





Measuring the Quality of Life Impact of Care, Education and Training

Summary Synthesis Report

September 2022

QUALITY-OF-LIFE IMPACT OF CARE, EDUCATION & TRAINING













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QOLIVET is an Erasmus + funded project aimed at improving the quality of vocational education and training (VET) and community care provision across Europe and raising its impact on the Quality of Life (QOL) of participants.

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The QOLIVET partners are:

- European Vocational Training Association EVTA (Belgium)
- EWORX S.A. (Greece)
- FUNDACION ONCE (Spain)
- <u>REHAB GROUP</u> (Ireland)
- Vocational Rehabilitation Centre of Gaia CPRG (Portugal)
- University Rehabilitation Institute (Slovenia)

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More info on the project is available here: www.qoliserv.eu, www.epr.eu/qolivet/?page_id=4072

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1. Introduction

The focus of the QOLIVET project is on how programmes and delivery mechanisms in community care, and in vocational education and training (VET), impact on the Quality of Life (QoL) of participants. The target audience is any one working in, or participating in, services across the spectrum from community care, and independent living and rehabilitation services, to services focused on developing pre-vocational and vocational knowledge and skills. The QOLIVET project builds on a benchlearning process that has been facilitated and supported by the European Platform for Rehabilitation over a number of years. This process was an exploration of how QoL measures could be used as an indicator to inform the continuous improvement of vocational rehabilitation and training for persons with disabilities.

The purpose of the synthesis report is to provide an overview of current policies and practices to inform the development of a good practice guide, a training course for interested parties, a resource portal and an online measurement tool to allow staff and participants to rate the impact of services on quality of life.

The World Health Organisation's WHOQOL Group provided a definition of QoL which is a useful starting point for a discussion describing quality of life as:

... an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards and concerns. It is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment (WHOQOL Group, 1998; p. 1).

The synthesis report describes the findings of a systematic search for evidence to inform good practice in enhancing the QoL outcomes of services and vocational programmes. Research findings included evidence of how QoL measures have been addressed in policy, valued by funders, measured by providers, detailed in programme specifications, included in quality guidelines, and explored by researchers. This Summary Report provides an overview the full report which is available

Two separate searches were carried out: One focused on vocational education and training and the other explored community care services.

The searches used a framework derived from the the International Association for the Scientific Study of Intellectual and Developmental Disability (IASSIDD) model of QoL to identify the domains and dimensions relevant to both community care and VET (Schalock et al., 2002). The framework comprised the following three domains (second order factors) which were broken down into eight dimensions:

- 1. Personal development with two dimensions; Interpersonal Relations and Self-determination.
- 2. Wellbeing with three dimensions; emotional, physical, and material wellbeing.
- 3. Social inclusion with three dimensions; employability, citizenship, and rights.

The search strategy used to identify relevant documents was iterative in that once a publication was identified, it was reviewed for additional sources that could add value to the review.

The relevance of a publication or article was based on four criteria:

- 1. Did it address the meaning and definition of QoL?
- 2. Did it discuss mechanisms for measuring and monitoring QoL?
- 3. Did it review tools that could be used to evaluate the impact of services?
- 4. Did it consider the challenges in using QoL as a quality indicator of services?

As a result, the documents reviewed in the report covered a wide range of contexts, participant characteristics and service types with a view to developing more effective service mechanisms and appropriate tools to promote to measure outcomes and impact.

This summary report presents the main findings of the synthesis report. Section 2 provides an oveview of the ways in which the concept of QoL has been explored and elaborated over the twenty years since the recommendations of the IASSIDD were published. Sections 3 and 4 explore the ways in which QoL is addressed in community care services and VET. Section 5 discusses mechanisms for developing inclusive learning environments including the application of the principles of Universal Design for Learning (UDL). Sections 6 describes a model for QoL supports. Section 7 discusses the challenges in measuring QoL and Section 8 presents the findings of a review of tools designed to assess QoL for a variety of populations. Section 9 goes into detail on tools devleoped on the basis of the Schalock/Verdugo model of QoL and Section 10 presents some concluding remarks.

2. The Evolution of the Concept of QoL in the Field of Disability

The initial QoL framework, first proposed by the IASSIDD special interest research group (SIRG) (Schalock et al., 2002; Schalock, & Verdugo, 2002), has been updated and refined over the years (Schalock & Verdugo, 2012, Gomez, Schalock & Verdugo, 2021). While the principles proposed by the SIRG maintain their relevance, the content and structure of the model itself have been evaluated and adapted through a number of exploratory studies.

The Factor Structure of the Construct of QoL

A number of studies set out to determine the best way to structure the dimensions of QoL into second order factors. Achieving this has the potential to provide a more easily interpreted and potentially applicable set of characterisations of QoL from the perspective of service providers and researchers.

A path analysis based on data from service recipients identified three clusters of dimensions (Bonham, Basehart, S., Schalock, R et al., 2004). These were:

- Personal Development, Self-Determination, and Rights
- Material Wellbeing and Physical Wellbeing
- Emotional Wellbeing and Interpersonal Relations.

The 'Salamanca' model (Verdugo, Prieto, Caballo, & Pelaez, 2005) consisted of three second order factors:

- Personal Well-Being which consists of four factors: interpersonal relations, emotional wellbeing, personal development, self-determination
- Empowerment represented by two factors: social inclusion and rights

• Wellbeing consisting of physical and material wellbeing

Based on data generated by a large cross-cultural study of QoL indicators, the 'Schalock' model was generated (Schalock, Verdugo, Jenaro, et al., 2005). This is structured in the following way.

- Independence/Personal Competence which consists of two factors: personal development and self- determination
- Social Participation/Integration which is composed of three factors: Interpersonal Relations, Social Inclusion, and Rights
- Personal Wellbeing which comprises of three first-order factors: Emotional, Physical, and Material Wellbeing

This is often referred to as the Schalock/Verdugo model.

The validity of the first and second order factors was explored and the explanatory power of different factor structures assessed (Wang, Schalock, Verdugo, & Jenaro, 2010; Gómez, Verdugo, Arias, & Arias, 2011). A confirmatory factor analysis (CFA) was used to test a number of QoL models.

- Model 1 characterised QoL as a single unidimensional construct with no dimensions.
- **Model 2** comprised the eight correlated factors specified by Schalock and Verdugo (2002) i.e., personal development self-determination, interpersonal relations, social inclusion, rights, material wellbeing, emotional wellbeing, and physical wellbeing.
- **Model 3** proposed that QoL consisted of the eight first-order factors, as listed above and one overall second order factor QoL.
- **Model 4** consisted of the eight first-order factors and three second order factors: personal wellbeing, empowerment and physical and material wellbeing.
- **Model 5** postulated that QoL comprised the eight first-order factors and an alternative set of three second order factors: independence, social integration and personal wellbeing.

The study concluded that there was no need to specify second order factors because the eight correlated first-order factors were found to represent the best fit with the data as long as a valid and reliable instrument was used.

In addition, the authors remarked that self-determination, emotional wellbeing and personal development were particularly reliable indicators and that social inclusion was the least reliable. The other factors were made up of indicators with low to moderate reliability.

It was concluded that while the eight first order factors provide the best explanatory power, the second-order factor loadings could be used to summarize individual QoL ratings of individuals as a weighted average. These could be useful in summative evaluation or as variables in future research studies (Wang, Schalock, Verdugo, & Jenaro, 2010).

On this basis, the model which provides the best lens to identify the domains and dimensions of QoL relevant to community care and VET consists of eight dimensions (Wang, Schalock, Verdugo, & Jenaro, 2010; Schalock, Verdugo, & Lee, 2016). The factors and indicators that were used in the Cross-Cultural Survey of Quality-of-Life Indicators instrument (Schalock, Verdugo, Jenaro, et al., 2005) provide a clear insight into the content and structure of the Schalock/Verdugo model of QoL. These are presented in Table 1.

Domain	Indicators and descriptors
	1. Contentment (satisfaction, moods, enjoyment)
Emotional Well-Being	2. Self-concept (identity, self-worth, self-esteem)
	3. Lack of stress (predictability and control)
	4. Interactions (social networks, social contacts)
Interpersonal Relations	5. Relationships (family, friends, peers)
	6. Supports (emotional, physical, financial)
	7. Financial status (income, benefits)
Material Well-Being	8. Employment (work status, work environment)
	9. Housing (type of residence, ownership)
	10. Education (achievements, education status)
Personal Development	11. Personal competence (cognitive, social, practical)
	12. Performance (success, achievement, productivity)
	13. Autonomy/personal control (independence)
Self-Determination	14. Goals and personal values (desires, expectations)
	15. Choices (opportunities, options, preferences)
	16. Health (functioning, symptoms, fitness, nutrition)
Develoal Wall Daing	17. Activities of daily living (self-care, mobility)
Physical Well-Being	18. Health care
	19. Leisure (recreation, hobbies)
Pights	20. Human (respect, dignity, equality)
Rights	21. Legal (citizenship, access, due process)
	22. Community integration and participation
Social Inclusion	23. Community roles (contributor, volunteer)
	24. Social supports (support networks, services)

QoL as a Hierarchical Construct

Another approach to exploring the validity of QoL factors involved assessing the extent to which they represented the views and priorities of service participants and researchers. Based on the feedback from focus group participants, the extent to which the factors reflected Maslow's (1970) hierarchy of needs was assessed (Elorriaga et al.,2000; cited in Wang, Schalock, Verdugo, & Jenaro, 2010). This study concluded that the QoL domain hierarchy could be specified from highest to lowest as consisting of

- 1. Emotional Well-Being
- 2. Personal Development and Self-Determination
- 3. Interpersonal Relations, Social Inclusion and Rights
- 4. Material Wellbeing
- 5. Physical Wellbeing

A path analysis based on participatory action research data identified the level of perceived satisfaction with each of the QoL factors (Schalock, Bonham, & Marchand, 2000). This provided a similar hierarchy from highest to lowest.

- 1. Emotional Well-Being
- 2. Social Inclusion and Interpersonal Relations
- 3. Personal Development and Self-Determination
- 4. Material Wellbeing and Rights
- 5. Physical Wellbeing

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An analysis of the frequency of reference to QoL in the literature in the field of intellectual and developmental disabilities identified a different hierarchy from highest to lowest (Schalock, Gardner, & Bradley, 2007).

- 1. Physical Wellbeing
- 2. Emotional Wellbeing
- 3. Interpersonal Relations
- 4. Social Inclusion
- 5. Personal Development
- 6. Material Wellbeing
- 7. Self-Determination
- 8. Rights

Analysis of data from a series of focus groups with self-advocates produced a hierarchy based on the participants needs and strengths (Schalock, 2004). The hierarchy from highest to lowest comprised:

- 1. Self-Determination
- 2. Interpersonal Relations and Material Well-Being;
- 3. Personal Development, Emotional Wellbeing, Physical Wellbeing, and Social Inclusion;
- 4. Rights

The QOLIVET project aims to create a framework that makes sense in both the community care and VET sectors and which can be used in mainstream settings within a European context. Consequently, a review of the application of QoL in each of these sectors was carried out as a basis for creating framework that reflects the essence of the Schalock/Verdugo model and provides policy makers, administrators, service providers and evaluators with relevant and interpretable performance indicators (Schalock & Verdugo, 2012; Schalock, Verdugo, & Lee, 2016). Sections 3 and 4 of this report present the findings of this review.

3. The Status of QoL in Community Care Services

Three important trends were revealed at an early stage of the review of the status of QoL in community care services. Firstly, community care was referred to in the literature using a variety of terms including health and social care services, independent living, social care, community living, and community integration. Secondly, the meaning of QoL was strongly influenced by the characteristics of the target participants and the types of services which were the focus of a report or article. Researchers found that health-related quality of life indicators (Hr QoL) (Makai et al, 2014) and social care related quality of life indicators (SrQoI) (Bowling, 2014) needed to be distinguished from each other. In addition, the age of the intended beneficiaries of services influenced the definitions of QoL indicators that were considered relevant (Turid Midjo, & Ellingsen Aune, 2018; National Health Executive, 2017; Wright, 2010). Another important influence on QoL definitions was the type of impairments that were addressed by a service (Connell, Carlton, J. Grundy, A., et al., 2018; Bigby et al., 2014; Bowling, 2014; Mental Health Commission, 2007;). Thirdly, while many services were aimed at facilitating individuals to transition from congregated settings to the community, from school to work, from youth to adulthood, or from care to independent living, other services, particularly those for older people, were designed at maintaining people in their current circumstances.

A Council of Europe review of policy and legislation governing rehabilitation and integration examined mechanisms in eleven member countries and noted that while QoL was frequently specified as an intended outcome of such services, it was only rarely defined. They went on to state that Norway was the only exception (Council of the European Union, 2002).

Quality of life (QoL) outcomes have been brought to the fore in the health and social care sector for a variety of reasons, not least of which is the strong impetus towards de-institutionalisation and away from congregated settings. This has fuelled a substantial interest in exploring the meaning of QoL and in finding the most appropriate approach to measuring outcomes and impact in different settings. Persons with disabilities need access to a range of quality individual supports and services to improve QoL and wellbeing. These supports and services need to be focused on inclusion, self-determination and community living and be based on the quality of life principles of safety, rights, anti-discrimination, person-centeredness, community integration, and responsive services (National Economic and Social Council, 2012).

The three key questions that need to be asked in disability service evaluation are:

- To what extent are persons with disabilities who participate in a support service attaining personal outcomes that contribute to a good quality of life?
- How does a service facilitate participants' reach their self-described outcomes?
- Are personal outcome predictors clearly in use in a service under evaluation? (National Disability Authority, 2019; p.6)

A number of terms were used to refer to the proactive and responsive interventions and services required to enable participants to progress towards their aspirations for an enhanced QoL (National Disability Authority, 2010). These included person-centred services, self-directed support, person directed services, independent living, consumer control, self-determination, self-directed services, consumer-directed services, and individualised funding. All of these approaches are based on the fundamental principle that citizenship for participants is dependent upon each person having choice and control over the resources and supports they need to go about their daily lives (p. 33).

Services need to achieve more positive outcomes as defined by persons with disabilities themselves including 'meaningful' measures of QoL and independence (Keogh, 2010; p. 145). Quality organisations can be characterised as those that compare information on individual progress against recommended QoL standards. Best practice indicates that this be an ongoing process of improving QoL outcomes for participants (Department of Health, 2012).

The European Association of Service Providers for Persons with Disabilities (EASPD) (Cited in National Economic and Social Council, 2012) has proposed a framework for QoL impact of services that could be applied at EU level. The values proposed were dignity, equal opportunities, independent living, participation in, and contribution to, society.

An important imperative for community care services is that they work towards the achievement of a society in which persons with disabilities can access the quality personal social supports and services they need to enhance their QoL. One central strategy in progressing this aspiration is the development of universally designed and accessible public services to support people with disabilities to gain and sustain optimum physical, mental, and emotional wellbeing (Pierce, Kilcullen, & Duffy, 2018)

The Scottish Government published a report on QoL which emphasised the importance of providing people with opportunities to develop and maintain friendships and relationships including romantic, sexual, and long-term relationships (Scottish Government, 2013).

In many jurisdictions, the starting point for responsive person-centred services is an assessment of what a person needs to participate independently in the community. This often includes an assessment of recreational, social and personal development needs, training and education needs, vocational and employment needs and, where appropriate, the needs of family and carers (Keogh, 2010).

The overarching goals of disability services need to balance full inclusion and self-determination with a cost-effective, responsive, and accountable system of support based on the underpinning principles and values of citizenship, self-determination, inclusion, participation, equity, and person-centredness (Keogh, 2010).

There is a strong dynamic towards the development and deployment of broad, community-based services to supplant traditional institutional settings (Ellul, 2020). Examples of this are the European Coalition for Community Living (ECCL) and the Associative Movement of Full Inclusion (Plena Inclusion; http://www.plenainclusion.org/). A central objective of the community living movement is to progress to a model of service that is based on QoL, full citizenship, adaptation to the needs of the person, and community inclusion.

Staff commitment is an essential factor in achieving positive QoL outcomes (McCarron et al., 2019; Chowdhury and Benson, 2011, Mac Domhnaill, Lyons, & McCoy, 2020). Equipping staff with the skills and attitudes required to provide active support is central to linking resource inputs to the quality of outcomes (Felce, 2005). The commitment of community service staff can result in enhanced choice and engagement in leisure activities, more interaction with staff and other residents, and improvements in material wellbeing and dignity. In the absence of robust evidence upon which to base service improvement, the participation of participants and carers in staff training could be viewed as a 'different form of evidence-based training' (Felce, 2005; p. 8).

It is important to take into account the life stage of the participant when describing QoL measures in health and social care services young adults, for example, may perceive themselves as being in control of their own lives, while carers may view them as young people in need of resources and assistance. Staff in health and social care services need to have the skills and strategies to facilitate young adults to define who they are and to be agents in their future lives, in a context in which organisational and family perceptions may hamper personal growth and confidence (Turid Midjo, & Ellingsen Aune, 2018).

Consequently, effective transition in life stages requires continuity between youth and adult services, a multidisciplinary ethos among professionals, and interagency collaboration across sectors and services. The evaluation of the effectiveness of transition arrangements needs to take into account the perceptions and experiences of the young person and, with that young person's permission, their family or carers in terms of satisfaction with interventions and with QoL outcomes. (Wright, 2010; p. 18).

The characteristics of community care services focused on promoting QoL measures identified in this study are summarised in Table 2 below.

Table 2: Overview of QoL-related Intended Outcomes fo		ility Serv		<u> </u>	[]	
	Lawton (Bowling, 2014)	UKCA (2014)	Noonan-Walsh et al. (2007)	Malley, & Fernández (2013)	Schalock & Verdugo (2012)	RRTC (n. d.)
Life satisfaction and Overall Quality of Life	Х		Х	Х	Х	
Personal development, Personal Skills,			Х		Х	
Self-esteem, Personal Dignity	Х	Х		Х		
Social, Family, Personal and Interpersonal Relationships and Connectedness, Social networks and Friendships	х	х	х		х	х
Choice and control over daily life, Self-determination, Independence, Person-Centred Planning and Coordination		х	х	х	х	Х
Emotional well-being, Positive Affect, Mental Health and Functioning, Absence of Challenging Behaviour or Psychiatric Symptoms	х	х	х	х	х	х
Physical Wellbeing, Health and Functioning, Access to Healthcare	х	Х	х	Х	х	
Material, Social and Economic Wellbeing, Physical safety, Access to Amenities, Freedom from Abuse and Neglect, Suitable Living Conditions, Housing	х	х	х	х	х	х
Social inclusion and Community based Activities			Х		Х	
Social environment, Social engagement, Meaningful Activity, Community Inclusion	х				х	
Employability, Employment, Participation in Work, Education or Training		Х	Х		х	x
Human and Legal rights, Equity, Freedom from Barriers and Discrimination, Privacy	х			Х	х	Х
Citizenship, Opportunities to Contribute to Society ¹ Lawton (Bowling, 2014): Bowling, A. (2014). Quality of life: Measures and Research. London School of Economics and Political Science. <u>https://eprin</u> UKCA (2014): UK Public General Acts (2015). Care Act 2014. The Stationer	nts.soton.a				X ool for Social	Care

various settings. National Disability Authority. <u>http://nda.ie/nda-files/Supported-Accommodation-Services-for-People-with-Intellectual-Disabilities.pdf</u>

Malley, & Fernández (2013): Malley, J., & Fernández, J. (2012). Measuring quality in social care services: theory and practice. Annals of Public and Cooperative Economics, 81(4): 559-582. <u>http://dx.doi.org/10.1111/i.1467-8292.2010.00422.x</u>

Schalock & Verdugo (2012): Schalock, R. L. & Verdugo, M.A. (2012). A Leadership Guide to Redefining Intellectual and Developmental Disabilities Organizations: Eight Successful Change Strategies. Baltimore: Brookes.

RRTC: Rehabilitation Research and Training Centre on Home and Community-based Services Outcome Measurement. (n. d.). Quality of Life Questionnaire (QOL - Schalock). Author. https://rtcom.umn.edu/database/instruments/qol.q

4. The Status of QoL in Vocational Education and Training

It became clear at an early stage in the review process that QoL is accepted as a clear outcome benefit of successful completion of vocational training and education (Cedefop, 2011; 2013). The more qualified a person is, the more likely they are to experience a better QoL in a number of life domains. However, it was also clear that there was a tendency for VET providers and policy makers to assume that this impact was primarily achieved through occupational skills and higher qualifications. A question that is being increasingly asked about VET is, "what is the QoL impact of VET on those who fail to complete a program successfully or who do not gain access on the first place?" One response to this question is that, at the very least, VET programmes and procedures must not disable learners who have additional learning needs. More importantly, the design of VET programmes needs to include components and mechanisms intended to directly enhance personal capabilities, promote social inclusion, and increase wellbeing.

There is an argument to be made that introducing practices aimed at reducing withdrawals from formal VET and increasing the effectiveness of participation of learners with additional needs can play significant role in enhancing VET QoL outcomes for all. A major implication of this argument is that there is an onus on mainstream VET providers to create more accessible and inclusive learning environments. A move from an approach based in the medical model of disability to a human rightsbased approach, and from a charity to a rights-based approach needs to underpin this process (International Labour Organisation, 2004; p. 13). The components of the Schalock/Verdugo QoL model can provide a framework to help map the pathway to a rights-based approach to VET. It has been benchmarked against the requirements of the UN Convention on the Rights of Persons with Disabilities (CRPD) and there is a strong association between the core domains of this QoL model and many articles of the Convention (Verdugo et al. 2012).

Education and training have been components of the European project for an extended period of time. The European Commission viewed them as a way to foster shared values, enable young people to participate more successfully as citizens of Europe, and effectively engender the meaning of good European citizenship (European Commission, 1997, p. 57).

The report of the European Agency for Development in Special Needs Education listed the EU publications that supported VET as a priority (European Agency for Development in Special Needs Education, 2013; p. 9). In successive policy documents since the Lisbon Treaty (2000), VET has been assigned a high priority as a means of promoting social inclusion, cohesion, mobility, employability and competitiveness (Lasonen, & Gordon, 2009; p. 20). However, there is a view that many VET programmes are restricted to occupational qualifications and/or progression to further or higher education (Hrvoje, 2014) and there is too great an emphasis on employability as the primary outcome of education. This has the potential to reduce the quality of VET outcomes (Šćepanović, & Artiles, 2020).

Preston and Green (2008) questioned whether VET should contribute to a broader conception of social inclusion, such as citizenship. They suggested that VET models that solely focus on competences and employment are not fit for purpose when viewed in the context of social inclusion as referred to in EU Member State's policy (p. 9). The UNESCO and ILO joint recommendations for technical and vocational education and training in the 21st century (2002) characterised VET as an element of a broader system of lifelong learning and an important part of a system designed to improve QoL. The European Centre for the Development of Vocational Training - Cedefop (2013; p.41) proposed a number of outcomes for VET that extend beyond occupational knowledge and skills required for successful participation in the labour market. Among the perceived benefits listed were:

• Enhanced QoL and wellbeing in terms of health, participation in public life, and life satisfaction.

- Improved health and health behaviours particularly for people with mental health difficulties.
- Increased self-confidence and motivation.
- More effective inclusion for learners at a disadvantage (p. 19).

Learning can improve the chances of getting a better job, enhance social standing in the community, foster positive self-esteem, and/or increase participation in political life (Cedefop, 2009). In the current context, inclusive lifelong learning is an important mechanism that can redress some of the disadvantages and vulnerabilities experienced individuals and groups who are at increased risk of social exclusion due to the Covid-19 pandemic (European Training Foundation, 2020).

An important reference document for reviewing the QoL impact of VET systems is the Council Recommendation on Key Competences for Lifelong Learning (2018). From a programme development and design perspective, it also elaborates a number of learning approaches and environments that can be particularly effective in fostering personal, social and learning to learn competences (The Council of the European Union, 2018; p. 12-13). These included:

- Cross-discipline learning:
 - Partnerships between different education levels, training and learning actors, including the labour market
 - Whole school approaches with an emphasis on;
 - Collaborative teaching and learning
 - Active participation and decision-making of learners
- Strengthening personal, social and learning competences from early age to provide a foundation for the development of basic skills
- Complementing academic learning with the development of broader competences such as:
 - Social and emotional learning
 - o Arts
 - Health-enhancing physical activities
 - Health conscious, future-oriented and physically active life styles
- Adequate support, for all learners, in inclusive settings to fulfil their educational potential such as:
 - Language, academic or socio-emotional support
 - Peer coaching
 - o Extra-curricular activity
 - Career guidance
 - Material support
- Cooperation by education and training providers with community-based organisations and employers, embracing formal, non-formal and informal learning opportunities, to support competence development and facilitate transitions from education to work and vice versa where appropriate
- Assisting educational staff to enhance the quality of their teaching and learning methods and practice by providing them with access to guidance, centres of expertise, appropriate tools and materials.

Developing and deploying effective adult learning policies and processes is a cross-disciplinary and inter-agency challenge that depends on collaboration between statutory, private and non-governmental actors, including the social partners and civil society, in a range of policy domains including education, employment, welfare, business, and health (ET2020 Working Group on Adult Learning, 2015). There is a need to develop a clear and robust adult learning policy focused on

creating more accessible and inclusive VET systems to promote QoL outcomes for all. However, it is important to bear in mind the caveat issued by Jason Laker, a professor at San Jose State University, at a recent seminar on inclusive education and societies:

"Policies alone don't make anything happen. To be effective policies need corresponding actions happening on the ground including building people's knowledge, skills and dispositions" (Jason Laker, cited in European Training Foundation, 2021, paragraph 5).

The Impact of VET on QoL

Prior to discussing the strategies that can be put in place to increase participation in VET for learners with additional needs, it is important to reflect on how VET contribute to enhanced QoL for successful participants. The following areas are viewed as being important factors in this process.

Personal Development: Learning has been accepted as an integral part of personal development and to play a crucial role in enabling people to adapt to evolving circumstances and achieve enhanced well-being. In this regard, effective networking and interpersonal skills are viewed as being very useful. VET has a role in developing these personal competences. (Marope, Chakroun, & Holmes, 2015; p. 118).

Systems must operate in synchrony with a balance between academic and technical competences, social and emotional development, wellbeing, and preparing participants to become effective workers and citizens (Cedefop & Lifelong Learning Platform, 2019).

The Council Recommendation on Key Competences (2018) recognised that interpersonal skills and the ability to adopt new competences (learning how to learn) are important outcomes of effective learning systems, alongside personal fulfilment, healthy and sustainable lifestyles, employability, active citizenship and social inclusion (see Table 3).

Social Inclusion: Social inclusion, which has a central position in the domain of QoL, is considered to be an important transversal issue in Europe. Consequently, it is important to explore what the term entails, particularly as it can be applied to the impact of VET on persons with disabilities. While social inclusion is often defined as a process whereby all people are participating in the economic, social and political processes of a society, the definition is not always elaborated in policy (Oxoby, 2009). In fact, it can be argued that it has gained a wide acceptance because it has become a generic term which can be interpreted in multiple ways, and that the term should be discarded in favour of more specific terms (Oxoby, 2009).

Nevertheless, social inclusion is associated with circumstances favourable to better quality of life outcomes, including economic wellbeing, employment, and political involvement. While it may seem logical to view inclusion as the opposite of exclusion, this assumption can create some conceptual challenges. For example, a person may actively opt to exclude themselves, as a matter of principle, from political participation. So, exclusion is not so much about a state but more about lack of access to the means to attain that state. In this regard, social exclusion needs to be related to a lack of access to rights and resources and the existence of barriers and challenges to achieving inclusion.

Oxoby (2009) cites a definition proposed by Avramov, 2002 which has a number of components that can help characterise social exclusion and inclusion.

- Social exclusion is apparent in the disadvantages faced by an individual, associated with membership of a specific group, arising from an accrual of challenges.
- It is experienced by an individual as restricted participation in major life activities and reduced access to economic resources.
- This results in both actual deprivation across intersecting social and economic domains and feelings of reduced life satisfaction.
- There is frequently a correlation between social stigma and isolation and a perception of not being part of a society and not being offered opportunities to participate.

In contrast, social inclusion may be defined as a positive process which endeavours to increase an individual's opportunities to engage or re-establish social connectivity by offering means of access to social activities and adequate income, the use of public institutions and facilities, the benefits of social protection and social and care supports and services (Oxoby, 2009; p. 5). Oxoby refers to the five domains of 'social rights' that are integral to inclusion proposed by the Council of Europe (2001; cited in Oxoby, 2009). These are access to employment, housing, social protection, health, and education. With regard to education, it is generally accepted that a lack of access to education and training is a major factor in the exclusionary process.

Employability: The concept of employability includes a capacity to be self-sufficient in the labour market and to achieve social inclusion and active citizenship (Preston & Green, 2008). Cedefop defines employability as '...a combination of factors (such as job-specific skills and soft skills) which enable individuals to progress towards or enter into employment, stay in employment and progress during their careers.' (EurWork, 2018; Paragraph 2).

Employability was initially adopted as a pillar of the European Employment Strategy in 1997. It was considered to be a prerequisite for increased employment rates in both the Lisbon Strategy and the Europe 2020 Strategy. Important actions to enhance employability include ensuring that general education and VET are adapted to prepare learners for new forms of work and working conditions, and applying the principles of lifelong learning and setting targets for the level of education attained. For example, the Europe 2020 strategy set a target to increase the proportion of adults with a tertiary qualification and reduce early dropouts from formal education. The acquisition of relevant skills and comparability of qualifications are at the centre of the strategy to strengthen employability (European Commission, 2016). Young people are considered a key target group for measures to improve employability.

However, Preston and Green, 2008) propose that it is essential from a VET perspective that employability is not solely regarded to be dependent on technical and professional skills and qualifications. Employability skills also include:

- Motivation and enthusiasm,
- Teamworking,
- Oral communication,
- Flexibility and adaptability,
- Initiative / proactivity,
- Ongoing development,
- Employability skills qualities not qualifications (Martin, et al. 2008; Cited in Preston & Green, 2008).

Active Citizenship: Citizenship has also been a recurring theme in European policy documents on VET and Lifelong learning over many years. It is usually referred to as 'active' citizenship and refers to the attainment and application of rights for civic and political participation. It covers participation in political and civic organisations, voting, running for office, volunteering, and participation in political processes at a community, regional, national and European level. Because there are diverse interpretations at national level, EU Member States have not reached consensus on how best to monitor active citizenship (Preston & Green, 2008).

This means that in addition to developing employability, it is essential that other social goals such as active citizenship be addressed (European Commission, 2000). It is acknowledged at a policy level that active citizenship requires enhanced cognitive and communication skills and that these can be facilitated through both social and educational activities. This requires that the role of VET in facilitating active citizenship be elaborated in more detail (Preston & Green, 2008). The challenge is to move beyond the necessarily generalised language of many reports and explore how different national VET systems enable participants acquire the knowledge and competences needed to achieve a 'satisfying and productive life quite apart from a person's employment status and prospects' (p. 136).

In the discourse of the EU, the term active citizenship can refer to democratic action orientation, a human capital orientation, and a social capital orientation (Zepke, 2017). The role of VET and lifelong learning could be described as moulding competent learners who vote, pay their taxes, and contribute to the economic health of their society. Another view of an active citizen is an individual who strives to reform existing systems to achieve enhanced QoL for all. Zepke (2017) provides a number of characterisations of active citizenship which have implications for QoL. These are listed in Table 3.

Table 3: Overview of QoL-related Intended Outcomes for Vocational Education and Training ¹						
	CRKC (2018)	Zepke (2017)	DAE (2011)	Goss (2018)	Stanwick et al (2006)	ET2020 WG (2015)
A sense of wellbeing; Life satisfaction and happiness; A sense of purpose, hope and motivation	х		х		х	
Personal Skills; Self-reflection and direction; Personal learning and development; Increased choice; Personal status; Participation in leisure activities,	x		х	х	х	х
Self Confidence, self-esteem and feelings of control; Resilience; Coping with uncertainty and complexity; Dealing with challenges or change	x		х		х	
Learning how to learn; Life coping strategies; Critical and analytical skills; Problem solving; Creativity; Using existing knowledge and previous experience in a constructive way		х	х		х	
Independent learning skills; Exploring new learning opportunities and life activities; Taking part in service learning; Participating in learning communities; Improved understanding of the concepts of 'lifelong learning'; A stepping stone into further education and training,	x	х	х	х		

Table 3: Overview of QoL-related Intended Outcomes for Voc	ational	Educati	on and [·]	Training	1	
	CRKC (2018)	Zepke (2017)	DAE (2011)	Goss (2018)	Stanwick et al (2006)	ET2020 WG (2015)
Social and communication skills; Collaboration, assertiveness and integrity; Increased capacity to relate well to others and social integration; Social interaction, friendship, concept of family; Interacting, networking and working constructively with other people, Empathize and manage conflict in an inclusive and supportive context,	x		х	x	x	
Employability; Individual and/or collective economic development; Managing time and information; Excellent Punctuality, attendance and behaviours	х	х	х	х		
Respect for the diversity of others and their needs; Willingness to overcome prejudices and to seek compromise; Generating, adopting and adapting commitments and obligations to the community; Democratic participation, Increased engagement or reengagement; Obeying laws, conventions and respecting the rights of other citizens; Solidarity, A sense of belonging and a supportive environment	x	x	х		x	
Establishing personal and community identities; Facilitating social and/or community development; Positive attitudes to voluntary and community activity; Collective action to improve society; Participating in environmental and political action		x				x
Participation in political and civic life; Connecting to the structures of social, political and economic activity; Working within local, national and international structures; Responding constructively to government policies; Formal democratic behaviour		x				х
Maintain physical and emotional well-being and positive physical and mental health; A health-conscious, future- oriented life, Improved health; Life expectancy; Protecting physical and psychological safety and health	x	х	х	х	x	x
 ¹ CRKC (2018): The Council of the European Union. (2018). Council Recommendation on Key Competences for Lifelong Learning. C 189/10 EN Official Journal of the European Union 4.6.2018. https://eur-lex.europa.eu/legal- content/EN/TXT/PDF/?uri=CELEX:32018H0604(01)&from=EN Zepke (2017): Zepke, N. (2017). Three Perspectives on Active Citizenship in Lifelong and Life-Wide Education Research. EPALE – Electronic Platform for Adult Learning in Europe. https://epale.ec.europa.eu/en/blog/three-perspectives-active-citizenship- lifelong-and-life-wide-education-research DAE (2011): Deloitte Access Economics. (2011). The Economic and Social Benefit of Increased Participation by Disadvantaged Students in VET. National VET Equity Advisory Council (NVEAC). https://www.voced.edu.au/content/ngv%3A47021 Goss (2018): Goss Consultancy Ltd. (2018). Disabled People's Inclusion within UK Technical and Vocational Education and Training. The British Council. https://www.britishcouncil.org/sites/default/files/disabled_peoples_inclusion_within_uk_tvet.pdf Stanwick et al (2006): Stanwick, J., Ong, K., & Karmel, T. (2006). Vocational Education and Training. Health and Wellbeing: Is there a Relationship? National Centre for Vocational Education-and-training,-health-and-wellbeing-is-there-a-relationship ET2020 WG 2015: ET2020 Working Group on Adult Learning. (2015). Improving Policy and Provision for Adult Learning in Europe. Publications Office of the European Union. https://ec.europa.eu/assets/eac/education/library/reports/policy-provision-adult- learning_en.pdf 						

5. Designing Inclusive Learning Environments

The proportion of persons with disabilities who are restricted in their participation in the labour market is significantly higher than in the general population. This is particularly the case for those with learning or intellectual impairments. This is a major concern for community support services, transition and VET providers, learners with additional needs and their representatives, and employer and work representative organisations (European Agency for Development in Special Needs Education, 2013).

In a monitoring report on VET policies 2010-14, Cedefop (2015) concluded that VET providers needed to address employability and economic growth outcomes, while responding positively to the individual needs and aspirations of learners. All this had to be managed while addressing the wider challenge of promoting social inclusion and active citizenship (p.121). It was acknowledged that substantial progress had been made in increasing VET participation for people at risk of exclusion. Nevertheless, there was a need for greater efforts to be invested in creating more responsive opportunities for people with additional learning needs. It described the lack of monitoring of the progress of at-risk learners as a major barrier to creating more effective and responsive VET provision (Cedefop, 2015).

In 2020, the European Economic and Social Committee (EESC) published an opinion on sustainable funding for lifelong learning and development of skills (European Economic and Social Forum, 2020). The focus was upon establishing the right to quality inclusive lifelong learning opportunities at work and beyond sustained through public funds and agreed by the social partners and civil society. It is equally valid to conclude that inclusive learning opportunities and work need to be an essential component of community care services for person with disabilities of working age.

High-quality community care and VET services can be viewed as critical factors in redressing social exclusion across the spectrum of needs. Consequently, there is an imperative to provide greater choice and more flexibility in access routes and methods of delivery and recognise informal alongside formal VET provision (Rodriguez, et al., 2010; p. 28). The EESC issued a call to develop and implement an inclusive quality education system at all levels of education (European Trade Union Committee for Education, 2016; paragraph 3; European Economic and Social Forum, 2017). The Helsinki communiqué on Enhanced European Cooperation in Vocational Education and Training (2006) advocated that the pursuit of excellence must be implemented in tandem with the quest for greater access, enhanced social inclusion, and more active citizenship (Lasonen, & Gordon, 2009; p. 20). This entails the provision of reasonable accommodations and supports to those who require them, driven by a non-rejection policy for all learners with disabilities. Creating a continuum of support across the community care and VET sectors is crucial in this process. A mandatory inclusive 'educational exchange' quality framework could be put in place to guarantee educational mobility for all learners as they progress on a pathway to inclusion.

There has been a debate about the pros and cons of providing segregated VET services that are targeted specifically for persons with disabilities. The debate revolves around the distinction between VET programmes targeted specifically for learners with additional needs and tailoring mainstream VET programmes to respond more effectively to meet the needs of such learners. The concept of targeting VET programmes can imply that a separate stream of VET programs for learners with different capacities is required, whereas tailoring VET can mean that learners with different needs (such as persons with disabilities or immigrants) are involved in the design of mainstream VET programmes and processes to meet their needs (Preston & Green, 2008; p. 180).

In a system approach that aims to create a seamless continuum of support across sectoral boundaries, it is likely that learning and work need to be viewed as important facets of all services, both disability specific and mainstream. On this basis, both targeted and tailored services are required to support the transition to full participation (Goss Consultancy Ltd, 2018).

Another important consideration is that, in parallel with a system emphasis on creating a pathway to inclusion for people in dependent settings, there are people who are on a pathway to dependency and disability as a result of exclusion from VET and work. The Bruges Communiqué on enhanced European Cooperation in VET called for a reduction in the proportion of learners exiting education at an early age through the implementation of prevention and remediation interventions. Many of the mechanisms listed have the potential to enhance the participation of persons with disabilities in VET including increased work-based learning and apprenticeships, flexible learning pathways, and effective guidance and counselling (European Commission, 2010; p. 15). These mechanisms are also integral to supported employment and individual place support approaches. According to the European Commission, inclusive VET needs to be addressed through mechanisms that support equality of access for people at risk of exclusion (European Commission, 2010). The development of a best practice handbook in including "at risk" groups through a combination of work-based learning and key competences was recommended (p. 16). From a system perspective, equality of access is not an intervention that operates at the threshold to mainstream VET but an objective that needs to inform every stage of an inclusion pathway.

To enhance the impact of inclusive and equitable lifelong learning, key components need to be integrated into community care and VET programmes to assist participants to learn how to learn and attain literacy and numeracy skills, transversal skills and citizenship skills (Wheelahan, & Moodie, 2016). Inclusive services can provide opportunities in life, sustain social and economic participation, and foster improved individual health and well-being (Goss Consultancy Ltd, 2018).

Vocational transition programmes have a particularly important role to play for young people with additional learning needs. These programmes foster attributes such as personal effectiveness, career readiness, employability skills, and social capital. They also prepare participants for progression to further training or education and work (Goss Consultancy Ltd, 2018). In order to design and deliver effective transition programmes, systems need to put a number of strategies into place including:

- Incorporating the insights of participants into the decision-making process,
- Encouraging participants to set high aspirations,
- Setting ambitious but attainable learning goals that are likely to challenge participants positively,
- Monitoring progress towards these goals,
- Continuing to evaluate the effectiveness of any additional or different supports interventions which are in place,
- Including interventions aimed at fostering broader capacities such as personal and social development,
- Using an evidence-informed approach to confirm that interventions are impacting positively on progress (Goss Consultancy Ltd, 2018; p. 34).

The Copenhagen Declaration (2002) proposed that VET systems could achieve a more active participation by people at risk of exclusion through involving them in a participant-orientated design process, e.g., focus groups. Further, it suggested that participation in the governance processes of

VET provision could create a greater consensus between staff and participants on the intended objectives of education or training. This approach is equally relevant at all stages of the inclusion pathway. It is also important to consider whether potential participants currently excluded from VET need to be involved in the VET design process.

The Council of the European Union priorities for enhanced European cooperation VET between 2011-2020 (Council of the European Union, 2010) included an aspiration to make VET accessible to all, with a particular emphasis on early school leavers. Mechanisms to meet the needs of those lacking adequate skills and those at risk of exclusion were recommended including the provision of guidance and support services, using new technologies and using effective monitoring systems. From a system perspective, timely access to these mechanisms in the inclusion pathway is essential whether a person is in education, or economically inactive and dependent on social services.

The capabilities approach is a methodology that warrants consideration within the context of inclusive learning (Cedefop, 2009; p. 39). This approach is supported through the personalisation of learning paths based on individual needs. As a flexible and learner directed process, personalisation can support progression through learning paths and optimise learning processes and outcomes (p. 57). Active learning engagement and personalised learning methods are important features of all services on the inclusion pathway.

The Shanghai Consensus of the Third International Congress on Technical and Vocational Education and Training (TVET) (2012) called for innovative measures to provide quality and inclusive TVET, especially to disadvantaged groups including learners with disabilities, marginalized and rural populations, migrants, and those in situations affected by conflict and disaster (Marope, Chakroun, & Holmes, 2015; p. 163). To respond to this call, VET provision needs to move away from a narrow view of training to meet the technical and vocational demands of the labour market and be viewed as a human right to be integrated into everyone's professional and personal development throughout life (p. 197). In addition to broadening its scope, VET needs to become more inclusive of the diverse needs of all learners and by catering for all participants regardless of gender, ethnicity, age, disability or location (p. 161). Collaboration with services, agencies and representative organisations providing support to currently excluded people will enhance the likelihood that VET can achieve this aspiration.

To achieve the goal of providing inclusive learning opportunities, changes will be required in how the system operates. The needs of an increasingly diverse population of learners must be reflected in learning materials and strategies for teaching and learning and changes to institutional practices are required to facilitate progression and access for people from at-risk populations. This can involve the provision of more accessible facilities and personal assistance for learners with mobility impairments, the provision of materials in alternative formats such as Braille or audio formats for learners who are print impaired, the provision of interpreter services for people who are hearing impaired and providing reasonable accommodation in assessment procedures for atypical learners. These are mechanism that need to be available to people who wish to access formal education and training as well as those who have gained access.

The European Agency for Development in Special Needs Education carried out a review of policy and practice in VET provision for learners with additional needs in 26 countries that identified a set of success factors for inclusive VET (2013). It proposed a range of practices that can enhance the quality and responsiveness of VET for learners with additional needs. Many of these have relevance for

providers who aspire to creating inclusive learning environments at all stages of the inclusion pathway (pp. 7-8). These included:

- Developing an inclusive policy which deems difference among learners as the norm in the organisational culture,
- Creating an ethos that encourages motivation and commitment,
- Adopting a distributed leadership style that empowers a teamwork approach and collaborative problem solving,
- Ensuring that roles within each multi-disciplinary team are clear,
- Providing effective channels for both internal and external communication to support collaboration,
- Encouraging cooperation between individuals and teams through peer coaching, informal discussions and collaborative problem solving,
- Utilising learner-centred approaches in the VET learning process to set goals, develop learning plans and design programme content,
- Implementing a tailored approach to curriculum development, learning methods, materials and assessment procedures to respond to individual learner needs,
- Being flexible in approaches to the development and implementation of individual learning plans,
- Producing learning plans that are easy-to-use and are considered to be living documents that can be reviewed and revised based on the feedback from learners and team members,
- Involving learners from the initial stages of individual planning and ensure that their voices are listened to throughout the learning process,
- Undertaking preventative educational actions in collaboration with the local social services to support learners at risk of withdrawing or dropping out,
- Where necessary, seeking out alternative learning options for those who disengage,
- Subjecting programmes to regular internal and external review to ensure relevance of content to current competence requirements,
- Training all staff in the skills and attitudes required to:
 - o Place learners' abilities at the centre of their approaches,
 - See opportunities rather than challenges,
 - Focus on what learners 'can' do, not what they 'cannot' do,
 - Foster the confidence and assertiveness of all learners,
- Respecting the wishes and expectations of learners and integrating them into the evolving transition process to ensure a successful transition to the open labour market,
- Working in partnership and actively network with local employers to ensure that supervised practical training is adapted to the needs and strengths of each learner and increase the likelihood and a successful work outcome.

Greater ambition needs to be evident in the targets and indicators for lifelong learning at all stages of the inclusion pathway. This could be informed by an inclusive key competences framework that extends beyond formal education to address adult learning needs such as learning how to learn, citizenship skills, and life competences. This requires that learners are enabled, at all stages, to make an active contribution to developing learning pathways a thereby ensuring that they are adapted to their needs

The European Skills Agenda (2020) for sustainable competitiveness, social fairness, and resilience has recognised that increasing the participation of adults in learning opportunities is a priority and set ambitious targets to be reviewed in 2025. Some of the strategies they recommend are:

- Dismantling discriminatory stereotypes,
- Increasing learning participation by adults with low qualifications or who are unemployed,
- Monitoring increases in participation in adult learning as an indicator of the performance of adult learning systems,
- Encouraging inclusiveness and equal opportunity for all including persons with disabilities and other at-risk groups,
- Implementing targeted measures and flexible training formats as a means of preventing early withdrawal from formal education and to support transition from school to work.

A broad lifelong learning perspective was adopted in the Council Recommendation on Key Competences for Lifelong Learning (The Council of the European Union, 2018). This is intended as a comprehensive framework for all sectors of education and training. The framework includes a number of elements that support inclusive learning in all contexts including:

- Emphasising life skills, citizenship, democracy and social participation,
- Allowing learners to navigate learner centred lifelong learning pathways,
- Inclusive education systems that can encourage acceptance of diversity and underpin equality of opportunity, while contributing to sustainable development and fostering the wider range of skills that will be required in the future,
- Developing a broader range of more flexible and responsive learning approaches through a collaborative approach between different learning settings.

Universal Design for Learning

Regardless of the type or purpose of a service, or the stage in the inclusion pathway of a participant, all people need to be addressed as learners. This principle means that Universal Design for Learning (UDL) can make an important contribution to more accessible programmes and services at all stages of progression. UDL is an approach to programme design and delivery that espouses the view that a "one-size-fits-all" services will not achieve success for all participants. It is based on a number of principles, originally proposed by the researchers at the Center for Applied Special Technology (CAST) in Boston

(https://udlguidelines.cast.org/?utm_source=castsite&lutm_medium=web&utm_campaign=none&ut m_content=aboutudl). These are:

- Multiple means of representation to give learners various ways of acquiring information and knowledge (The 'What' of learning),
- Multiple means of action and expression to provide learners alternatives for demonstrating what they know (The 'How' of learning),
- Multiple means of engagement to tap into learners' interests, challenge them appropriately, and motivate them to learn (The 'Why' of learning) (Edyburn, 2005; p. 17; Quirke & McCarthy, 2020).

The underpinning policy basis for adopting a UDL approach is set out in Article 24 of the UN Convention on the Rights of Persons with Disabilities which holds that state parties shall "ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others" (UN Enable, 2006; p. 18).

Quirke and McCarthy (2020) described a conceptual UDL framework for further education and training sector in Ireland that brings together many of the most useful and relevant design and delivery concepts and strategies for programmes and courses. UDL is about eliminating barriers to learning at the design stage rather than having to adapt things at a later stage. They described a continuum of support which increases to meet the level of need a learner may have (Quirke & McCarthy, 2020; p. 29):

- At Level 1 learning supports are provided for all learners using the UDL principles as part of the mainstream learning context,
- At Level 2 learners with similar needs, who can benefit the same kind of supports, are catered for, perhaps in small groups,
- At Level 3 accommodations are provided to learners with specific individual needs identified through a needs assessment to ensure that they can participate on an equal basis in learning activities,
- At Level 4 learners who might require more personal and professional supports such as a personal assistant are provided with support.

It is suggested that a key component of the approach is the ethos of the learning context whether this is taking place in a formal classroom, in the community, a workplace, or whether it is virtual or physical.

A UDL approach is likely to be more effective when it is informed by the values of inclusion. Inclusion addresses the tenet that a learner with additional needs is entitled to participate in all activities on an equal basis with their peers. This means that it is not adequate to merely integrate a learner with a disability into a mainstream learning environment and expect them to adapt to the demands of that environment. What is required is that the environment adapts to the needs of the learner to ensure that they are included in the learning process alongside their fellow learners and have the same opportunities to excel. Inclusion requires that all activities can be accessed by a learner with a disability. Lack of such access can be viewed as a disabling factor in the learning environment. This entails that access is not solely about gaining entry to the learning context but must be facilitated throughout the learning process in terms of conditions and outcomes.

Consequently, UDL principles must be applied, not only in the design of a programme, but also in teaching and learning practices and materials, in methods of assessing progress, and in access to support, services, and facilities.

The authors refer to a number of insights that could be useful in considering the application of UDL to services.

Learning is no longer about ensuring that learners accumulate content because this is virtually universally available. It is about learning how to learn. People need to become experts in their own learning (Rose & Meyer, 2000; Cited in Quirke & McCarthy, 2020; p. 41),

- UDL is a process that provides a diversity of learners with access to the means to improve their performance, their health and wellness, and their social participation (Steinfeld & Maisel, 2012; Cited in Quirke & McCarthy, 2020; p. 44),
- It is more effective and efficient to build in flexibility to learning resources and materials at the design stage of a programme rather than having to adapt it retrospectively (Johnson & Fox, 2003; Cited in Quirke & McCarthy, 2020; p. 46).

6. A QoL Supports Model

While the Schalock/Verdugo model of QoL can provide a frame of reference for measuring the QoL impact of services, its effective application requires that systems and organisations change the ways in which they operate. A change strategy is essential to achieve enhanced and sustainable improvements. A description of the changes required is central to the proposal for a QoL Supports model (Gómez et al., 2021a, 2021b; Verdugo et al., 2021). The model attempts to integrate many of the current significant changes occurring in the domain of disability with the QoL factors in order to develop a schema for guiding system and organisational change. Specifically, the QoL Support model encompasses a holistic and integrated approach, focused on the human and legal rights of people with disabilities; eligibility for services and supports based on significant limitations in major areas of life activity; an emphasis on supports provided within inclusive community settings; and effective outcome assessment.

A systems approach is adopted in which different levels of action are required.

- At the macrosystem level, policies, programmes and regulation need to reflect the priority of QoL impact and access to timely and relevant supports in terms that influence culture, attitudes and values; expectations and standards; and professional and individual practice.
- At the mesosystem level, it is essential that service providers, support organisations and communities ascribe and aspire to the principle of enhanced QoL in terms of reduced physical and psychosocial barriers; more supportive and responsive environments; and transformative action.
- At the microsystem level, attitudes, values and behaviours need to be informed by the principle that enhanced QoL is a priority for the individual within the family, social networks, the workplace and circles of support.

Systems of supports can be characterised in terms of the elements that can impact positively on QoL.

- Choice and personal autonomy can be supported by making sure that individuals are provided with opportunities to make choices and to exercise self-determination. This requires that they are recognized as having the right to legal capacity on an equal basis with those without a disability and that they can exercise their rights with the support of facilitated decision making.
- Inclusive environments need to be created in educational, living, and work environments which support individuals to access to resources, information, and relationships; encourage their growth and development; and provide accommodations to meet their physical and psychological needs in the pursuit of autonomy, competence, and connectedness.
- Generic supports, which are widely available to all people, need to be provided in a form that is accessible and of practical use to the individual These include natural supports, technology, life-long learning opportunities and reasonable accommodations that are provided with dignity and respect and activate personal strengths.

• Specialized supports, which are customised to the needs of the individual, must be made available in a timely manner and matched to the individual's stage of development. These can include supports that are provided by trained professionals, therapeutic interventions, specialised assistive technologies and personal assistance.

7. QoL as an Outcome Indicator

The review carried out for this report identified QoL and its dimensions as being widely accepted outcomes for community care services and VET. However, it also revealed a variety of challenges in measuring such outcomes. While there is little doubt that QoL is intuitively attractive as an outcome for social services and VET, it cannot be assumed that access to services automatically results in a better QoL for participants (Keogh, 2010). A lack of adequate information on the overall QoL status of persons with disabilities, or participants in services, makes it difficult to reach any robust conclusions in this regard. A more critical review of the disability sector could be supported by adopting QoL as basis for quality assurance beyond measures of service delivery (National Economic and Social Commission, 2012).

Despite the long history of the use of QoL indicators, no universally accepted definition or measurement tool has evolved (Guillemin et al., 1993; Mathias et al., 1994; Wolfensberger, 1994; Barcaccia, et al., 2013; Bowling, 2014). Nevertheless, even in the absence of agreement on a single standard definition, QoL research can contribute to understanding and comparing the outcomes of interventions (Post, 2014). The recommended approach is to use a variety of quality indicators, both subjective and objective, to inform a comprehensive approach. Many of the conceptions of QoL that have been proposed are listed in Table 2 and Table 3 of this summary and a selection of over 30 measurement tools and their dimensions are listed in Table 4.

The WHOQOL Group (1998) identified six domains: physical health, psychological wellbeing, level of independence, social relations, environment, and spirituality/religion /personal beliefs. While their definition of QoL is clear, operationalising it in a way that is measurable and useful in enhancing the relevance and quality of services is challenging.

Types of Measurement: It is generally accepted that there are two primary types of QoL measures, namely objective and subjective measures. Objective indicators based on external and easily observed conditions of life (Ventegodt et al., 2003; p. 1031) and subjective indicators that reflect the way in which people rate their quality of life. It has been documented that the perceptions of quality of life of people with disabilities are impacted by a variety of personal characteristics including age, age at which a health condition emerges, the nature and severity of the condition, employment status, income, and relationship status (Mehnert, Krauss, Nadler & Boyd, 1990). Perceptions of QoL can also be coloured by the collective or personal experiences of living in a particular community or culture, and the personal values developed in interaction with family, school and community. It is also important to be aware of the way in which items are worded in a measurement tool. For example, Health related QoL (HrQoI) measures are often based on a negative conception about the gap between present health and functioning and a desired state.

Specific versus General Measures: There can be a challenge in balancing the need to gather information about wider life experiences and a person's experience of a life lived well, and avoiding a measure that is too general to be sensitive to the outcomes of specific services. A potential response

to this in community care services is using patient-reported outcome measures (PROMS) that include participants in the development and evaluation of the tool.

Service versus Individual Outcomes: It is essential that the assumptions underpinning outcome measures are made explicit so that potential conflicts among individual personal outcomes, service provider outcomes, and system-wide outcomes are identified (National Disability Authority, 2019). Ultimately, the function of outcome measurement must be to make sure that the participant has access to the supports and opportunities they need to work towards their personal aspirations and attain a good QoL. This can be achieved by using indicators that monitor each person's progress towards their personal goals across a range of outcome domains.

Some important methodological challenges in achieving this include:

- A broad scope is required in measuring QoL but there are few suitable broad measures available that cover the span of life activities,
- It is essential that content and items are customised to different characteristics of the relevant target group in terms of age and culture and to the type of service and setting being provided,
- This can be achieved by including a 'core' measure of QoL that is augmented with additional items to reflect different characteristics of the target group or interventions being provided,
- When developing a scale, it is essential to start by gaining insight into the perspectives of the intended target group and continue engagement throughout the process to ensure the relevance of the measure,
- It is crucial that the changing views of respondents (response shift) over time are taken into account (Bowling, 2014; p. 18).

A response shift bias occurs when the internal subjective standard against which a person is rating themselves is actually changed by the intervention or by a change in their circumstances. For example, older people tend to rate their subjective QoL more positively than would be expected based on external objective criteria (McPhail, & Haines, 2010). This can result in self-ratings underestimating the impact of an intervention, support, or changed life or health circumstance, particularly when pre-post- ratings are used.

These challenges can make it difficult to draw conclusions that can be used to enhance the quality of a service or to inform the development of more person-centred models.

Measuring Direct Service Impacts: In developing and selecting appropriate indicators, it is crucial to keep in mind that most life outcomes are the result of multiple factors, many of which do not relate directly to the service being provided (National Disability Authority, 2019). For example, interacting factors can include personal characteristics, such as motivation and health status, and environmental factors including family support and access to sources of independent finance. Further, life circumstances can change for a service participant as a result of reduced or improved health or a change in personal relationships.

Consequently, the challenge is to find indicators that can provide insights into the contribution of a specific disability service to the progress made by a specific individual, acknowledging that all life outcomes are highly unlikely to be the result of a single service or other factor (National Disability Authority, 2019). There is a need for approaches to outcome measurement in disability services to be more sensitive to what is important to the individual participating in a service.

A number of mechanisms have been used to try to pick up on such impacts (National Disability Authority, 2019: p. 11-12). These include:

- Using observations to gain insight into QoL of people with severe and profound intellectual disabilities,
- Carrying out interviews with a randomly selected group of service participants to explore the extent to which person-centred plans actually reflect personal aspirations,
- Using Goal Attainment Scaling (GAS) to generate indicators of progress towards personal goals based on person-centred plan reviews,
- Evaluating a service on the extent to which the outcome predictors, used to indicate the quality of service, reflect individual goals and aspirations,
- Investing effort in the development of instruments targeted at particular populations, e.g., persons with challenging behaviour or participants with brain injury, intended to explore key outcomes which are difficult to measure such as integration in the community,
- Developing 'nuanced' approaches to gaining insight into crucial outcomes which are challenging to measure such as meaningful friendships, self-determination, autonomy, community participation and integration.

Involving Service Participants: One initiative that adopted the premise that end users need to be involved in developing an appropriate assessment tool, and enhance content validity, was the Recovering Quality of Life (ReQoL) project (Connell, Carlton, J. Grundy, A., et al., 2018). The researchers consulted with people experiencing mental health challenges about the items to be included in a new tool aimed at gathering information from people in similar circumstances. The study identified five criteria that need to inform tool development:

- Relevance and meaning,
- Clarity,
- Ease of responding even when distressed,
- Sensitivity to the possibility of causing upset,
- Non-judgemental phrasing.

Items in the ReQoL request respondents to self-rate on a range of items covering trust, confidence, energy, being in control, independence, clear thinking, self-care, positive relationships and self-esteem (Connell, Carlton, J. Grundy, A., et al., 2018).

Taking Account of Individual and Context Differences: The most elaborated explorations of the concept of QoL, and how to measure it, were carried out in relation to people with specific types of impairments and with those moving from congregated settings. Intellectual impairment (learning disabilities) and mental health were the impairments for which the 'QoL question' has been raised most frequently in the health and social care sector. For example, QoL measures were viewed as particularly important in the evaluation of services for persons with severe or chronic mental health conditions. In addition, the perceptions of service participants, and their families, were seen as essential criteria in service evaluation. Relevant and appropriate outcome measures need to be developed in consultation with service participants (Mental Health Commission, 2007).

An international team of researchers, which included Robert Schalock, reviewed models and instruments used to measure quality of life in various settings (Noonan-Walsh et al. 2007). The focus of the study was upon supported accommodation. Nevertheless, the report provides a comprehensive summary of the extent to which the meaning of QoL, particularly for persons with intellectual disabilities, was evolving at that time. The authors noted that QoL has an appeal as an

indicator of the effectiveness of community supports. They highlighted the consensus on the multidimensionality of the construct and the view that QoL domains were relevant to all people regardless of ability. They emphasised the importance of using both objective and subjective indicators to compare between QoL impacts for diverse individuals and groups, and to gain insight into individual perceptions of QoL at a particular time.

Quality Criteria for a QoL Measurement Tool: Bowling (2014) explored a range of tools aimed at older people. She proposed a number of criteria for judging a QoL measure. While these were mainly focused on normed and standardised tools, some of the standards can be applied to other types of tools. Relevant tool selection or development criteria for a user-focused tool are:

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

Bowling went on to list the criteria proposed by Fitzpatrick et al (1998) for clinical trials.

- Validity (the instrument should measure what it purports to measure),
- Responsiveness (the instrument should be sensitive to changes of importance to patients),
- Precision (the number and accuracy of distinctions made by an instrument),
- Interpretability (how meaningful the instruments' scores are),
- Acceptability (how acceptable do respondents find its completion?),
- Feasibility (the amount of effort, burden and disruption to practitioners and services arising from the use of an instrument) (Cited in Bowling, 2014; p. 13).

These seem to be the most relevant criteria for the development of a service impact tool that is not intended to be normed.

QoL measurement tool items need to be checked for response consistency i.e., the extent to which respondents can answer an item regardless of the accuracy of the response. This is important because items that are frequently omitted by a high proportion of participants reduce the validity of the results (Perry and Felce, 2002). The universal design of a tool, and the provision of parallel versions designed to meet the needs of those likely to be challenged by the items, can increase the consistency of results.

The test-retest reliability of a tool is an important characteristic of usefulness (Perry and Felce, 2002). It means that the ratings of respondents are stable over time. However, an important balance needs to be struck between the stability of a test over time and its sensitivity to change. For example, a tool that is reliable over a six-month period is less likely to reflect substantive changes in QoL that can occur while in receipt of services. While there is no specified ideal time period for reliability, it is likely that stability over a six-week period would be adequate.

The structure and format of a tool need to take into account the possibility that some respondents have a tendency to choose ratings that they believe are expected by the administrator of the assessment tool or the organisation. This is referred to as response bias, or acquiescence, and can result in responses to items with a similar meaning being rated differently depending on the

understanding of a respondent about the desired answer (Perry and Felce, 2002). Items need to be evaluated for this in the test development phase. Preparatory items can identify respondents who are likely to acquiesce and training can be provided in how to complete the scale so that it reflects their own views.

A QoL impact assessment tool is a subject measure which reflects the views of participants. As such, it needs to be viewed as one perspective on the extent to which services are meeting the QoL goals of participants (Perry and Felce, 2002). Using other sources of information about the QoL impact of a service, such as the views of staff or family members, can create insight into areas of consensus and divergence, that can then be explored in more depth through focus groups or individual interview.

Questions to Guide the Selection of a QoL Tool: A number of critical questions that need to be answered when selecting an appropriate QoL tool to gather data on service impacts (Noonan-Walsh et al. 2007.

- Is the instrument based on a clearly articulated QOL conceptual model (e.g., factors, domains and indicators)?
- Is the conceptual model explained clearly in the Standardisation Manual?
- What are the psychometric (reliability and validity) properties of the instrument?
- Do the scores answer the questions being asked by the potential user?
- Do the resultant items/ item scores meet the following criteria?
 - Do they reflect the domains outlined in the QOL model?
 - Do they represent what people want in their lives?
 - Are they ones that the service/supports provider has some control over?
 - Do they relate to current or future policy issues?
 - Can they be used for reporting and quality improvement purposes? (Noonan-Walsh et al., 2007; p.67)

8. Selecting an Appropriate QoL Measurement Strategy

Over the past 15 years, the Irish National Disability Authority (NDA), the Economic and Social Research Institute (ESRI), the Health Research Board (HRB) and the National Economic and Social Council (NESC) have published a number of useful reports that explore QoL in community services. This culminated in a review of the international literature on specialist supports for persons with disabilities living in the community (Mac Domhnaill, Lyons, & McCoy, 2020). The report from this review concluded that community settings impacted positively on wellbeing, freedom and independent decision-making.

In parallel, there has been a growing body of opinion that enhanced QoL is a core intended outcome for VET services. Specifically, VET needs to be viewed as an element of a broader system of lifelong learning and an important part of a system designed to improve QoL (UNESCO International Centre for Technical and Vocational Education and Training & Programme on Skills, Knowledge and Employability, 2002). A number of QoL outcomes that extend beyond narrow technical competences have been proposed. These include enhanced QoL and wellbeing in terms of improved health and health behaviours, increased self-confidence and motivation, participation in public life and life satisfaction (Cedefop, 2013). Consequently, an approach to QoL that spans the continuum of interventions and supports from community care, through rehabilitation and transition services, to VET has the potential to facilitate a seamless pathway to inclusion for persons with disabilities. This requires that the QoL model adopted is relevant to all stages of a pathway and that the QoL impact of interventions made by a service at any point on the continuum are measurable. A QoL impact assessment tool that can be used across the spectrum of specialised and mainstream programmes is essential in creating such accountability, bridging the gap between sectors and facilitating mutual learning across system boundaries.

For example, the aspiration that outcome measurement contributes to building more effective person-centred services and organisations is one that is relevant at all stages of the pathway to inclusion. This requires an approach that avoids reductionist and linear perspectives and prioritises conversations between staff and participants about the quality of services, whether these are about health and social care, transition, education or training (Cook & Miller, 2012: cited in NDA, 2019: p. 3).

There are a number of guidelines for the development of quality indicators that have cross-sectoral relevance (Schalock et al., 2006; cited in Noonan-Walsh, 2007). These were developed primarily with disability services in mind but have equal applicability to inclusive mainstream services. Specifically, QoL impact measurement tools need to:

- Recognise the multi-dimensionality of quality of life,
- Develop indicators for the respective quality of life domains,
- Base the assessment on objective aspects of QoL, on life experiences, circumstances and lifestyles,
- Focus on the predictors of quality indicators/outcomes,
- Use quality indicators as a basis for quality improvement, monitoring social inequality and making normative comparisons (p. 66).

Similarly, measurement tools that aim to assess individual outcomes, regardless of the type of service, need to include a customised person-centred planning process. One useful approach is Goal Attainment Scaling (GAS) that allows a person to rate the progress they have made in attaining goals(National Disability Authority, 2019).

An important choice faces those responsible for selecting or developing a QoL impact assessment tool, whether that be for a community care or a VET service. That choice is whether to opt for a normed, standardised instrument, or a criterion-referenced tool. There are strengths and challenges with both. The advantage of a standardised tool is that is allows comparison with population norms and direct benchmarking between programmes and services. One drawback of normed assessment tools is that because they are designed to be reliable (stable) over time, they are insensitive to short term changes. In this regard, criterion-referenced tools may be more useful. Nevertheless, there are a number of standardised outcome measurement tools that have been used to assess the impact of services on QoL (National Disability Authority, 2019; pp. 37-59).

For example, the National Core Indicators (NCI) Instrument, deployed in the United States, is focused at organisation, State, and Federal levels. It uses surveys alongside other forms of assessment and quality assurance. The NCI monitors outcomes from a number of perspectives including:

• The individual: self-determination, choice and decision-making; work, relationships, community inclusion and personal satisfaction

- Health, welfare and rights outcomes: safety, health, wellness, medications, restraints, respect/rights
- o Staff stability and competence outcomes
- System performance outcomes.

Another approach is to use the observations of trained observers to assess outcomes and outcome predictors, particularly for people with profound intellectual disability. A good example of the application of observations was the approach adopted by Bigby et al. (2014) to generate qualitative indicators of the quality of group homes. They used observations based on the Schalock/Verdugo QoL model to assess the quality of residential service for people with severe intellectual impairments.

Alternatively, generic patient-reported outcome measures (PROMS) that are domain based can be used to assess QoL for persons with disabilities. These measures need to be linked to a personcentred planning process in which respondents are actively involved. This approach can be structured based on a model of QoL to produce data that can be interpreted in terms of life domains.

Makai et al (2014) carried out a systematic review of QoL measures to be used in the economic evaluation of services for older people. It focused particularly on HrQol and wellbeing and evaluated a number of tools. They found that standard HrQol instruments tended to measure physical, social, and psychological aspects, while wellbeing tools provided insight into life purpose and achievement, security and freedom.

The UK National Institute for Clinical Excellence reviewed measures of QoL in the health and social care sector (National Health Executive, 2017). Although this report was focused, again, on older people, its findings have a more general relevance. It found that existing measures did not effectively reflect important benefits other than HrQoL such as independence or improved interpersonal relationships. It recommended that new tools be developed to assess QoL that can be applied across different sectors and measure aspects of life that were viewed as important by participants.

An influential approach to developing more responsive and person-centred services is the Council on Leadership and Quality Personal Outcome Measures (POMS) (see <u>https://www.c-q-l.org/tools/personal-outcome-measures/</u>). POMS allows a person to select objectives to be addressed by their personal plan. These are transformed into specific, measurable goals to be addressed within a specific timeframe. A combination of a POMS approach to service delivery and the application of Goal Attainment Scaling (GAS), using the Schalock/Verdugo framework to structure results may well be an effective approach for community care services.

A range of additional tools have been reviewed in the development of this report, and in previous projects. The EPR benchlearning process reviewed a variety of tools designed to evaluate the outcomes of health and social care, and training interventions (European Platform for Rehabilitation, 2019). The current review updated that process by identifying the views of researchers and authors on the tools available for evaluating QoL service impact. As a result of both processes, 31 tools were identified. The dimension of each tool reviewed are summarised in Table 4 below.

Table 4: Quality of Life Me	easurement Tools Reviewed
Title	Domains
	Health-Related Physical Limitations,
The Short Form-36 - (SF-	Social Activity or Role Limitations,
36) (36 Items)	 Pain, Psychological Distress & Well-Being,
Short Form-12 12	• General Health,
items2)	• Energy &Fatigue,
	General Health Perceptions
	Physical health
The WHOQOL-Bref (26	Psychological wellbeing
items)	Social relationships
Short form of WHOQOL	• Environment (e.g. financial resources, freedom, physical safety
(100 items)	and security, health and social care, home environment, etc.
	Health
	Mobility
EUROQOL - EQ-5D (5	Self-Care
items)	Usual Activities
	Pain/Discomfort
	Anxiety/Depression.
The Patient-Reported	Physical Health
Outcomes	Mental Health
Measurement	Social Health
Information System -	• Pain
PROMIS Global-10 (10	Fatigue
Items)	Overall Perceived Quality Of Life.
	Control over daily life
	 Personal cleanliness and comfort
The Adult Social Care	Food and drink
Outcomes Toolkit -	Personal safety
ASCOT (8 items)	 Social participation and involvement;
	Occupation
	Accommodation cleanliness and comfort
	Dignity (impact of service on self-esteem
	• Home
The Life Experiences	• Leisure
Checklist - LEC (16	• Freedom
items)	Opportunities
	Relationships
The Quality of Life	Satisfaction
Questionnaire - QOL-Q	Competence/Productivity
(39 items)	Empowerment/Independence Seciel Belowering (Integration
	Social Belonging/Integration
	Material Well-Being Bhysical Well Being
	Physical Well-Being Community Assocs
Life Circumstances	Community AccessRoutines
Questionnaire – LCQ (19	
items)	Self-Determination Secial Emotional Well Roing
	 Social-Emotional Well-Being Residential Well-Reing
	Residential Well-BeingGeneral Factors.

Table 4: Quality of Life Measurement Tools Reviewed			
Title	Domains		
The GENCAT Scale (69 items)	 Self-Determination. Interpersonal Relationships Personal Development Material Wellbeing. Emotional Wellbeing Physical Wellbeing 		
The San Martin Scale	 Personal Development Self-Determination Interpersonal Relationships Social Inclusion Rights Material Wellbeing Emotional Wellbeing Physical Wellbeing 		
The INICO-FEAPS Scale (2 subscales of 72 items)	 Emotional Wellbeing Interpersonal Skills Material Wellbeing Personal Development Physical Wellbeing Self-Determination Social Inclusion Rights 		
The Quality of Life Impact of Services Questionnaire -QOLIS (QOLIS -Full: 55 items; QOLIS Easy Read and Simplified: 29 items)	 Interpersonal Relations Self-determination Employability Citizenship Rights Material Wellbeing Emotional Wellbeing Physical Wellbeing 		
The Craig Handicap Assessment and Reporting Technique – CHART (32 items)	 Physical Independence Mobility Occupation Social Integration Economic Self-Sufficiency Cognitive Independence 		
The Craig Hospital Inventory of Environmental Factors – CHIEF (Full: 27 items; Short: 12 items)	 Policies Physical and Structural Work and School; Attitudes and Support Services and Assistance 		
WHO Disability Assessment Schedule Version 2.0 - WHODAS 2.0 (Full: 26 items; Short: 12 items)	 Cognition Mobility Self-care Getting along Life activities Participation 		

Table 4: Quality of Life Mo	easurement Tools Reviewed
Title	Domains
Impact on Participation and Autonomy Questionnaire – IPAQ (39 items)	 Autonomy Indoors Autonomy Outdoors Family Roles Social Relationships Paid Work and Education General Assimilation
Community Integration Measure – CIM (10 items)	 Support Occupation Independent Living
Reintegration to Normal Living Index – RNLI (11 items)	 Indoor, community, and distance mobility self-care daily activity (work and school) Recreational and social activities Family role(s) Personal relationships Presentation of self to others General coping skills
The Sense of Well-Being Inventory – SWBI (36 items)	 Psychological wellbeing Family and social wellbeing Financial wellbeing Medical care
The Canadian Occupational Performance Measures - COPM (27 items (5 monitored)	 Self-Care Productivity Leisure
Satisfaction with Life Scale – SWLS (5 items)	 Quality of Life Life conditions. Life satisfaction Life achievements Lack of regrets.
Quality of Life Index – QLI (Full: 66 items; Short: 33 items)	 Health and functioning Social and economic Psychological/spiritual Family
Life Satisfaction Questionnaire - LISAT-9 and 11) (9 or 11 items)	 Life as a whole Self-care Vocational situation Financial situation Leisure situation Sexual life Partner relations Family Life Contact w/ friends Physical Health Psychological Health The final two items are included in the LISAT 11

Table 4: Quality of Life Me	asurement Tools Reviewed
Title	Domains
Perceived Quality of Life	Physical Health Satisfaction
– PqoL (20 items)	Social Health Satisfaction
	Cognitive Health Satisfaction
Global QoL – GQOL (1 item)	• Perception of quality of life on a scale from 0 to 100
	Living situation
Multifaceted Life	Social/love relations
Satisfaction Scale –	Leisure/creativity
MLSS (Interview)	Community/ productivity
	Subjective Self-esteem/well-being
	Material Wellbeing
	Health
Comprehensive Quality	Productivity
of Life Scale - Com-QOL-	Intimacy
ID (35 items)	Safety
	Place in Community
	Emotional Well-Being
	Standard of living
	Personal Health
Personal Wellbeing	Achieving in life
Index 5th edition - PWI-	Personal Relationships
ID (7 or 8 items)	Personal Safety
	Community-connectedness
	Future security Californian (antion of)
	Spirituality/religion (optional)
	Health Services Service Servi
	 Family and Guardianship Income Maintenance
	 Education, Training and Employment
Quality of Life Interview	 Housing and Safety Transportation
Schedule -QUOLIS (48	TransportationSocial and Recreational
items)	 Religious and Cultural
	 Case Management
	 Advocacy
	 Counselling
	Aesthetics
	Learning and applying knowledge
	 Communication
	Mobility
	Self-care
Evaluation of Quality of	Domestic life
Life Instrument – EQLI	 Interpersonal interactions and relationships
(18 items)	 General tasks and demands (carrying out single or multiple task,
	organising routines and handling stress
	 Major life areas (engage in education, work and employment)
	 Community, social and civic life

9. Schalock/Verdugo QoL Impact Assessment Tools

In recent years, significant progress has been made in developing tools based on the framework developed by the Schalock/ Verdugo (Schalock, et al., 2002; Schalock & Verdugo, 2012, Gomez, Schalock & Verdugo, 2021). There is evidence that this framework is an 'influential academic QoL framework' (McCarron et al., 2018; p. 12). Given the broad acceptance of the model, it can be stated that it is the most appropriate choice for a framework that spans the community care and education and training sectors.

It is useful to describe four of these tools in more detail here.

The GENCAT scale: This is focused on social services and can be used with a wide variety of beneficiaries including persons with disabilities, older people, and people with mental health conditions. It facilitates an assessment of QoL outcomes by a third-party informant (proxy) nominated for an individual who is in receipt of services. Ratings must be based on systematic observations and a good knowledge of the person concerned. The instrument contains 69 items. Details are publicly available in ResearchGate from the authors (Gómez et al., 2013).

Respondents use a 4-point scale ranging from always to never to rate how the participant engages, or experiences, the theme of each item. It is a normed and standardised instrument. A Web-based application automatically calculates standard scores for each dimension and a QoL Index for the whole scale.

An important feature of the GENCAT is that scores are reported taking account of the Standard Error thereby controlling for random variation.

The San Martin Scale: This was developed subsequent to the GENCAT. It is designed to be used for persons with significant disabilities, persons with severe and profound intellectual impairment, persons with autism and intellectual impairment, and persons with severe cerebral palsy (Verdugo et al., 2014).

It allows a service provider or programme evaluator to assess the QoL of persons with significant disabilities through the ratings of a third-party informant (proxy) who knows the person well (at least for 3 months) and can observe the person for long periods of time in multiple contexts. The San Martin Scale and manual are available online.

INICO-FEAPS Scale: This instrument was development by the University Institute on Community Integration (INICO) at the University of Salamanca and the Spanish Confederation of Organisations in Favour of Individuals with Intellectual or Developmental Disabilities (FEAPS). It contains two subscales, one of which is a self-report and the other which is the report of another person who could be a professional or a family member (Verdugo, Gomez, Arias, et al., 2013). The tool generates an individual QoL profile and aggregated results for an organisation. It is intended for use with adults with intellectual or developmental disabilities. It can be administered on a one to one or group basis. The aim of the tool is to identify the QoL profiles of individuals in support of person-centred planning and to measure progress and the impact of individual plans. It has the capacity to highlight differences and congruence between an individual's perceptions of their QoL and the perceptions of those supporting the individual, either a professional or a family member. It has been evaluated for reliability and validity (Gomez, Verdugo, & Arias, 2015). Both subscales contain 72 items broken down into the eight factors of the Schalock/Verdugo model of QoL. The instrument is available free of charge (Verdugo, Gomez, Arias, B., Tassé, & Schalock, 2013).

Both subscales address the same content using a 4-point ranging from always to never. The selfreport scale is phrased in the first person, uses simpler language and can be administered with the support of an interviewer or independently. If a person is considered not to have the understanding or ability to communicate, the questionnaire can be complete by two people who know the individual well. This is effectively a proxy version.

The raw scores are transformed into standard scores for each QoL factor from which percentile ranks can be generated. A Composite QoL Index can be generated which combines the two sub-scales.

The Quality of Life Impact of Services Questionnaire (QOLIS): This is also based on the Schaolck/Verdugo model but adds an additional dimension to reflect the importance of employability in enhancing QoL. In the Schalock/Verdugo model employment is addressed under the dimension of material wellbeing. The QOLIS includes items that allow respondents to rate the extent to which they

feel that a service has prepared them for participation in work and the labour market.

It differs from the GENCAT and the San Martin Scale on two characteristics. Firstly, it is phrased in terms of the person who is the intended beneficiary rather than a third party, and secondly, the QOLIS is not a measure of a person's perception of their QoL but rather the extent to which a person perceives that participating in a program or receiving a support or intervention has enhanced their QoL (McAnaney, & Wynne, 2016).

The rationale underpinning the development of the QOLIS is that linking respondents' ratings of the perceived QoL directly to a programme, or intervention will provide the means for them to give relevant feedback to providers and professionals.

There are a number of advantages to this:

- Gaining an insight into the perceptions of participants is an important strategy in coproduction
- The direct focus on the impact of a specific programme, or intervention, eliminates the need to administer another measure of QOL twice (pre-post) and correlate the results
- The use of benchmarks, generated by collaborating professionals or organisations, rather than standard scores means that it can be customised to any context
- Interpretation of the score does not require an inference from self-reported QOL to a specific programme or intervention. The question is about the programme or intervention.

Three versions of the QOLIS are available.

- 1. QOLIS 16-1 has 55 items which are rated on a 6-point Likert scale from Totally Agree to Totally Disagree and uses standard language,
- 2. QOLIS-ER The Easy Read version has 29 items which are rated on a 6-point Likert scale from Totally Agree to Totally Disagree and expressed in more accessible language,
- 3. QOLIS-SR: The Simplified Rating scale version has 29 simplified language items which are rated on a 2-point scale meaning agree or disagree, supported by concrete examples and visual and gestural cues.

10. Concluding Remarks

This review used the IASSIDD and Schlock/Verdugo frameworks to analyse the literature on QoL in the community care and VET sectors and explored 33 different impact assessment tools aimed at measuring the QoL of services. Most of the QoL outcomes for both sectors that were identified, and the scales addressed in the assessment tools, could be classified using the domains and dimensions of the Schalock/Verdugo model.

The documents reviewed in the development of these guidelines span a wide range of contexts, participant characteristics, and service types. The purpose of this review was two-fold; to bring together ideas that could be used to develop more effective service mechanisms to promote enhanced QoL and appropriate tools to be used across sectors and service types to measure outcomes and impact.

A broad consensus was identified, that evolved over the past two decades, that QoL is an important impact of systems and services in both the community care and the VET sectors. The review of policy documents, research, and measurement tools identified a range of indicators related to QoL in both sectors. There are differences in the scope and focus of services aimed at enhancing independence and those targeted at participation in the world of work. These differences are described in terms of mechanisms, programme components, qualifications of staff, and how services are organised and funded. Nevertheless, the two sectors can be located on a pathway to inclusion in which enhanced personal development, social inclusion, and wellbeing are considered important outcomes (Lord, & Hutchinson, 2007; Rose, & Shevlin, 2021).

For some people, particularly those who are starting out in adult life, this pathway spans a number of sectors that are frequently viewed as being distinct silos of policy and provision. An aspiration of the QOLIVET partners is the belief that a seamless continuum of supports and interventions can bridge the progression and transition gaps between the health and social care and the VET sectors. It is also acknowledged that there is an alternative pathway leading to exclusion and dependency that often originates within the VET sector and that can be reversed through collaboration between sectors.

It is a prerequisite of an effective cross-sectoral system response that there is an underpinning framework that is compatible with the intended impacts of both sectors. This framework can be used to align priorities and monitor progress along the inclusion pathway. It is the contention of the QOLIVET partners that QoL impact has the potential to provide such a framework. This view is supported by the priority that QoL impact has accrued in both the health and social care sector and the VET sector over the past two decades.

It is acknowledged that conceptions of QoL vary between the sectors. In the health and social care sector QoL has become a matter of high policy priority in the move to community care from congregated living. In the VET sector, it is reflected in the increasing calls to broaden its scope beyond narrow technical and occupational competences to transversal skills, active inclusion, and citizenship.

The scope of the inclusion pathway addressed by the QOLIVET project can be described as covering health and social care service, transition, and vocational rehabilitation services and specialised and mainstream VET. It must not be assumed that the route along this pathway is linear, nor that the

steps are sequential. An effective pathway provides access to all these types of services at all stages of the journey to inclusion. For example, a person attending a mainstream VET course may need access to health or social care supports. Equally, a person participating in a social care service may need access to formal learning opportunities. It is likely that inter-agency and cross-sectoral collaboration is a core building block of any pathway to inclusion.

In addition to a unifying framework, QoL impact needs to be adopted as a key performance indicator across sectors so that progress along the inclusion pathway can be monitored and good practice can be identified. In this regard, it is important to acknowledge that there are a number of challenges that need to be addressed in creating a suitable suite of tools to measure QoL impact.

Firstly, QoL impact needs to be viewed as one of a variety of performance indicators in a comprehensive evaluation scheme. Secondly, concerns have been raised about the use of QoL questionnaires to evaluate the effectiveness of services. For example, one of the four factors in the Schalock QOL-Q cannot be considered stable (Kober, & Eggleton, 2002).

Thirdly, a systematic review of QoL measures for persons with intellectual disabilities and challenging behaviours concluded with the caveat that while QoL is an important outcome indicator, it is essential to avoid the 'tyranny of quality of life' (Townsend-White, Pham, & Vassos, 2012; p. 281). Fourthly, an overemphasis on QoL has the potential to ignore the subjective experience of the participant and miss out on other areas in which a person may be experiencing deprivation. A 'holistic' approach to QoL is required which includes participatory action research and evaluation to make sure that the characterisation of QoL is influenced by the subjective experiences of persons with disabilities (Townsend-White, Pham, & Vassos, 2012).

Finally, it is important that comparative measures are used which reveal the extent to which the QoL of participants falls short of what is acceptable for the general population even where an improvement in their QoL has been documented. This reflects the distinction between outcomes that are 'important to' and 'important for' participants.

Nevertheless, there is a strong case to be for adopting the Schalock/Verdugo framework as the basis for a QoL impact assessment tool that can be applied to health and social care, rehabilitation and transition and VET programs, interventions and supports.

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