since come under criticism (e.g., Perrin and Nirje, 1985; Szivos, 1992; Culham and Nind, 2003). **The Quality of Life framework described above has the potential to give services a focus and a clear set of operationalised outcomes that they can work towards supporting people to achieve, at the same time as ensuring they focus on each individual in a person-centered way.**

In order for this to happen, **it is essential that outcomes are clearly operationalised and in a way that can be applied to ALL people with disabilities, including those with severe and profound disabilities** who are generally the most excluded and marginalized group of all. It has to be possible to operationalise and monitor any Quality of Life indicators even for this group of people. This may require a different approach to what has traditionally been used - with the combination of robust objective indicators (e.g., what would you see and hear if you visited people while they were receiving support) with self-reported subjective measures (i.e., what do people tell you about their lives and what is important to them), wherever it is possible to do so.

Mansell and Beadle-Brown (2012) highlighted the importance of asking the question “what would you see if...” people were experiencing social inclusion, people were growing in independence, were experiencing real choice and control, etc. They went on to highlight **how active participation in what is going on around an individual at home and in their community is key to promoting quality of life** - they refer to this as “**engagement in meaningful activities and relationships**” and note that **such engagement can be seen as both a route to achieving many of the QOL domains and as an indicator of quality of life.**

- ➔ It is not possible to achieve social inclusion if you are not actively participating in ordinary activities, everywhere with other people.
- ➔ It is not possible to build relationships if you never do anything that builds shared interests or even just something to interact over.



- ➔ It is not possible to learn new skills if you never do anything new.
- ➔ It is not possible to grow in self-esteem if you never experience success in things you try.

**On the contrary, when people’s physical or emotional well-being is poor, then one of the first indicators of this is a lack of participation or engagement in tasks, activities and interactions (new and every day).** This does not in any way deny the importance of capturing the subjective experience of people where at all possible but **helps providers to have a clear picture of not only how each person they support might be experiencing life and the support they receive but also of what it is possible to achieve even for people with the most severe disabilities** – in other words, it acts as a sensitising notion.

The importance of assessing processes and structure

**In order to improve outcomes for people providers need to recognise the impact the way they work can have on how that person experiences life.** Service providers can rarely change much in terms of the wider context (state of the nation; government policy; etc) but can and do impact on people’s QOL, both positively and negatively (Mansell and Beadle-Brown, 2012; Bigby and Beadle-Brown, 2016; Claes et al., 2012; Marquis and Jackson, 2000).

As noted at the beginning of this section, Donabedian suggested that **in order to understand and influence outcomes, it was important to understand both the processes and structures in play.** The importance of providing support to people with disabilities to achieve the rights enshrined in the UNCRPD, is emphasised in every article of the Convention itself.

Theoretically, the importance of understanding and providing integrated systems of support has been highlighted, including by Schalock and colleagues (e.g., Schalock et al., 2019).

They identify four systems of supports:

1. choice and personal autonomy (e.g., supported decision making),
2. inclusive environments (supported employment, supported living, inclusive education and aging in place),
3. generic supports (services available to general population, technology, reasonable accommodation, etc.)
4. and specialized supports (professionally based supports and therapies – education, medical, psychological, speech, occupational or physio- therapy).

Although there is some research looking at predictors and facilitators of better quality of life for people with disabilities more generally, this primarily focuses on health-related quality of life and the impact disability or health conditions can have on quality of life and their



acceptance (e.g., Benedict et al., 2005; Shivayogi et al., 2017; Ogawa et al., 2021). **When intervention or services are evaluated, the focus is usually on subjective quality of life** (e.g., McCauley and Bremner, 1991; Goldberg and Harrow, 2005).

In terms of understanding the service level factors that impact on quality of life, the majority of the research in this field focuses on intellectual and developmental disability services. Mansell and Beadle-Brown (2012) summarised the literature from the early pioneering deinstitutionalisation studies to the current day and concluded that **variability was extensive both between and within different types of services and that only two factors had consistently been found to impact on the lived experiences of people with intellectual disabilities being supported by community based services: the level of functional skill/severity of disability of the individual and the working practices of staff – quality of life outcomes were better where staff facilitated and enabled individuals to be involved in all aspects of their lives**, including interacting with others, making choices and having control – a way of working usually referred to as **“Active Support”**. In terms of what facilitates the development of such working methods, Mansell and Beadle-Brown (2012) highlighted the **importance of both ensuring those providing support have the skills to do so through training and support and that they are motivated to do so**.

Bigby and Beadle-Brown (2016) also collated all the hypotheses related to what produces better quality of life for people with IDD and conducted a realist review into the empirical evidence for those hypotheses. They also found that **it was staff and management working practices that had the strongest evidence base** – if staff were working in a way that enabled and empowered the individuals they supported (usually referred to as Active Support) and managers supported staff through what was known as “practice leadership”, then quality of life outcomes experienced by people in supported accommodation settings were better. **Other factors linked to QOL outcomes included having adequate resources in terms of staff, a service culture that is coherent, enabling motivating and respectful; staff having training in active support; living arrangements that are small, dispersed and homelike**.

Beadle-Brown et al (2015 and 2020) found that **active support was a robust indicator of skilled staff support and was strongly related to other person-centered approaches to support as well as to positive outcomes on a wider range of QOL domains than previous research had explored**. Better active support was not associated with greater support package costs and did not require more staff and was associated with more efficient use of the resources available (Beadle-Brown et al., 2020). Finally, a large-scale study looking at what predicts strong implementation and maintenance of Active Support (Bigby et al., 2019a; 2019b; 2020; Bould et al., 2019) confirmed previous findings related to practice leadership,

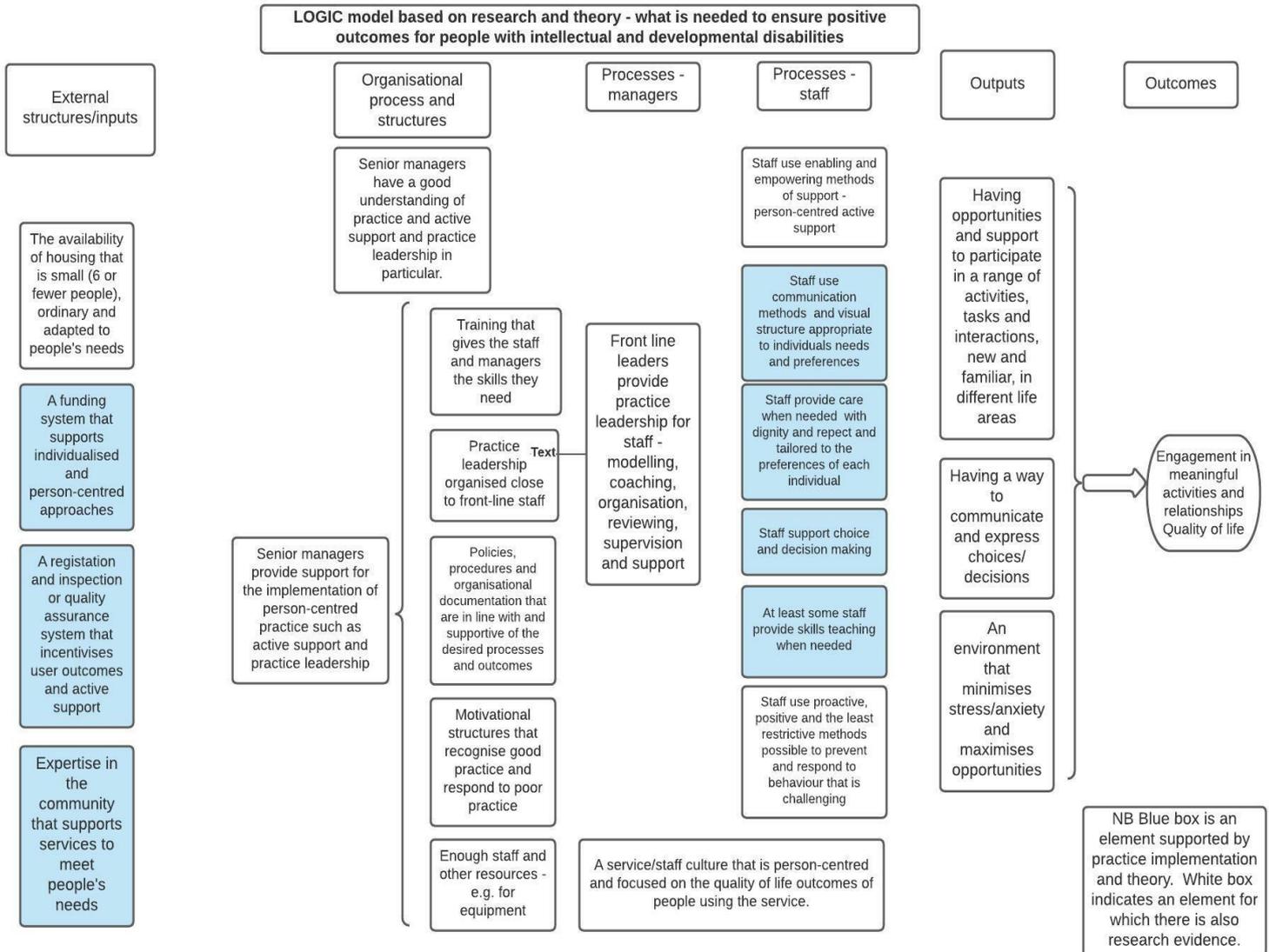


training and the impact of adaptive functioning, but also found that **size of setting, size of organisation, and commitment and support from senior managers, were also important.** below provides a logic model created to summarise the findings from research and theory in intellectual and developmental disability services. Although Figure 1 is based on theory and research in intellectual and developmental disabilities, it is highly likely that many of the elements will be relevant to all people with disabilities, especially if the framework is applied within a person-centred context. For example, the essential elements of Active Support are based on what is known about what works for anyone who needs support to learn new skills or to participate in what is going on in their lives (Mansell and Beadle-Brown, 2012). These principles can apply in any context – home, school, work, leisure, social, even in medical or therapeutic contexts. Elements of practice leadership such as coaching have long been considered key elements of shaping staff performance in many industries and practice leadership was a concept used in nursing practice for many years (Mansell and Beadle-Brown, 2012 chapter 5.



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Figure 1: Logic Model of factors influencing quality of life for people with intellectual disabilities using services



Some key considerations related to the evaluation of service quality

**The importance of viewing QOL and quality of services in terms of people’s subjective experiences has long been recognised. However, almost all conceptualisations of QOL also acknowledge the need to include objective indicators.** Research has identified a number of methodological and practical issues that should be considered when quality of life outcomes are used. We will draw out just three here as particularly relevant in the context of monitoring and improving service quality:

1. Without dismissing or invalidating the importance of seeking people’s perspectives, it has been highlighted that people’s views and perspectives on their quality of life can be affected by a range of factors, resulting in issues of bias, reliability or validity of responses.
  - a. Firstly, subjective well-being is considered to be under homeostatic control - it remains fairly stable and also generally positive (Cummins, 2015).
  - b. Secondly, it has been recognised that people’s ability to reflect on their current situation will be very much influenced both by their cognitive capacity and by their experience. For example, if people have limited experience of services/activities/opportunities and/or difficulties with communication and processing information, then their ability to comment on their current situation may also be limited, although of course creative ways of asking the questions can sometimes reduce these limitations (Perry, 2004).
  - c. Thirdly, it has been found that people will sometimes report their lives and their satisfaction with services as better than it might appear to be from objective indicators. This can often be driven by a desire to please the person asking the questions or sometimes by fear of losing their service or other repercussions if they say something negative.
2. Another approach to collecting information on quality of life and quality of services has been to use “proxy” respondents. This is where someone else (usually a family member or a member of staff) complete a survey or interview about the experiences of individuals who receive support. Research has highlighted that whilst proxy responses can be reliable around more objective indicators, there is less concurrence for subjective indicators (Stancliffe, 2000; Rand et al., 2017; Robertson et al., 2020). Proxy views may be influenced by different agendas and in addition, family carers expressed views on the quality of services can also be impacted on by fear of losing the service (e.g., Beadle-Brown et al., 2006).
3. Finally, as noted earlier, if we only focus on subjective indicators measured through self-report measures, then we risk omitting the experiences of people with severe or profound intellectual disabilities or others who might find it difficult to complete questionnaires or participate in interviews, even with the use of alternative and augmentative communication techniques.



Mansell (2011) sets out the importance of observational methodologies as a research tool for gathering information about people’s lived experiences and particularly in relation to people with severe and profound intellectual disabilities.

Other research has also highlighted the importance of observation as a tool for evaluating service quality more generally – exploring both the lived experiences of people who use services and looking at the quality of support and the practices and processes in use within services. (Mansell and Beadle-Brown, 2012; Beadle-Brown, Bigby and Bould, 2015; Beadle-Brown et al., 2016). Although limited in quantity, research has generally found that staff and manager reported measures of different aspects of quality overestimating the quality of services (Higgins, cited in Mansell and Beadle-Brown 2012; Bould et al., 2018).

In summary, **it is therefore essential to acknowledge the need for “triangulation” of different sources of evidence on service quality.** We need to combine subjective measures that look at what is important to people and how they experience life and the services they receive, with objective indicators (that will usually require observation) that ensure that basic needs are being met and that people have the same rights and opportunities as people without disabilities along with the support they need to realise those rights and make the most of the opportunities available to them.

## Scope of the research and methodological approach

This section will outline the key elements of the research undertaken – the review of the literature, the country templates, the development of the proposed indicators and then the stakeholder consultation.

### Scope of the work

The research focused on social care settings, in particular:

- any service providing in-home support for living of any type to children or adults with disabilities living in their own home,
- any service providing short term care and support/respice/short breaks (in home or out of home),
- any service providing residential care for people with disabilities,
- any service providing day activities, occupation, training for work or independent living, etc.



Not included in this exercise were:

- services providing solely support for health,
- services providing support within an employment setting,
- schools and primarily education-based settings.

In addition to the main aims identified above, a number of key assumptions and secondary aims guided this work. Firstly, the aim of the research was to identify a potential framework and set of associated indicators rather than the definitive measures or evaluation tools. It was assumed that this would be an important next step. Secondly, it was felt important that any resulting framework (and ultimately any associated measures and data generated using this framework) would potentially be able to inform about the progressive realisation of the UNCRPD. As noted by Šiška and Beadle-Brown (2020) the data available to even judge whether even Article 19 is being progressively realised is very limited, more than 15 years after the publication of the UNCRPD. Thirdly, any framework or measurement tool should identify the “bad” as well as the “good” and serve as an indicator of what we are aiming for in terms of “good/excellent”. It should not be possible for services that are not in line with the UNCRPD to be able to be viewed as good or excellent using this Framework.

Finally, **any framework and resulting measures need to be useful for informing service improvement – not just measuring quality.** This is likely to be particularly important to achieve engagement and commitment from service providers, especially if the framework is a voluntary one.

### Methods 1 - Literature review

The aim was to conduct a realist review of the literature (both academic and grey literature) using as systematic methods as possible in the time available. The review drew on three sources: a detailed search of published literature using a small range of relatively broad search terms in order to be as inclusive as possible; a general Google search using the same search terms to identify sources not published in academic journals; and the authors existing knowledge, academic networks and a recent book on Quality in Social Services (Šiška, Beadle-Brown, et al., 2021). A total of 126 publications were identified for initial review. Of these, 35 were excluded completely after full-text review, forty publications were identified for inclusion in the extraction process (covering 14 individual countries, with several papers having relevance to Europe more generally or internationally).



11 were identified as useful background sources and 6 related to research aim question 2 only. Thirty-four were used to complete the country templates for the UK, Australia and USA (see below).

Following initial reading of each of the 40 papers identified for inclusion, key elements were extracted, details of whether and how service quality was defined, did any framework suggested include outcomes and if so did QOL feature in these outcomes and how was quality measured.

Detailed information about the search strategy, data extraction and the resulting number papers can be found in Annex 1. The list of papers and documents reviewed are included in Annex 2.

## Methods 2 - Country templates

Using a specifically defined template, national experts were asked to help collate information on both formal (i.e., embedded in legislation) methods of defining and measuring quality and more informal measures, such as voluntary frameworks used by service providers, or disabled people's organisations. Relatively detailed country templates were possible for eight countries (Germany, UK, Ireland, Romania, USA, Czech Republic, Finland, and Australia). In addition, some less detailed information was available from country experts and written sources for Sweden, Norway, the Netherlands, Slovenia and Spain.

In addition to the information provided by national experts, the research team drew on published information identified during the literature review for each focal country and on other sources such as the DOCTOM<sup>2</sup> database which served as a prime source of data for the European countries.

The aim was to understand the systems used in different countries with different social care systems and at different points in the journey towards community-based services for people with disabilities. Secondly, the objective was to identify potential similarities and difference in policies and practices as well as strengths and weaknesses.

Analysis focused on identifying for each country:

- whether a quality monitoring system was embedded in the national legal and/or policy structure,

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<sup>2</sup> <https://www.disability-europe.net/dotcom>



- on which target groups quality assessment processes focused,
- how the quality services were conceptualised within the formal system,
- whether the concept of Quality of Life featured in how service quality was defined,
- the influence of UNCRPD,
- the focus of the quality monitoring system and the methodologies used to monitor quality,
- the involvement of service users in quality assessment,
- whether there existed any other more informal systems or frameworks for defining or measuring quality.

## Findings from literature review and country templates

### Conceptualisation of quality and the role of Quality of Life

For the most part the literature reviewed did not specify a definition of service quality, although one paper did equate service quality with “standards being met and organisational performance between enhanced through continuous improvement” (Queensland Government Human Services Quality Framework, 2020). Four publications drew on Donabedian’s model (Barelids et al., 2010; Ghenta et al., 2014; Melão et al., 2017; Šiška et al., 2021) and two publications provided descriptions of what good services look like for people with IDD (United Response and Tizard Centre, 2014)

**The definition of service quality is implicit in most of the papers reviewed and these definitions range from service quality equating to people’s needs being met, including both basic needs and enhanced needs (Netton et al., 2012; Towers et al., 2019) to service quality equating to people having good quality of life outcomes.** Around half the papers reviewed describe a framework or at least some indicators of service quality and user outcomes featured as key in 17 of the papers – most of these make reference to “quality of life” as a concept, with just over half of these specifically referring to the Schalock et al. domains outlined in the introduction. However, as noted in the introduction there are different conceptualisations of QOL used and, in some cases, QOL was not related to service quality directly but applied only in the context of individual or personal outcomes (e.g., the Personal Outcomes Measure (from the USA).

In terms of other elements of service quality, two frameworks/publications refer to the “SERVQUAL skeleton” (Zeithamkl et al. 2006) which included five dimensions of quality: 1) **Reliability** (ability of the organisation to distribute, actually and accurately the promised services). Safety and absence of errors and complaints are important indicators; 2) **Responsiveness** (willingness of organisations to help clients and to cater to their wishes and needs.



The competencies of the service providers are its most important indicators); 3) **Assurance** (this refers to the relationship of trust and confidence between client and social worker. The knowledge and courtesy of social workers and a relationship of trust are needed to ensure that all relevant information is brought forward; 4) **Empathy** (capacity of social workers to take the views of clients and to interpret their feelings and emotions); and 5) **Tangibles** (facilities such as people, equipment, and buildings - accessibility, reachability and encourage are most important indicators).

Some of the papers reviewed did not set out frameworks or indicators on what might be associated with quality services (Porter et al., 2020) and on how some aspects of quality such as could be measured, for example, Hostyn et al (2011), Lundqvist et al., (2016). **Looking at the ways user outcomes/quality of life is measured it appears that, for the most part, user surveys (and sometimes interviews) are the most common ways** that user outcomes are assessed. **Some studies used proxy measures** (where staff or family rated people's quality of life). **A much smaller number of frameworks used observational methods** to look at service quality and the lived experience of people with disabilities and this was suggested to be particularly important when looking at the experience of people with severe and profound intellectual disabilities.

Some publications looked at the elements of service quality most valued by different stakeholders (e.g, Barelds et al., 2010; Šiška, Beadle -Brown et al., 2021; Larson and Larson, 2021). These latter papers illustrated that **where people with disabilities are asked about what is important in terms of assessing quality and what they want a service to be like – generally they focus most on the interpersonal aspects of service –**

- i.e., the quality of the relationships they have with those who provide the support,
- the fact that they are treated with respect and kindness,
- that they feel that the staff want to be with them,
- and that they will enable and do things with them (not just do things for or to them), that they are empowered, not controlled.

They do however still mention wanting to feel safe and having their needs met. Barelds et al., (2010) found that the Responsiveness domain of the ServQUAL framework was most represented in both user and family preferences.



How does the UN Convention on the Rights of Persons with Disabilities feature in the published literature?

In general, **the UNCRPD was mostly invisible in the publications reviewed**, although is mentioned in Geogriadou et al (2021) and human rights and the UNCRPD is clearly set as the context for the European Quality in Social Services (EQUASS) Framework and the New Zealand Health and disability services standard NZS 8134: 2021. The exception to this was: 1) the Health Information and Quality Authority of Ireland's 2019 Guidance on a Human Rights Based Approach in Health and Social Care Services, which operationalises UNCRPD Articles into five key principles – Fairness, Respect, Equality, Dignity and Autonomy (FREDA); 2) The National Disability Authority of Ireland Outcome measurement in evaluating the quality of services paper; and 3) the paper by Gómez et al (2020), which mapped the UNCRPD Articles and Quality of life domains. **However, most conceptualisations of quality of life set out in the papers did include reference to some basic human rights such as dignity and to some disability specific rights such as accessibility.**

How do countries compare in terms of formal and informal systems of measuring the quality of services?

Concerning the formal systems for monitoring the quality of disability support services, only Czechia and Romania had service quality and the assessment processes embedded in specific law. In Ireland, quality monitoring and assessment is embedded in law but only for residential services.

In the UK, the initial standards and processes for monitoring them were set out in law in 2000 but have since evolved several times and now one body is responsible for registration and inspection of all health and social care services in England, with different systems in each of the nations. Similarly, in Australia and Sweden, the monitoring of the quality of disability support services is combined with health care in legislation.

**Most of the countries appear to have the assessment of quality services set out in legislation only as an overarching objective, rather than with definitions or methodologies specified.** However, there is evidence that the legal frameworks related to service quality are presently evolving in some countries such as the Netherlands and Germany. Slovenia currently does not seem to be addressing the quality assessment in the national legal structure. In countries in which a quality system is set down in law, apart from Ireland, services for all disability groups are covered.



In the US, although a framework or methodology of monitoring quality is not set down in legislation, there is a requirement for States to measure the impact and quality of the services they deliver to people with disabilities, in order to receive their funding. Several different frameworks and tools have been developed to measure service quality and the outcomes of service users, with different measures used in different ways across states and service providers. Examples include the National Core Indicators, the Home and Community Based Care outcomes measures and the Personal Outcomes Measure.

**In terms of how quality is conceptualised in formal systems, most countries studied had some conceptualisation of quality in their formal systems but with variations.** For some countries, reference is made only to quality as an overall objective of social services. For Netherlands and Germany, the overarching objective is social participation for service users. For Spain, it is personal autonomy. In Sweden, the concept of “good living conditions” serves as a quality framework. In Norway a “loose” reference is made to individual needs of services or to professional standards. In contrary, several countries have the requirements for the service quality articulated into a set of quality standards – Australia, UK, Czechia, Ireland, Romania. The quality standards typically include rights, participation and self-determination, complaints, service management, and emergency situations.

**Regarding the presence of the quality-of-life concept in the quality assessment systems, the countries with quality standards in place significantly differ.** In Ireland ‘Quality of life’ is a key principle on which the National Standards for Residential Services for Children and Adults with Disabilities are based. However, in most systems the QOL concept is just mentioned in passing (Australia) or only some elements of QOL identified.

**The influence of the UNCRPD was more visible in countries which have adopted legislation on service quality after ratification (Romania).** Nevertheless, the concepts of quality of social services draws on human rights principle either directly or indirectly in all countries.

**In the countries in which a set of quality indicators is applied, the focus is predominately on structures and processes rather than on individual outcomes.** However, in some countries there is a combination of structures, processes and outcomes explored – in the UK, Australia, Ireland and to some extend also in Czechia, Romania.

In the US, The National Quality Forum’s (NQF) HCBS measurement framework has included a heightened emphasis in recent years on evaluating the outcomes of people with disabilities receiving long term services and supports as well as the quality of these services.



In the Netherlands, service providers only have a duty to regularly conduct a quality assessment monitoring without any further specification on measures or indications. In Sweden, the municipalities and, in Spain, the regions hold the responsibility for quality assurance of social services with substantial autonomy between municipalities and regions in terms of deciding which monitoring instruments should be used. Decentralisation is also visible in who oversees the systems of quality assessment, such as seen in Germany. On the other hand, in some countries, the responsibility of quality assessment sits with municipalities or regions but with a central authority which supervises the entire system. This is the case of Spain, Sweden, Norway, Finland and Netherlands. In other countries such as in Czechia, Australia, Ireland, Romania, the UK there is one authority such as ministry of social affairs or national agency which is responsible for quality monitoring and often also for registration or accreditation of service providers. In at least some countries (e.g., Czechia and Ireland) a Public Defender of Rights (sometimes called an ombudsman) is entitled to assess the quality of services although this is usually on an ad hoc basis and in response to issues or complaints.

**Two models appear to be applied in quality monitoring processes in most of the countries studied.** First, there is often a self-assessment model conducted by individual service-providers with guidance provided by central authorities or associations of service providers. The second model is the inspection visits model used in Czechia, Romania, Ireland and the UK. However, there are differences between countries in terms of the frequency of inspections and who initiates an inspection – for example, in some countries, inspections might happen in response to complaints or on a regular cycle (such as in Romania where services are inspected every five years).

In the US, every state was required by federal law to develop its own assessment systems but with the stipulation that measures of compliance and quality improvement need to demonstrate reliability, validity, accuracy, and sensitivity to change primarily at the state level when applied to large numbers of participants. To date, many states in the US are struggling to put into place measurement programs capable of cutting across disability groups and that have adequate psychometric evidence to support their use at this level. In addition, in many states, the focus on measurement appears to be primarily directed at providing evidence of compliance as opposed to quality improvement.

The strengths of the national systems reported by experts included some of the systems now focusing on user outcomes, not just on structures and processes. In addition, clarity of the quality standards across different residential settings was mentioned as a strength by an expert from Ireland.



**There seems to be a general interest to improve the assessment processes.** For example, in the UK, inspectors now spend more time talking to individuals who use services, to staff and observing. These observations now focus more on interactions and relationships rather than just environmental factors and administrative processes. Other strengths given is availability of the inspection reports in public domain (Australia, Ireland, UK). Weaknesses reported included the fact that most of the quality monitoring systems appear to be based on self-assessment as opposed to independent observations. If service users are involved in assessment of quality, it is grounded primarily in self-report surveys which exclude those with most severe disabilities. However, in some countries such as the UK, experts by experience can be involved in inspections and provide their views on the service to inspectors who will include this in their ratings of the service. Where the inspection model, is applied the assessment is focused more on processes structure rather than on individual outcomes. The report from Romania indicates that very few monitoring and evaluation visits are made by inspectors during the period that a centre is accredited. Visits which are made tend to be formal and not thorough.

One alternative model to assessing service quality, used primarily in Scandinavian countries, was based on comparing the living conditions of people using services with the living conditions of the general population. This was, however, found to be problematic, for example as illustrated in Norway, where the surveys used to assess living conditions do not reach many people with disabilities, in particular those with intellectual disabilities. With the existing general systems for contacting respondents, intellectually disabled people simply disappear. This is also true of some of the alternative ways of assessing service quality in the UK – for example, although the Adult Social Care Survey has an easy read version, this still does not capture the experiences of many people with intellectual disabilities, dementia or others with difficulties processing information and responding to surveys. This applies not only to living conditions or service satisfaction surveys, but all types of population surveys.

In summary, **policies, and systems around the quality assessment of disability support services appears to be evolving in all countries studied.** One of the reasons for this suggested by one of the national experts was that the longstanding increase of service users and at the same time the decline of skilled workers in the entire social sector, is posing new challenges for service providers in terms of efficiency and effectiveness as well as the quality of the services.



## Development of proposed framework

### Identifying draft indicators

Following the review and synthesis of the literature and country templates, 20 frameworks or tools were identified as being relevant to the current research in some way. These were then summarised in a separate excel spreadsheet to draw out the dimensions of quality and outcomes included and how quality was measured and then each identified framework or tool was mapped onto the Schalock et al. 2002 quality of life domains. Annex 2 provides the detailed mapping of the outcomes set out in the 20 identified frameworks/measures onto the Schalock et al QOL domains. Two of the frameworks were connected – the National Quality Forum framework and the Home and Community-based Services Outcomes (USA). These have been included as just one row in Table 2.

Table 2 lists the frameworks/measures included in this process and summarises which QOL domains they mapped onto. As can be seen the Schalock et al domains were the most inclusive set of domains. No other framework suggested outcome indicators that could not be mapped onto one of the Schalock et al. domains.

Only two frameworks/tools used the Schalock et al domains directly (Bigby et al., 2014; The Quality Cube). Six frameworks focused on outcomes and used domains that for the most part could be mapped as whole domains to the Schalock et al QOL domains, but which may not include all of the indicators. For example, the most common way that frameworks mapped to the material well-being and the personal development QOL domains was through the inclusion of employment (see Annex 4 for the more detailed mapping). The remaining frameworks didn't necessarily focus on user outcomes or QOL directly but many of the indicators related to user outcomes and experience could be mapped onto the QOL domains.

In order to have the most complete and holistic view of QOL outcomes, it was clear that the Schalock et al. domains appeared to be the most appropriate set of domains to use to structure the draft outcome-based indicators. Although many of the existing frameworks and tools, assessed outcomes using surveys and interviews with individuals themselves or through proxy respondents, it was felt essential that **to be useful as a framework for evaluating quality of services for ALL people with disabilities, the quality of life domains had to be operationalised not only in terms of what people would say if they were asked about their experiences and the quality of the services they receive and but also in terms of what would be seen (and heard) by anyone visiting the service to look at quality.** As such indicators such as those identified by Bigby et al. (2014) for services supporting people with severe and profound intellectual disabilities were felt important to include.



**It is also important to note that the QOL domains are interconnected and should be considered holistically.** For example, in line with the UNCRPD, the domain of self-determination (including choice and control) should underlie all other domains – e.g., people should be able to see family *as much as they want to*; people should be able to access their *preferred* activities and community facilities; people should be able to eat *what and when they choose to*, for the most part. It is also important to acknowledge that with rights come responsibilities for all of us, and sometimes we don’t have choice over what we do, but we do have control over how, when, where, with whom etc. we do the things that we have to do.

Finally, in relation to this issue, **it is important, if ALL people with disabilities are to be included in the framework, to acknowledge that services have an important role in helping people to have self-determination, choice and control.** If someone has very limited experiences, limited communication and a staff team that isn’t skilled in noticing and responding to people’s attempts to communicate choices, needs and preferences, then having self-determination is very difficult. You have to have something about which to make a choice or decision, options to choose from – tasks around the home, self-care tasks, leisure, education, and work-related activities and tasks, relationships, lifestyle and exercise, medical care, etc. You also have to have some skills (and support) to communicate your choices and decisions. So, without at least some realisation of the domains of personal development, interpersonal relationships, physical well-being, social inclusion etc. there would be very limited opportunities for people to have choices and take control, to identify their preferences and potential aspirations. This is particularly important when we are looking at the quality of services for people with intellectual and developmental disabilities.

*Table 2 Mapping of the domains, dimensions and indicators of each of the framework identified in the research to the Schalock et al. (2002) Quality of life domains.*

Framework/tool	To which Schalock et al. QOL domains could at least some domains or indicators be mapped?							
	PD	IR	R	SI	SD	MW	PW	EW
Frameworks where whole domains could be mapped								
Bigby et al. (2014, Australia)	✓	✓	✓	✓	✓	✓	✓	✓
The Quality Cube (Netherlands)	✓	✓	✓	✓	✓	✓	✓	✓
ASCOT – Social Care related quality of life (UK and internationally)	✓	✓	✓	✓	✓	✓	✓	✓
Changing our Lives Quality of life Standards (UK)	✓	✓	✓	✓	✓	✓	✓	✓



Framework/tool	To which Schalock et al. QOL domains could at least some domains or indicators be mapped?							
	PD	IR	R	SI	SD	MW	PW	EW
Social Services Quality Standards (Czechia)	✓	✓	✓	✓	✓	✓	✓	✓
Personal Outcomes Measure (USA and internationally)	[✓]	✓	✓	✓	✓			✓
National Quality Forum framework AND the Home and Community-based Services Outcomes (USA)	✓	✓	✓	✓	✓	[✓]		
National Core Indicators (USA)	✓	✓		✓	✓	[✓]		✓
Quality of life Outcomes Domain Framework (Ireland)	✓	✓	✓	✓	✓	[✓]	✓	✓
<b>Frameworks where individual indicators, standards or parts of domains could be mapped</b>								
National standards for residential services for children and adults with disabilities (Ireland)	✓	✓	✓	✓	✓		✓	✓
EQUASS (Europe)			✓	✓	✓		✓	
Guidance on a Human Rights-based Approach in Health and Social Care Health Services. By Health Information and Quality Authority (Ireland)			✓	✓	✓		✓	
National longitudinal Transition Study (Shrogren et al) USA	✓	✓			✓	✓	✓	✓
Standards New Zealand Health and disability services standard NZS 8134: 2021	✓	✓	✓	✓	✓	✓	✓	✓
Quality of life impact of services tool (QOLIS) (Europe)	✓	✓		✓	✓	[✓]		✓
Šiška et al. (2021, Czechia)	✓	✓	✓	✓	✓	✓	✓	✓
National Standards for Disability services (Australia)	✓		✓	✓	✓		✓	
NDIS Practice Standards and Quality Indicators (Australia)		✓	✓		✓	✓	✓	✓
Person-centred advocacy, vision and education (USA)	✓	✓	[✓]	✓	✓	[✓]	✓	[✓]



SD = self-determination	MW= Material well-being	R = rights
PD = Personal development (including meaningful occupation)	PW= Physical well-being	SI = Social inclusion
IR = Interpersonal relationships	EW = Emotional well-being	[✓] = link is indirect or related to one indicator only (e.g. employment)

Secondly, other service quality indicators identified in the publications and frameworks were reviewed to identify how these fitted within Donabedian’s framework in terms of outcomes for staff and families, processes, and structures and with what is known from research in terms of producing good quality of life outcomes for people with disabilities. These particularly drew on elements identified in the research as needed for good quality of life outcomes (e.g. recent research in the field of intellectual and developmental disability by Bigby et al., 2019) and on the five dimensions of the SERVQUAL Framework (Zeithamkl et al. 2006 and used in the Quality Cube) and the 10 principles of the European Quality in Social services (EQUASS) framework. Although there is limited research evidence outside of intellectual and development disabilities of the factors that impact on user outcomes, it was felt important to keep in all elements of the service system that had been theoretically and practically linked to service quality and outcomes in other conceptualisations at this stage. The lack of research evidence reflects a lack of research conducted rather than research that says these factors are not relevant or important. As for outcome indicators, the aim was to be as inclusive and holistic as possible.

**These two processes generated a set of indicators at three different levels: Outcomes, Support Practices and Processes and structures.**

Level 1: Outcomes

- Two types of service user indicators were identified for each of the eight quality of life domains:
  - 47 Subjective indicators – i.e., what people would say/report if you asked them – formulated as “I statements”.
  - 68 Objective indicators – i.e., what would you see or hear during a visit to the service or when talking to staff and managers.
- 6 Outcomes indicators for staff
- 4 Outcomes indicators for families

Level 2: Support Practices - what would we see or what would people tell us about the support they receive and their staff



- 5 Attitudes and ethos related indicators
- 10 Working methods and technical skills indicators
- 3 Environment and planning indicators

Level 3: Processes and structures - Ensuring staff have the skills and motivation to implement these practices and ensure quality of life outcomes for individuals supported are realised

- 7 Service/staff team level indicators encompassing teamwork, leadership, support and training
- 24 Organisational level indicators encompassing leadership, tangibles, staff, individual assessment, planning and review, ethics, partnership and access to targeted, enhanced or external support.

### Stakeholder consultation

The set of quality indicators were consulted on with stakeholders including members of the EASPD task force group on disability service quality, other service providers, academics, and representatives of disabled peoples' organisations. Stakeholders came from a range of different countries across Europe as well as more widely. Several elements of the Delphi technique were used during the process to arrive at a group opinion. These included an online survey, individual consultation via email or in person and discussion or individual feedback via the group facilitator following a presentation. The feedback provided by the stakeholders was systematically analysed and considered during preparation of the final set of proposed indicators. Some of the more general concerns and issues raised by stakeholders have been acknowledged in the report more generally.

The feedback from the stakeholders was generally very encouraging. Overall, the comments gained were positive. There was great excitement about the project – both in terms of mapping the different frameworks in the literature and in practice and the proposed set of indicators themselves. Overall, the proposed set of indicators were found to be relatively exhaustive, well prepared, soundly structured with broad (inclusive) domains of service quality. *“The focus content is well structured and could enable the optimal measurement.”* The stakeholders found the set of proposed indicators adequately detailed and at the same time easy to understand. One expert highlighted that the set of indicators are presented in a way which do not require prior technical knowledge to read and understand. The descriptions of the indicators were found to be sensitive in referring to staff behaviour and attitudes and that the indicators were formulated respectfully towards both staff and users.



In general, stakeholders were particularly pleased to have both subjective and objective indicators and to see family and staff represented in outcomes as well as direct reference to the support elements.

One stakeholder, an expert from a European organisation representing people with disabilities and their families, commented on the distinction between "I statements" and "Objective indicators" as most important to him. The list of Family outcomes was also central for him. *"This part is short but just what we are expecting from the service provider - nothing more. If every sentence in that list can be "ticked" with ok, then it will leave us right where we want to be - be just family members."*

In terms of suggestions for improvements and going forward, a number of points were raised. We outline these below along with a response in terms of how we have taken them forward.

Firstly, a few areas were felt to be missing or underrepresented in the list of indicators: it was suggested that an indicator that would address cases where it is necessary to restrict certain rights of individuals receiving services should be added and that more information around legal capacity and supported decision making was added. The need for some indicators relevant to service users as parents and the support needed to be a parent was recognised. Finally, it was suggested to add something about staff about being encouraged to develop and update their skills, knowledge and refresh their values, and an element of helping and challenging each other within the service e.g., 'Staff reflect on their practice and are open to constructive feedback.'. Indicators relevant to all of these have been added.

Secondly, some issues were raised about the context in which this research is taking place and the significant differences between countries regarding the systems currently used for service quality assurance. It was suggested to make reference to this point in the introduction and to acknowledge the difficulties of elaborating a pan-European framework on quality indicators. One expert raised the issue about whether a QOLe framework was appropriate for constructing measures and indicators for disability service quality assessment and whether some other option such as the International Classification of Functioning, Disability and Health (ICF). We have attempted to deal with these issues in the introduction to this report and in our justification for using the QOL framework to structure the Outcomes based indicators.

Thirdly, a few stakeholders found the layout a little difficult to follow and did not necessarily see how the outcome indicators relate to the support practice indicators which related to the process and structures indicators. We hope this is now clear from the main report.



The final set of comments and issues raised related to providing more detailed operationalisation of some of the indicators and to the issue of who would use such a list of indicators, how quality would be assessed using the indicators and what would those doing this role need to know or what training would then need. The role of service users, families and friends were also highlighted. *“Who will finally assess the indicators, who will answer the questions and in what circumstances will the questions be asked. There needs to be a system which with honest assessment can be made by people with intellectual disabilities, their friends and family members and staff. Properly prepared group interviews with extra independent support for people with intellectual should be established. If not, any indicator can be abused”.*

This leads us to the second aim of the project – a proposal for converting the draft framework and indicators into a tool (or set of tools) that could be used to evaluate the quality of disability support services. This proposal will be set out in the final section of the report below.



## Revised framework, indicator list and potential sources of evidence



represents a summary of the quality Framework used to organise the proposed indicators.

The full list of indicators within each dimension (outcomes, practices, service and staff team level structures and processes, and organisational structures and processes) are listed in Table 3 below.

It is important to recognise that this list is not a measure or a checklist for assessing quality per se but a set of indicators that would indicate good quality and as such serves as a sensitising tool to increase awareness of what service providers should be thinking about. The next stage is to develop a range of measures and tools that can be used to guide people (in a range of different roles) to assess how well a service might be achieving these indicators. There are a number of existing tools which were identified as part of this review that could be drawn on to help develop such guidance and tools. It is likely that there needs to be a “toolkit” of different measures and tools that can be tailored to specific services and individuals with disabilities rather than one set tool to be used in all settings.

However, there are many advantages to having a consistent set of tools that can be used in different organisations, countries etc., not least the fact that this would allow comparison and benchmarking and monitoring of many aspects of the UNCRPD and other human rights conventions. This would also require some element of compulsory monitoring, but one could create a minimum dataset from the indicators that had to be reported. The option to create a dashboard such as the UNICEF Transmonee or a data analysis/comparison tool such as exists for the EQUASS measure or Adult Social Care Outcomes Toolkit, could be considered further down the line.

Drawing on the literature reviewed to date, potential sources of information to assess the indicators is likely to include:

- Observation of the lived experience of people, the environment, staff support.
- Getting the views of people who use the service and their families (e.g., by survey or interview).
- Collating the views of staff about their experiences and the support they receive from their organisation to do their job in line with the framework.
- Reviewing planning and reviewing processes being used by the organisation.
- Talking to managers and senior managers about how things happen in the organisation, how they assess quality internally, what plans they have for improving quality etc.



The first of these is particularly important if the aim is to develop a framework and toolkit that will ensure the experiences of all people with disabilities are included, even those with the most severe intellectual disabilities (Mansell, 2011). However, this is also the more challenging element to implement as it requires careful operationalisation of the objective indicators and definitions of what good (and poor) services would look like. Fortunately, there are a number of tools with administration guides that already exist that can help explore potential formats for doing this.

Figure 3 Summary of proposed framework for measuring the quality of disability services

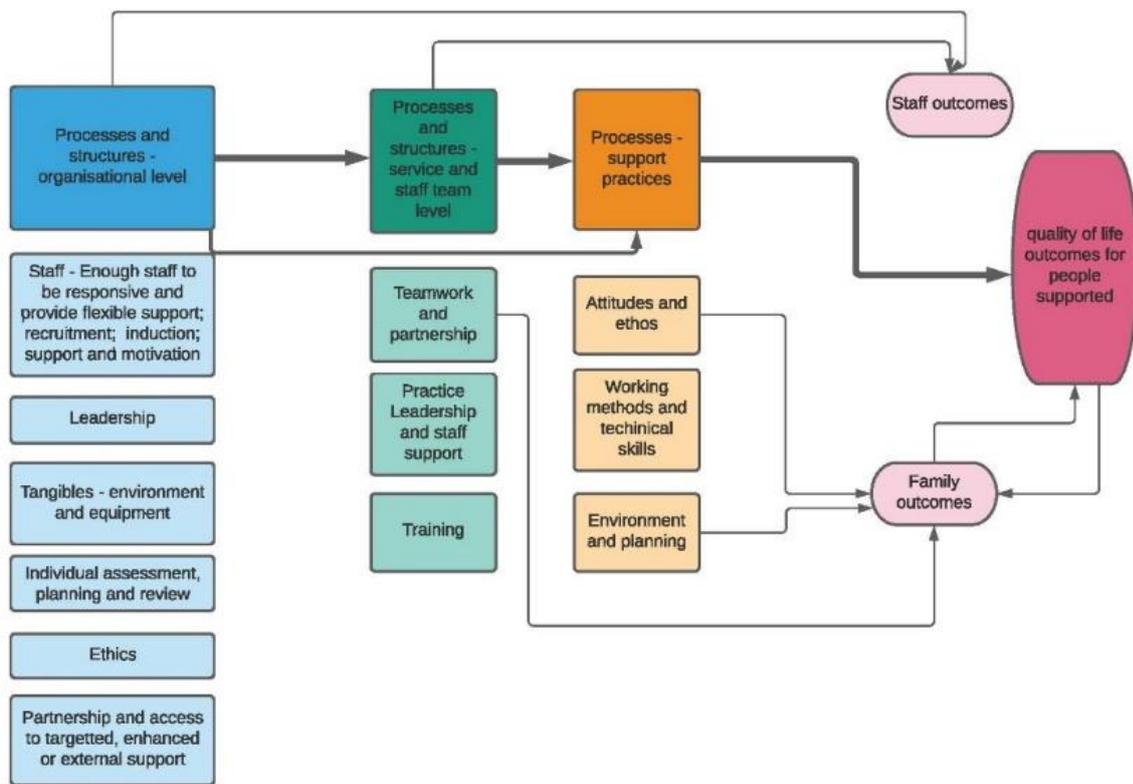


Table 3: Final list of indicators, following stakeholder consultation.

Outcomes at the level of an individual		
Quality of life domain	Self-reported indicators - what we would like the people in receipt of services to say?	Objective indicators – what would we see and hear?
<b>Personal Development (including meaningful occupation)</b>	<ul style="list-style-type: none"> <li>I have things to do during the day that allow me to use the skills I already have and things that I am interested in and make me happy. This might include having a job, doing voluntary work, leisure, looking my own home and garden.</li> </ul>	<ul style="list-style-type: none"> <li>Individuals are engaged in a range of activities, tasks and interactions that span different areas of life (e.g., employment, education, household, gardening, leisure, social).</li> <li>Individuals have the opportunity and support to demonstrate what they can already do (their competence) and therefore experience self-esteem.</li> <li>Individuals appear to want to engage in the activities offered to them – they take the opportunities offered by staff and may even be clearly showing enjoyment.</li> </ul>
	<ul style="list-style-type: none"> <li>I can learn new skills and knowledge and become more independent - at home, at school or college, at work and in the community.</li> </ul>	<ul style="list-style-type: none"> <li>Individuals participate in new activities and experiences. They receive just enough help and support to experience success and therefore to develop their skills.</li> </ul>
	<ul style="list-style-type: none"> <li>I can try new things and have new experiences, even if they may be a bit risky.</li> </ul>	<ul style="list-style-type: none"> <li>Individuals participate in more complex activities and tasks, for example, that involve using gas or electrical equipment. These are adapted in a way that minimises risk and increased participation.</li> </ul>
<b>Interpersonal relationships</b>	<ul style="list-style-type: none"> <li>I feel staff like me and want to work with me.</li> </ul>	<ul style="list-style-type: none"> <li>Interactions between staff and those they support are observed to be warm and respectful.</li> </ul>
	<ul style="list-style-type: none"> <li>I feel staff understand me and what I need and like</li> </ul>	



Outcomes at the level of an individual		
Quality of life domain	Self-reported indicators - what we would like the people in receipt of services to say?	Objective indicators – what would we see and hear?
	<ul style="list-style-type: none"> <li>Staff treat me with kindness and are helpful and friendly. They encourage me and use positive language.</li> </ul>	<ul style="list-style-type: none"> <li>Staff appear to enjoy working with individuals.</li> <li>Staff use positive language and work in a way that shows understanding of people’s needs and skills and respect for people’s preferences.</li> <li>Individuals appear to be enjoying the company of their staff.</li> </ul>
	<ul style="list-style-type: none"> <li>I can see my family when I want to. I can visit them, and they can visit me.</li> </ul>	<ul style="list-style-type: none"> <li>Individuals can, and do, see their family on a regular basis.</li> <li>Family can visit at any time.</li> <li>People with disabilities are supported to be part of their family network, events etc. (if family contact is positive, respectful and in line with known wishes of the individual).</li> </ul>
	<ul style="list-style-type: none"> <li>I live with people I get on with and want to live with.</li> </ul>	<ul style="list-style-type: none"> <li>Individuals have members in their social networks that are not paid staff and immediate family.</li> <li>Individuals experience friendly interactions with the people they live with. They appear to like each other and are supported to interact in positive ways.</li> <li>They access opportunities to meet new people and develop shared interests with others. This includes a mixture of people with disabilities and people without disabilities.</li> <li>Individuals are supported to maintain friendships. They see their friends regularly and have the possibility of living with</li> </ul>
	<ul style="list-style-type: none"> <li>I have friends and get to see them whenever I want to.</li> </ul>	
	<ul style="list-style-type: none"> <li>I can have a boyfriend/girlfriend/partner if I want to.</li> <li>I can have a family of my own if I want to.</li> </ul>	
	<ul style="list-style-type: none"> <li>I feel I am loved and treated well by those who are important to me.</li> </ul>	



<b>Outcomes at the level of an individual</b>		
<b>Quality of life domain</b>	<b>Self-reported indicators - what we would like the people in receipt of services to say?</b>	<b>Objective indicators – what would we see and hear?</b>
	<ul style="list-style-type: none"> <li>I can show affection to others and can care about and care for other people, pets, etc.</li> </ul>	<p>friends. If they develop a special or intimate relationship with someone this is encouraged and supported.</p> <ul style="list-style-type: none"> <li>Individuals are treated with warmth and respect by most of those they come in contact with.</li> <li>Individuals have the opportunity and support to show and receive affection to/from friends and family.</li> <li>Individuals have the opportunity and support to help and do things for other people or to look after their children, pets, etc.</li> </ul>
<b>Rights (human and civil)</b>	<ul style="list-style-type: none"> <li>I have a private space where I can be alone or with visitors when I want to be</li> <li>People knock on the door before they come into my room.</li> </ul>	<ul style="list-style-type: none"> <li>Individuals have a private space in their home where they can be alone or with their visitors.</li> <li>Staff and the people they live with, show respect for people’s privacy, knock on the door and wait to be invited in, or check someone’s non-verbal communication to see if it is ok to enter.</li> </ul>
	<ul style="list-style-type: none"> <li>I can use the bathroom in private.</li> <li>I am treated with dignity and respect.</li> </ul>	<ul style="list-style-type: none"> <li>Individuals can close their bedroom and bathroom door when they are in there.</li> <li>Staff ensure that people have privacy when engaging in personal care related tasks.</li> <li>Staff do not talk about an individual’s more intimate needs (e.g., personal care needs) in front of other staff, people supported or visitors.</li> </ul>
	<ul style="list-style-type: none"> <li>People show respect for my belongings and personal information.</li> </ul>	



<b>Outcomes at the level of an individual</b>		
<b>Quality of life domain</b>	<b>Self-reported indicators - what we would like the people in receipt of services to say?</b>	<b>Objective indicators – what would we see and hear?</b>
	<ul style="list-style-type: none"> <li>I can vote in elections</li> <li>I feel I contribute to my local community in some way.</li> <li>I have the opportunity to represent others and influence how things are done in my service or in my community.</li> </ul>	<ul style="list-style-type: none"> <li>People are supported to be active citizens in their community – for example, they are supported to vote, to volunteer, to represent others in civic duties etc.</li> </ul>
	<ul style="list-style-type: none"> <li>I can access all parts of the community that I want to visit – I can use public transport and get into buildings without any problem.</li> </ul>	<ul style="list-style-type: none"> <li>The individual can access all the areas of the community that it is important to and for them to access. They can use public transport and the same facilities as others.</li> </ul>
	<ul style="list-style-type: none"> <li>I have the right to complain and information about how to do this is provided to me in a way that I understand.</li> </ul>	<ul style="list-style-type: none"> <li>The individual or their advocate or other representative can and know how to make a complaint should this be necessary.</li> </ul>
<b><i>Social inclusion (community presence and participation)</i></b>	<ul style="list-style-type: none"> <li>I live in an ordinary house in an ordinary street.</li> </ul>	<ul style="list-style-type: none"> <li>The house that the individual lives in is an ordinary house in an ordinary street. It is not identifiable as “a service” from outside, is not clustered with other houses occupied by only individuals with disabilities and is similar in size and nature to those in which people without disabilities live locally.</li> </ul>
	<ul style="list-style-type: none"> <li>I do things outside of my home, participating in activities, accessing community facilities etc.</li> </ul>	<ul style="list-style-type: none"> <li>Individuals have the opportunity and support to access a range of activities and facilities in the local community and more widely.</li> </ul>
	<ul style="list-style-type: none"> <li>I feel I belong and am a valued member of my community - People recognise me, talk to me and use my name when I meet them in the community. I am invited to join in community events. I contribute to my local community.</li> </ul>	<ul style="list-style-type: none"> <li>Individuals are not just present in the community but are actively participating in activities with and without other people without disabilities.</li> </ul>



Outcomes at the level of an individual		
Quality of life domain	Self-reported indicators - what we would like the people in receipt of services to say?	Objective indicators – what would we see and hear?
		<ul style="list-style-type: none"> <li>• Individuals are recognised by others they meet and referred to by name.</li> <li>• Individuals are treated as if they are welcome at community events and facilities.</li> <li>• Individuals are invited to attend important community events</li> <li>• Individuals have the opportunity to contribute to their local community and to be seen as a valued member – e.g., through volunteering, raising money for charity etc.</li> </ul>
<b>Self-determination/ autonomy</b>	<ul style="list-style-type: none"> <li>• I have choice and control over the big things in life – where I live, who I live with, where I work, how I spend my money, who provides my support and what they help me with.</li> </ul>	<ul style="list-style-type: none"> <li>• Individuals are offered the opportunity and supported to express preferences and make choices about day-to-day aspects of their lives.</li> <li>• Staff use appropriate communication to support choice and respect people’s decisions.</li> <li>• People’s choices and preferences guide what staff do rather than staff preferences and agendas.</li> <li>• People are helped to understand and predict what their day will be like.</li> <li>• Individuals are supported to understand what is involved in bigger life decisions, with information provided in an accessible way.</li> <li>• Where people might find it difficult to make such decisions, services ensure that the person’s will and preference,</li> </ul>
	<ul style="list-style-type: none"> <li>• I have control over my day-to day life – what I do, where I go, what I eat and drink, when I do things, how I do things.</li> </ul>	
	<ul style="list-style-type: none"> <li>• I am provided information about choices, decisions or opportunities in a form that I understand.</li> </ul>	
	<ul style="list-style-type: none"> <li>• I have a way to communicate my needs, wishes and decisions that works for me.</li> </ul>	
	<ul style="list-style-type: none"> <li>• People listen when I tell them or show them what I want.</li> </ul>	
	<ul style="list-style-type: none"> <li>• I have help (e.g., an advocate), if I need it, to let others know what I want and need.</li> </ul>	



<b>Outcomes at the level of an individual</b>		
<b>Quality of life domain</b>	<b>Self-reported indicators - what we would like the people in receipt of services to say?</b>	<b>Objective indicators – what would we see and hear?</b>
	<ul style="list-style-type: none"> <li>I attend meetings about my care and support and am involved in planning my life and my support.</li> <li>I get help to achieve the goals I want to achieve.</li> <li>I am treated as an individual.</li> </ul>	<p>based on experience of supporting the individual over time as well as their previous choices and decisions, is used to guide decisions.</p> <ul style="list-style-type: none"> <li>Individuals have access to independent help such as an advocate to ensure their views are heard.</li> <li>Individuals are involved in a meaningful way in identifying goals and aspirations during planning processes.</li> <li>Individuals are supported to be attend and participate in their planning meetings.</li> <li>People are treated as individuals rather than being seen as part of a group of “residents” or “service users”. They are not “forced” to do things with others because of how the service is organised.</li> </ul>
<b>Material well-being</b>	<ul style="list-style-type: none"> <li>I live in a home that is right for me – it is adapted to my needs and I can afford it.</li> <li>I own or rent my own home/ have a tenancy agreement that means I am secure in my living arrangement.</li> <li>I have a key to the place where I live and I get to use it.</li> <li>I have the things around me that are important to me.</li> </ul>	<ul style="list-style-type: none"> <li>The house that the individual lives in is adapted to their needs, homely and in good repair.</li> <li>The person’s housing situation is secure – they are not at risk of not being able to pay their rent or of eviction for any other reason.</li> <li>The person has a key for their house and is supported to use it.</li> <li>The person’s home is personalised, decorated in a way that is in line with the</li> </ul>



Outcomes at the level of an individual		
Quality of life domain	Self-reported indicators - what we would like the people in receipt of services to say?	Objective indicators – what would we see and hear?
	<ul style="list-style-type: none"> <li>I have enough money to afford the things I need and sometimes to buy things that are important to me.</li> <li>I can afford to participate in the leisure and social activities that I want to do.</li> <li>I can go on outings and on holidays.</li> <li>I have access to transport in order to access the community, education, work.</li> </ul>	<p>person’s choices and preferences.</p> <ul style="list-style-type: none"> <li>The person has some personal possessions that are important to them.</li> <li>The person has enough income to be able to afford the things they need – pay their bills, enough food and drink.</li> <li>The person has enough money to be able to afford some of the things that are important to them:                             <ul style="list-style-type: none"> <li>New clothes and personal possessions</li> <li>Leisure and social activities</li> <li>Outings and holidays.</li> </ul> </li> <li>The person has access to the transport to access the community, education, work etc.</li> </ul>
<b>Physical well-being</b>	<ul style="list-style-type: none"> <li>I feel well most of the time.</li> <li>My personal care needs are met quickly, and, in a way, I like.</li> <li>I feel clean, comfortable and am happy with how I look most of the time.</li> <li>My environment is safe, healthy and comfortable</li> </ul>	<ul style="list-style-type: none"> <li>Individuals are taking part in their daily routine and activities, appear to be content and well, not in pain etc.</li> <li>Staff respond quickly when people need personal care or support with mobility etc.</li> <li>Individuals appear to be happy with the way this care is provided.</li> <li>Individuals look content and comfortable in their clothes and where they are sitting, etc.</li> <li>The environment is free from hazards, is hygienic (but not necessarily clinical), has</li> </ul>



<b>Outcomes at the level of an individual</b>		
<b>Quality of life domain</b>	<b>Self-reported indicators - what we would like the people in receipt of services to say?</b>	<b>Objective indicators – what would we see and hear?</b>
	<ul style="list-style-type: none"> <li>I eat well and get enough to drink. I have access to healthy food including snacks. The food available is appropriate for my culture/religion.</li> <li>I can exercise and I am able to move around my environment.</li> <li>If I have pain or am unwell people help me.</li> <li>I can get an appointment with a doctor or other professionals when I need to.</li> </ul>	<p>comfortable furniture, which is in general in good repair.</p> <ul style="list-style-type: none"> <li>Individuals have a healthy lifestyle at least most of the time – good diet and some exercise</li> <li>People have access to food and drinks throughout the day, not just at set times.</li> <li>Staff notice when people are in pain or unwell and provide medication or facilitate access to medical care.</li> <li>Individuals are helped to access health care both in a preventative capacity and when needed. This includes physical and mental health support.</li> </ul>
<b>Emotional well-being</b>	<ul style="list-style-type: none"> <li>I am happy with my home, the people I live with, the activities I do and the support I get</li> <li>I feel safe in my home and community (at work, college etc.)</li> <li>I get the chance to succeed and feel good about myself.</li> <li>I am not stressed or anxious most of the time.</li> </ul>	<ul style="list-style-type: none"> <li>Individuals appear to be content and comfortable in their environment and when staff are near them.</li> <li>They take up opportunities that are offered to them and participate at least to some extent in activities and interactions tailored to their needs.</li> <li>People appear willing to interact with staff and their housemates and do not appear to be afraid or avoiding them.</li> <li>People are supported to succeed and experience self-esteem and confidence.</li> </ul>



Outcomes at the level of an individual		
Quality of life domain	Self-reported indicators - what we would like the people in receipt of services to say?	Objective indicators – what would we see and hear?
	<ul style="list-style-type: none"> <li>I have things to do that make me happy and calm.</li> </ul>	<ul style="list-style-type: none"> <li>People appear calm and happy most of the time. They do not seem anxious or worried.</li> <li>They have a way of knowing what is happening and the environment is adapted to reduce stress, overarousal or anxiety.</li> <li>Staff work in an organised, calm and gentle manner</li> <li>People have access to preferred or calming activities, familiar items and therapy (if appropriate) as needed.</li> </ul>

Staff outcomes	
	Staff feel valued and supported by their organisation.
	Staff feel safe and that their well-being is ensured by the organisation.
	Staff enjoy their job and working with the people they support.
	Staff are committed to the organisation and are not considering leaving.
	Staff feel they are involved in decisions related to the service/organisation, in monitoring and in quality improvement.
	Staff feel that their views are listened to and are clear why decisions have been made.
Family outcomes (where appropriate and possible)	
	Family members feel connected to their relative and involved in their lives.
	Families feel listened to and respected.
	Families have peace of mind/trust the service.



	Families feel the person is achieving good outcomes/is happy etc.
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<b>Support Practices – what would we see or what would people tell us about the support they receive and their staff.</b>	
<b>Attitudes and ethos</b>	
<b>Person-centred</b>	Staff put the person they support at the centre of their activity, seeing people as individuals.
<b>Empathy</b>	Staff understand people’s needs and the things that are important to and for the person. They adapt their approaches to respect people’s needs and preferences.
<b>Reliability</b>	Staff are reliable, trustworthy, come when expected etc.
<b>Dignity</b>	When people need personal care, this is done with dignity and in a timely manner. Privacy is respected and maintained.
<b>Positive interactions</b>	Staff are positive, warm and respectful in their interactions. They work on the basis that people can do things, have skills, are valued. They work on the basis that the environment is someone’s home and not just their workplace (if appropriate).
<b>Working methods and technical skills</b>	
<b>Enabling support</b>	Staff provide support that enables people to participate in all aspects of their lives and have control. People are engaged in a wide range of meaningful activities and relationships that lead to maintenance of, and improvements in, quality of life.
<b>Effective communication</b>	Staff use the methods of communication that work for the individual(s) they support. Verbal means of communication are accompanied by environmental cues and non-verbal forms of communication to support understandings and processing.
<b>Responsiveness</b>	Staff notice and respond when people need support e.g., for personal care, to have their physical needs met, for help to participate etc.
<b>Predictability and supportive environments</b>	Staff provide an environment that reduces anxiety and stress through the use of structure, helpful routines, and consistent support, is accessible and supports engagement, independence and autonomy and responds to people’s physical or sensory needs.
<b>Supporting independence and skills</b>	Staff identify opportunities, facilitate access and provide support for people to acquire new knowledge and skills; goals and aspirations are identified, and realisation supported.



<b>Support Practices – what would we see or what would people tell us about the support they receive and their staff.</b>	
<b><i>Supporting self-determination, autonomy and self-advocacy</i></b>	<p>Staff ensure people are involved in choices and decisions related to their lives, including their care and support. This is true for both day-to-day choices and decisions (what to do, how and when to do it, what to eat, daily routines, etc) and bigger life choices and decisions such as where people live, with whom; health care decisions; decisions about relationships, money, etc.</p> <p>Planning meetings are accessible, and people’s involvement is meaningful.</p> <p>Services seek consent for changes to care and support, using whatever means are necessary to support understanding and decision making. However, they are also able to ascertain will and preference where needed.</p> <p>Where restrictions to an individual’s independence, control and choice are required this complies with relevant legislation and any restrictions are justified, kept to a minimum and carried out sensitively.</p> <p>Staff support individuals to develop the skills they need to advocate for themselves (e.g., to ask for information in adapted formats etc.).</p>
<b><i>Supporting Relationships</i></b>	<p>Staff support people to maintain contact with their family, to access opportunities to meet new people and make friends and to maintain existing friendships, in a way that works for each individual.</p>
<b>Environment and Planning</b>	
<b><i>Information</i></b>	<p>Individuals are provided with information about their rights and associated processes (e.g., how to complain), support, schedules, activities and appointments in a way that is accessible to them and with the support they need to read or understand them.</p>
<b><i>Assessment, planning, and review</i></b>	<p>Processes are in place at a service or individual level to ensure that assessments of individual needs, skills and preferences happen and are updated, that people are supported to be involved in the development of their goals and plans and that the person’s support circle is involved.</p>
<b><i>Tangibles - equipment</i></b>	<p>People and staff have access to equipment that promotes the engagement of individuals in all aspects of their lives – this might include communication aids, mobility aids, adapted kitchen equipment, or just generic equipment that meets the specific needs of individuals – e.g., a long-handled duster so they can clean their own shelves). It can be equipment that allows risks to be managed (e.g., a kettle cradle) etc. or increases accessibility of tasks and activities e.g. wheelchair tables, adjustable workbenches etc.). It can even be creative solutions using everyday equipment.</p>



<b>Processes and Structures: Ensuring staff have the skills and motivation to implement these practices and ensure quality of life outcomes for individuals supported are realised</b>	
<b>Service/staff team level – what would we see if we visited or reviewed the service or organisational documentation, processes and systems</b>	
<b>Teamwork and partnership</b>	<ul style="list-style-type: none"> <li>Staff work as a team, providing consistent support, reflecting together, and supporting each other. They also work collaboratively with other members of the individual’s circle of support.</li> </ul>
<b>Leadership and support</b>	<ul style="list-style-type: none"> <li>Staff receive regular supervision which includes reflection on their practice and user outcomes.</li> <li>Regular team meetings occur which enable the team to work together consistently with a clear focus on the quality of life of the people they support, reflecting and problem solving.</li> <li>Staff support is organised in a way that maximises their ability to respond to people needs and to provide support where and whenever people need it. There is a clear and accessible plan of who is providing support, when and for what.</li> <li>Staff receive coaching, feedback, and the support they need to further develop their skills in situ</li> <li>Staff are supported to understand how national and organisational policies, procedures etc should be applied to the individuals that they support.</li> <li>Front-line managers show by actions and words that they prioritise the quality of life of the people supported as well as the well-being of staff.</li> </ul>
<b>Training</b>	<ul style="list-style-type: none"> <li>Staff receive the training they need to be able to provide support in line with the practices identified above and the needs of the individuals they support. They are encouraged to refresh and update their skills regularly.</li> </ul>
<b>Organisational level</b>	
<b>Leadership</b>	<ul style="list-style-type: none"> <li>There is a clear written description of the Mission, vision and values of the organisation and senior managers show understanding and commitment to this in their actions, priorities, what they monitor and pay attention to, etc.</li> <li>The organisation mission, vision and values are in line with human rights policy and community-based, person-centred practice in promoting better outcomes for individuals. They focus on equal opportunities, equal treatment, freedom of choice, self-determination and participation.</li> <li>Senior managers understand and provide support for the practices and processes that produce better outcomes for individuals.</li> <li>The Mission, vision and values are communicated clearly to employees across the organisation.</li> <li>Policies and systems (e.g., monitoring systems, recruitment processes, promotion etc.) are in line with the mission, vision and values.</li> </ul>



Processes and Structures: Ensuring staff have the skills and motivation to implement these practices and ensure quality of life outcomes for individuals supported are realised	
	<ul style="list-style-type: none"> <li>• The organisation has a system of monitoring, reviewing, learning and improving the nature and quality of the support provided. This focuses on ensuring good outcomes of individuals supported, not just meeting minimum standards.</li> <li>• The roles of staff at different levels is are clearly defined and reviewed regularly.</li> <li>• There is a clear system and a process for gaining the views of the people they support and of staff and families including a clear and accessible system for suggestions, compliments and complaints.</li> </ul>
<b>Tangibles - Environment and equipment</b>	<ul style="list-style-type: none"> <li>• Community based - the organisations provide (or is clearly and robustly working towards providing) all services in the community and not through institutional, congregated, segregated or clustered models of provision– e.g., support is provided in the person’s own home, or to access the same facilities and opportunities available to others in the community for the most part.</li> <li>• Accessibility and information                         <ul style="list-style-type: none"> <li>○ environments are accessible in terms of physical environment, adapted to the needs of the individuals supported.</li> <li>○ services are located close, or with easy reach by public transport, to local facilities and activities.</li> <li>○ buildings are well maintained, and repairs carried out promptly.</li> <li>○ the organisation provides information in a way that is accessible and tailored to the people they support – about the services available, their rights, the support they would receive, their responsibilities etc.</li> </ul> </li> <li>• Equipment - the organisation supports services and individuals to obtain the equipment that is needed to ensure the participation and involvement of individuals in all elements of their lives. This might be disability specific equipment but may also be generic equipment that makes a task or activity easier for someone.</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>• <i>Responsiveness</i> there are ENOUGH staff available to respond when people need help and support.</li> <li>• <i>Flexibility of support</i> – the organisation of staffing allows flexibility to meet changing or fluctuating needs of individuals supported</li> <li>• <i>Recruitment:</i> <ul style="list-style-type: none"> <li>○ Assurance - the organisation recruits’ staff that are committed to the work they do and care about the people the support, families, and the work they will do.</li> <li>○ Qualifications - the organisation recruits’ staff with the appropriate qualifications where these exist. Alternatively, they attempt to identify staff with the right attitudes and provide a</li> </ul> </li> </ul>



Processes and Structures: Ensuring staff have the skills and motivation to implement these practices and ensure quality of life outcomes for individuals supported are realised	
	<p>comprehensive training programme for staff across the organisation.</p> <ul style="list-style-type: none"> <li>○ Diversity - the organisation implements inclusive practices in recruitment and staff support but also pays attention to the cultural needs of those being supported and attempts to match staff to client needs and preferences, where possible.</li> <li>● <i>Induction</i> – new staff are introduced to the Mission, vision, values, and practices of the organisation early in employment, with emphasis placed on the service being there to meet the needs and improve the outcomes of the people who access it.</li> <li>● <i>Support for staff</i> <ul style="list-style-type: none"> <li>● A system for recognising and responding to staff performance exists.</li> <li>● Staff outcomes are valued and supported by the organisation including:                             <ul style="list-style-type: none"> <li>○ providing physical and emotional support for staff in a range of contexts.</li> <li>○ staff have opportunities and support to learn, develop and advance in knowledge, skills and career.</li> <li>○ staff health and safety is ensured in line with legislation and good practice.</li> <li>○ adequate wages and benefits.</li> </ul> </li> </ul> </li> </ul>
<b>Individual Assessment, Planning and Review</b>	<ul style="list-style-type: none"> <li>● The organisation has a process for assessing and documenting the needs, skills, and preferences of each person they support.</li> <li>● There is a secure way of sharing this information with those who provide support.</li> <li>● The organisation has a clear system for helping individuals identify their personal goals and aspirations and reviews these regularly to make sure that people are realising these goals/aspirations.</li> <li>● Individuals are supported to be as involved as possible in the development of any plans for their care and support.</li> </ul>
<b>Ethics</b>	<ul style="list-style-type: none"> <li>● The organisation provides services based on trust, dignity, confidentiality and honesty.</li> <li>● There is a clear system for ensuring that client and staff information is kept safe at all times. The organisation has clear procedures for and evidence of protecting people they support any form of abuse or mistreatment of those supported.</li> </ul>
<b>Partnership and Access to targeted,</b>	<ul style="list-style-type: none"> <li>● The organisation helps the people they support to access advocacy, employment support, financial and legal advice, healthcare, mental health services and other professionals as needed, to ensure that their needs are met in a holistic way.</li> </ul>



**Processes and Structures: Ensuring staff have the skills and motivation to implement these practices and ensure quality of life outcomes for individuals supported are realised**

***enhanced or external support***

- The organisation works in partnership with relevant stakeholders to support the organisation to achieve its vision and mission and to ensure consistency and reliability of services for the individuals supported. This includes, but is not limited to, working with:
  - Families to ensure they feel involved, empowered, and confident in the support their relative is receiving and to ensure that support provided is consistent across different environments.
  - Outside agencies to ensure that people they support experience social inclusion, personal development, employment and self-determination (including capacity and decision making) and have access to the same facilities, opportunities and experiences as everyone else.



## Proposal for future development of a framework to measure the quality of services for persons with disabilities

The literature review described above, identified a small number of publications that focused on the development quality frameworks or indicators in different fields (Mental Health Commission, 2005; Lee and Park, 2018; Doody et al., 2019; National Disability Insurance Agency, 2015; Sayal et al., 2012; Rehabilitation Research and Training Center on HCBS Outcome Measurement, 2021). These publications outlined a number of different stages and elements that have been used in the development of quality frameworks and indicators, including:

- Literature review
- Delphi/ modified Delphi process
- Stakeholder consultation – focus groups, surveys or interviews. Sometimes more general workshops were used, or people/agencies were asked to pilot the frameworks/ indicators and provide feedback
- Preference/ importance testing/ field testing.
- “cognitive testing” – reliability, validity, consistency etc. (more important for the development of specific measures).

The current research has conducted elements of the first three of these, conducting a review of the literature, stakeholder consultation and a modified Delphi process to develop the draft Framework with an associated list of indicators, as outlined above. The next stage of the development process which is expected to involve several European countries should ideally include three elements:

1. **Testing out the framework and indicators** as it currently stands with a small group of different types of service providers in a number of countries with different welfare / social care systems. Initially this would be as a framework to guide their internal evaluation (as a sensitising tool) but would also explore how current systems used for measuring quality might be relevant or might need to be adapted.
2. **Develop a comprehensive measurement toolkit** that could be used to gain the specific information needed to judge the quality of a service against the indicators and the domains/ dimensions. This would involve reviewing additional literature focused on measures and tools (not just frameworks and indicators) and would involve consultation with additional groups of stakeholders. How well existing tools related to the different dimensions, domains and indicators of the framework would need to be mapped and gaps identified. Some of this work has already been done as part of the current project. However, a wider remit would need to be taken to ensure individual measures and tools are not missed, especially from different languages and social care systems. In addition to drawing on published literature, a wider consultation across



social care systems to identify potentially useful measures and tools would be helpful and to gather information about some of the challenges of implementing the framework in practice and how these might be overcome. Following the collation of existing measures and the development of any new measures, these would be brought together into an online measurement toolkit with guidance produced for their use. The emphasis would be on creating an inclusive and comprehensive set of measures at this stage. Guidance would focus on different audiences and how they could use the toolkit to assess the quality of services. Audiences might include service providers themselves, disabled people, family carers, inspection bodies, municipalities, regional authorities, ombudsman etc.

3. The third element would be to **field test and conduct cognitive testing for the framework and associated toolkit**. This would involve two core elements:
  - a. recruiting as many individuals with disabilities, families, staff as possible to complete each individual tool/measure to test its validity and reliability (where this is not already available)
  - b. recruiting service providers and potentially other stakeholders such as municipalities or local/regional authorities to participate in administering the whole framework and complete measurement toolkit as an overall assessment of the quality of their service with external validation of the quality.

The aims of this element would be to:

- a. Identify the most useful and valid measures with which to assess service quality against the framework.
- b. To explore similarities and differences between diverse evaluators.
- c. To eliminate indicators that were found not to be relevant or not reliably assessed by evaluators.
- d. To identify indicators that were more difficult to evidence and where specific guidance or training was needed.
- e. To identify a minimum dataset of indicators that could be useful to provide evidence of the realisation of the UNCRPD for ALL people with disabilities and of the quality of community-based social care services.
- f. To explore the feasibility and sustainability of the framework going forward – interviews would focus on how service providers, municipalities and regional/local authorities, families and other relevant stakeholders, have used the Framework and associated measurement toolkit, whether they would continue to use it and what support would be needed for them to do so.



This final element would be the most extensive. In addition to the research costs themselves, it would require **the development of data capture tools** that people could use in different languages and would require funding for translation, networking, technical assistance, and a designated team to monitor how the framework and indicators are being used and provide training and support where needed. However, there are some well-established teams with sound experience of doing such research. A collaborative approach to carrying out this work effectively would be needed.

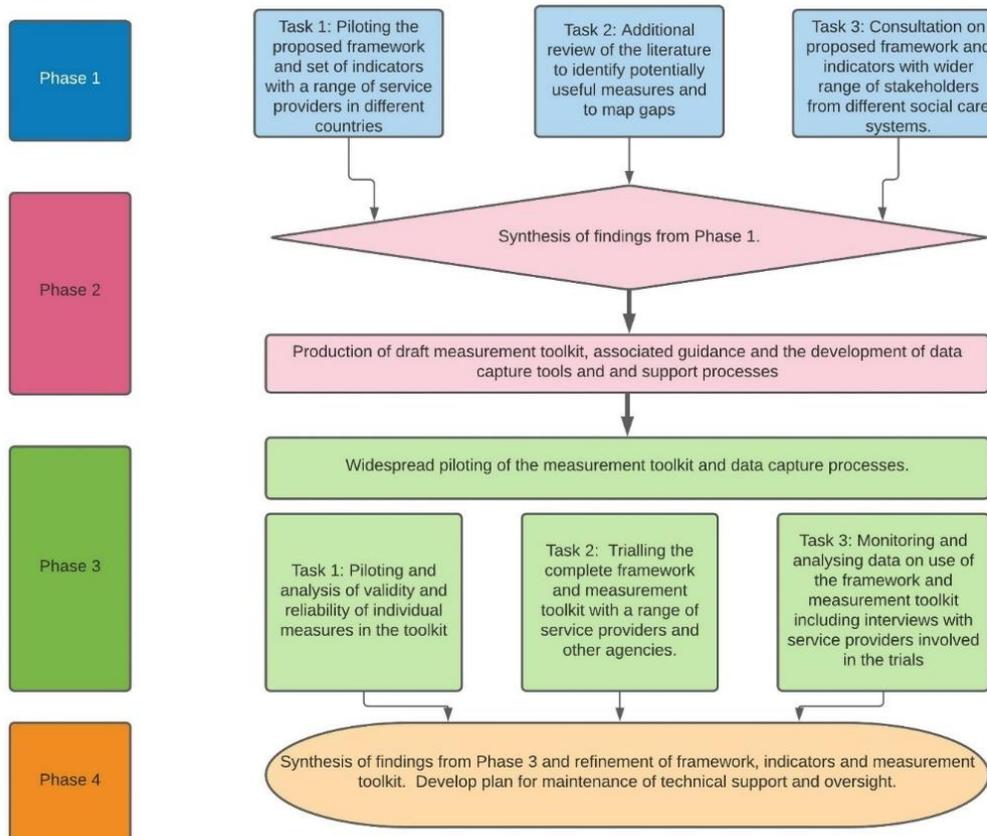
**Figure 4** summarises the phases and tasks recommended for the next stage of developing the Framework.

Following the consultation process involved in preparing and revising this framework several organisations and international colleagues have expressed interest in being involved in the further testing and development of the Framework. One organisation has even identified the funding and resources they would need to do so. This is not only a sign of how useful they felt the framework was but of their commitment to being involved in its development overtime.



Figure 4 Summary of recommended process to develop the Disability Service Quality Framework

Summary of recommended process for the further development of Disability Service Quality Framework



## Conclusions

- The literature review and expert consultancy explored the models of service quality used in a range of different welfare systems and identified a potential framework and a set of associated indicators.
- There were differences between countries in terms of formal and informal systems of measuring the quality of services. However, most of the countries investigated appear to have the assessment of service quality set out only as an overarching objective in legislation, rather than with definitions or methodologies specified. Where quality standards existed, they typically comprised rights, participation and self-determination, complaints, service management, and emergency situations. In the countries in which a set of quality indicators was applied, the focus was predominately on structures and processes rather than on individual outcomes.
- Donabedian's Structures-Process-Outcomes model was found to be the most commonly used framework for conceptualising service quality. Although the focus of this framework is primarily on outcomes, the importance of assessing the structures and processes at work in order to understand how to improve quality, is highlighted by Donabedian and others.
- In terms of conceptualising outcomes, this research used the framework of Quality of Life as a starting point and identified the Framework set out in 2002 by an International consensus led by Schalock as the most useful one to use for the purpose of this study. It was felt that this Quality of Life framework acts as a sensitising notion – i.e., it helps service providers to understand what they should be working towards helping people achieve, at the same time as ensuring they focus on each individual in a person-centred way.
- The literature review and expert consultation identified twenty frameworks for conceptualising and measuring service quality from across the world, all of which could be mapped at least to some extent to the Schalock et al.'s eight quality of life domain or to some element of structures or processes as defined by Donabedian. The frameworks identified ranged from validated research-based measures to state or national policy documents to standards and indicators used by service users to check service quality.
- Drawing on detailed analysis of these frameworks and measures, as well as the wider literature around what different stakeholders valued in terms of service quality, a set of indicators were identified. For each Quality of Life domain, two sets of indicators have been developed – one focuses on capturing people's subjective experiences and what they would *say* if experiencing a good quality of life. The second is a list of objective indicators that identify what one would *see or hear* during observation,



interviewing staff or reviewing paperwork. Following Donabedian's recommendation, outcomes for staff and families are also considered. Finally, the proposed framework included indicators related to the working practices or care processes that have are associated with improved quality of life outcomes and to the processes and structures that are needed at different levels to ensure provision of successful support for people to experience a good quality of life.

- Feedback from the consultation on the draft set of indicators was overall very positive and was used to produce the final list of indicators and to write the report.
- For the further development of the framework, it is proposed to pilot the current framework and indicators with a group of different types of service providers in a number of countries with different welfare /social care systems followed by developing a comprehensive measurement toolkit for gaining the specific information needed to judge the quality of a service against the domains and indicators. The final element is to field test and conduct cognitive testing on the framework and associated toolkit with the involvement of various stakeholders.



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## Annexes

### Annex 1: Detailed methodology used at each stage

#### Literature review

##### Search strategy

Literature was identified through three different sources:

1. Academic Publication Database search using EBSCO Host, Scopus and Web-of-Science
  - a. using the following string of search terms: Service quality AND Disab\* AND Concept\* OR Defin\* OR Measur\*.
  - b. Citation searches for “Donabedian”
2. General Google search using the same search terms.
3. Authors existing knowledge, academic networks and chapters by co-authors in 2021 book on Quality in Disability Support Services

	Number of papers
Number of peer-reviewed academic papers identified as potentially relevant on title and abstract scan	31
Number of publications identified from other sources (including grey literature)	96
<b>Total identified for possible inclusion</b>	<b>126</b>
Number excluded completely on reading full text	35
Number identified as relevant to introduction/background	11
Number only relevant to research aim 2 in terms of informing methodology for framework development (i.e., they were not related to social care settings or people with disabilities but looked at methodologies for developing frameworks)	6
Number used for detailed country templates (UK, Australia and US and not used in the more general review)	14 (UK) 17 (Australia) 5 (USA) 34 Total
<b>Final number of papers, reports and other documents included in the review of literature on quality frameworks and indicators and data extracted</b>	<b>40</b>



<p>Countries from which literature on Frameworks and Indicators was included</p>	<p>USA Australia UK Ireland Netherlands Sweden New Zealand Lithuania Europe (generally) Serbia Canada Czechia Spain Romania Greece</p>
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Following initial reading of each of the 40 papers identified for inclusion, key elements were extracted into an excel spreadsheet. The following information was extracted from each source where available:

- Publication details.
- Aim of the paper.
- Does paper describe framework of service quality and if so what is this?
- Is outcomes part of this framework and if so is QOL part of the conceptualisation. Which domains are covered?
- Other indicators of service quality.
- What level of quality is being assessed (e.g., internal service audit, inspection processes, etc.)?
- Information on how indicators were developed and stakeholder involvement.
- What definition of service quality is given if any?
- Are indicators mapped to UNCRPD?
- How are the indicators or dimensions measured?
- Other information.

### Country templates



A template was designed for completion by national experts (See Annex 3) and was initially sent to the National Disability Experts who were part of ANED, in the case of European countries. Where no response was gained from the national experts, other contacts were approached, e.g., through EASPD and through Inclusion Europe. Some of the country templates were completed by members of the research team using the information identified in the literature review specific to those countries and then checked with local experts where possible.

The template was available in two formats – a detailed structured form guiding people with a list of questions to answer and a more open, descriptive format, if people felt there was limited information, or they did not have sufficient time to complete the detailed version. Information about the project instructions for completing the template were provided.

The template was designed to collate information on both formal (i.e., embedded in legislation) methods of defining and measuring quality and more informal measures, such as voluntary frameworks used by service providers, or disabled people’s organisations.

It was possible to complete relatively detailed country templates for the following countries (either by disability experts in the country or by members of the research team using their existing knowledge and published documentation):

- Germany
- UK
- Ireland
- Romania
- USA
- Czech Republic
- Finland
- Australia

In addition, some less detailed information was available from country experts and written sources for Sweden, Norway, the Netherlands, Slovenia and Spain. Very little information was available for Slovenia.

The information gathered by the templates was then reviewed and analysed with a focus on how service quality was conceptualised or defined, whether outcomes featured in these conceptualisations and if so which quality of life domains were featured (even if quality of life was not specifically mentioned). The relationships with the UNCRPD were also explored. In addition, analysis focused on how service quality and outcomes are measured and with people with disabilities and other stakeholders have been involved in the development of frameworks and tools.



Finally, innovative frameworks and tools that were in line with the objectives of this research were identified and synthesised into a separate datafile to draw out the dimensions of quality and outcomes included and how quality was measured.



## Annex 2. Mapping of the 20 identified innovated frameworks or tools to the Schalock et al QoL domains

Framework/ tool	Quality of Life domain							
	Personal development	Interpersonal relations	Rights	Social Inclusion	Self-determination	Material well-being	Physical well-being	Emotional well-being
Frameworks where whole domains can be mapped								
Bigby et al. (2014, Australia)	✓	✓	✓	✓	✓	✓	✓	✓
The Quality Cube (Netherlands)	✓	✓	✓	✓	✓	✓	✓	✓
Social Services Quality Standards (Czechia)	✓ Independence (legal)	✓ Social participation	✓ Dignity	✓ Social participation	✓ Choice and control	✓ Material, technical, healthy environment	✓ Personal safety	✓ Safety
ASCOT – Social Care related quality of life (UK and internationally)	✓ Occupation	✓ Social participation and involvement	✓ Dignity	✓ Social participation and involvement	✓ Control over daily life	✓ Accommodation comfortable and clean	✓ Personal cleanliness and comfort Food and drink Personal safety	✓ Personal safety
Changing our Lives Quality of life Standards (UK)	✓ Having a full life Employment	✓ Having a full life	✓ My Voice My home	✓ Having a full life	✓ Being in control of my life My voice	✓ My Home Buying my own support (Employment)	✓ Staying safe Personal care	✓ Staying safe



Framework/ tool	Quality of Life domain							
	Personal development	Interpersonal relations	Rights	Social Inclusion	Self-determination	Material well-being	Physical well-being	Emotional well-being
Personal Outcomes Measure (USA and internationally)	(Goals)	✓ My relationships	✓ My human security	✓ My community	✓ My choices My goals			✓ My human security
National Quality Forum framework (USA)	✓ Employment	✓ Social Connectedness	✓ Human and Legal rights Equity	✓ Community Inclusion	✓ Choice and control	✓ Transport (Employment)		
National Core Indicators (USA)	✓ Employment	✓ Relationships		✓ Community inclusion and belonging Community participation	✓ Choice and decision making	(Employment)		✓ Satisfaction
Home and Community-based Services Outcomes (USA)	✓	✓ Social connectedness	✓ Freedom from abuse and neglect	✓ Social connectedness	✓ Choice and control	✓ (Employment) Transport		
Quality of life Outcomes Domain	✓ [have a job] Have opportunities	✓ Have meaningful	✓ People living in own home in community	✓ Have a job or other valued social roles	✓ Are exercising choice and	[have a job]	✓ Achieving best possible health	✓ Are enjoying a good quality of life



Framework/ tool	Quality of Life domain							
	Personal development	Interpersonal relations	Rights	Social Inclusion	Self-determination	Material well-being	Physical well-being	Emotional well-being
Framework (Ireland)	for personal development and fulfilment of aspirations	personal relationships		Are participating in social and civic life	control in their everyday lives		Are safe, secure and free from abuse	and well being
Frameworks where individual indicators, standards or parts of domains can be mapped								
National standards for Residential services for children and adults with disabilities (Ireland)	✓ Standard 4.4 Educational, training and employment opportunities are made available... promotes their strengths, abilities, and individual preferences	✓ Standard 1.4 Each person <i>develops and maintains personal relationships</i>	✓ Standard 1.1 The rights and diversity of each person are respected and promoted. Standard 1.2 The privacy and dignity of each person are respected Standard 1.7: Each person's complaints and concerns are listened to and acted upon in a timely, supportive and	✓ [Standard 1.4 Each person develops and maintains ... <i>links with the community</i> in accordance with their wishes]	✓ Standard 1.3 Each person exercises choice and control in their daily life in accordance with their preferences. Standard 1.6 Each person makes decisions and, has access to an advocate and consent is obtained in accordance with legislation and current		✓ Standard 3.1 Each person is protected from abuse and neglect and their safety and welfare is promoted. Standard 4.1 The health and development of each person is promoted.	✓ Standard 3.2 Each person experiences care that supports positive behaviour and emotional wellbeing. Standard 3.3 People living in the residential service are not subjected to a



Framework/ tool	Quality of Life domain							
	Personal development	Interpersonal relations	Rights	Social Inclusion	Self-determination	Material well-being	Physical well-being	Emotional well-being
			effective manner.		best practice guidelines.			restrictive procedure unless there is evidence that it has been assessed as being required due to a serious risk to their safety and welfare.
EQUASS (Europe)			✓ Dignity and respect, confidentiality Non-discrimination	✓ Partnerships “full participation and active inclusion of people service ...within the community”	✓ “..Pursue personal goals and aspirations in line with their choices, needs and abilities” Access to advocacy		✓ Protecting people from abuse and misconduct Safety of environment	



Framework/ tool	Quality of Life domain							
	Personal development	Interpersonal relations	Rights	Social Inclusion	Self-determination	Material well-being	Physical well-being	Emotional well-being
					“full participation and active inclusion of people served and representation at all levels in the organisation....”			
Guidance on a Human Rights-based Approach in Health and Social Care Health Services. By Health Information and Quality Authority (Ireland).			✓ Equality (presuming and supporting capacity, communicating respectfully) Dignity (maintaining privacy, supporting peoples preferred lifestyle,	✓ Promoting participation in society	✓ Autonomy Seeking consent Involvement in service evaluation. Participating in decisions		✓ Dignity (meeting basic needs)	



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Framework/ tool	Quality of Life domain							
	Personal development	Interpersonal relations	Rights	Social Inclusion	Self-determination	Material well-being	Physical well-being	Emotional well-being
			minimising restrictive practices) Respect (respecting property and personal information) Fairness, providing relevant information, seeking consent Autonomy (supporting independent living)					
National longitudinal Transition Study (Shrogren et al) USA	✓ Postsecondary education Financial independence Employment	✓ Social relationships			✓ Advocating for needs	✓ Financial independence Housing Employment	✓ Health status Access to services	✓ Perceptions of emotional well-being



Framework/ tool	Quality of Life domain							
	Personal development	Interpersonal relations	Rights	Social Inclusion	Self-determination	Material well-being	Physical well-being	Emotional well-being
						Financial supports Access to services		
Standards New Zealand Health and disability services standard NZS 8134: 2021	✓ Support people to maintain and develop their interests	✓ Supported to participate in meaningful social activities Family involved	✓ Our rights Treated with dignity and respect; confidentiality, free from discrimination and abuse; information in preferred format etc. Can complain	✓ Supported to participate in meaningful community activities	✓ Informed and able to make choices. Can give feedback, ask questions and complain	✓ Environment designed in a way that is safe, accessible and sensitive to needs. Enough space, including bathrooms, etc.	✓ Pathways to well-being (assessment, access to services, medication, nutrition, Protected from abuse Safety Least restrictive options used	✓ Service providers ensure people experience consistency and continuity (esp in transition) Least restrictive practices Satisfaction with activities etc. Cultural needs, values and beliefs



Framework/ tool	Quality of Life domain							
	Personal development	Interpersonal relations	Rights	Social Inclusion	Self-determination	Material well-being	Physical well-being	Emotional well-being
								taken into account
Quality of life impact of services tool (QOLIS) (Europe)	✓ More independent in data to day life. More able to define goals Helped me learn how to look for a job Helped me be able to handle demands of a job	✓ Increase in number of people in regular contact And improve relationships with those close to me, better communicate etc.		✓ Helped identify more opportunities to participate	✓ Defining goals More capable in taking decisions	✓ [improved chance of getting a job]		✓ Feel more satisfied (e.g. with family relationships) Improved confidence
Šiška et al. (Czechia)	✓ Regular leisure, educational, cultural, spiritual activities for service users	✓ Staff friendly and patient Supports social contacts with family and friends	✓ Staff respectful Environment offers privacy	✓ Support to participate in activities in the community	✓ Experiences sense of self control over daily activities Person involved in finding	✓ Suitable and well-equipped, pleasant, comfortable	✓ Health is carefully monitored and evaluated Medical care and specific	✓ Experiences sense of trust Feel supported emotionally Feels safe



Framework/ tool	Quality of Life domain							
	Personal development	Interpersonal relations	Rights	Social Inclusion	Self-determination	Material well-being	Physical well-being	Emotional well-being
					solutions and making decisions		therapies provided nutrition	Satisfaction with services
National Standards for Disability services (Australia)	✓ Services and supports build my strengths and helps reach life goals		✓ Dignity and respect, freedom of expression, freedom from discrimination, provision of information and access to legal advice, advocacy etc.	✓ Meaningful activities and participation in society	✓ Access to advocacy Determination and decision-making (including about support and services)		✓ Being safe minimal restrictive practices Prevent abuse	
NDIS Practice Standards and Quality Indicators (Australia)		✓ Supported to engaged with family and friends and chosen community	✓ Legal and human rights upheld Privacy and dignity Right to Intimacy and		✓ Makes informed choices, exercises control and maximises independence	✓ Participant money and property is secure Can use own money and	✓ Safety, and protection. Medication. Complex health needs met.	✓ Culture, diversity, values and beliefs of individual identified



Framework/ tool	Quality of Life domain							
	Personal development	Interpersonal relations	Rights	Social Inclusion	Self-determination	Material well-being	Physical well-being	Emotional well-being
			sexual expression respected Information communicated in appropriate way Freedom from violence, abuse, neglect exploitation or discrimination.		related to supports provided Access advocate	property as they choose	Safe practices for managing behaviour	and responded to
Person-centred advocacy Vision and Education (USA)	✓ Skills Setting goals	✓ Relationships	[Equity]	✓ [relationships – with local community and environments] Events	✓ Choice and control Setting goals	[employment might be one goal or lifestyle choice]	✓ Health Safety [lifestyle]	[indirectly linked] Satisfaction with lifestyle



**EASPD is the European Association of Service providers for Persons with Disabilities. We are a European not-for-profit organisation representing over 17,000 social services and disability organisations across Europe. The main objective of EASPD is to promote equal opportunities for people with disabilities through effective and high-quality service systems.**



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