



Enhancing the Quality of Life Impact of Services Good Practice Guidelines

September 2022

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

[Type here]

ACKNOWLEDGEMENTS

This publication is a direct result of the European project “QOLIVET - Enhancing the Quality of Life Impact of inclusive Vocational Education and Training and Community Care”, Reference Number: 2020-1-BE02-KA202-074781

The project is co-funded by the Erasmus+ Programme of the European Union. However, it is worth mentioning that the European Union's support for the production and publication of this publication does not constitute an endorsement of the content. It reflects the views only of the authors, and the Union cannot be held responsible for any use which may be made of the information contained therein.



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.

QOLIVET Partnership: The project partnership is led by the [European Platform for Rehabilitation - EPR](#) (Belgium).

The QOLIVET partners are:

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

Content Expert: Donal McAnaney Ph.D.

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

Contacts:

Roberto Zanon, Senior Project & Policy officer at EPR, QOLIVET Coordinator: rzanon@epr.eu,

Benedetta Pesce, Project & Administration assistant at EPR: bpesce@epr.eu

European Platform for Rehabilitation
Avenue des Arts 8, 1210 Brussels - Belgium

This Report should be cited as following:

QOLIVET Partnership. (2022). *Enhancing the Quality of Life Impact of Services: Good Practice Guidelines*. European Platform for Rehabilitation, Brussels, Belgium.



This work is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License

Table of Contents

Introduction..... 1

Background and Context 2

Towards a Definition of Quality of Life (QoL)..... 2

Generating the Good Practice Guidelines 6

QOLIVET Good Practice Guidelines 7

 Guideline 1: QoL is a fundamental impact of both community care and VET 7

 Guideline 2: QoL is multidimensional and influenced by personal and environmental factors..... 7

 Guideline 3: QoL has the same components for all people 7

 Guideline 4: QoL principles must underpin interventions and outcomes for persons with disabilities..... 8

 Guideline 5: QoL needs to be measured using both subjective and objective indicators 8

 Guideline 6: Enhanced QoL impact is an essential key performance indicator for services 8

 Guideline 7: Enhanced QoL implies respect, dignity, equality, inclusion, participation and rights... 8

 Guideline 8: Staff need to be equipped with the competences that impact on the QoL of participants through mandatory training 9

 Guideline 9: Meaningful participant involvement in service development leads to better QoL impact..... 9

 Guideline 10: Participants need to be actively involved in setting QoL goals and evaluating outcomes..... 9

 Guideline 11: Collaboration with communities and other agencies enhances QoL impact 10

 Guideline 12: Synergies between community care and VET are central to improving QoL impact 10

 Guideline 13: Community-wide awareness of QoL principles need to be promoted..... 10

 Guideline 14: QoL impact must be supported by system policies, processes and training..... 11

 Guideline 15: QoL outcomes can be enhanced through inclusive and person-centred strategies . 11

References..... 15

Introduction

The focus of the QOLIVET project is upon the quality of life (QoL) impacts of programmes and delivery mechanisms in community care and vocational education and training (VET). The target audience is anyone working in, or receiving, services, across the spectrum, from community care, independent living, and rehabilitation to services focused on developing pre-vocational and vocational knowledge and skills. The QOLIVET project builds on a benchmarking process supported by the European Platform for Rehabilitation over a number of years which explored how QoL could be used as an indicator to inform the continuous improvement of vocational rehabilitation and training for persons with disabilities.

The QOLIVET project set out to build the capacity of systems of delivery and services to impact more positively on the QoL of participants with disabilities. The mechanisms intended to achieve this aspiration include a set of good practice guidelines for services; an online training programme for staff and leaders; a forum to support constructive communication, collaboration and discourse within and between agencies operating in the different sectors of health and social care and VET; and a tool that can be used as part of a suite of indicators to allow service providers, in all sectors, to monitor their impact on the QoL from the perspective of participants and staff .

The QOLIVET approach is based on an approach to QoL first proposed by a special interest research group established by the International Association for the Scientific Study of Intellectual and Developmental Disability (IASSIDD) (Schalock *et al.*, 2002; Schalock, & Verdugo, 2002). The initial framework has been updated and refined over the years (Schalock & Verdugo, 2012, Gomez, Schalock & Verdugo, 2021). This model provides a lens to identify the domains and dimensions of QoL relevant to community care and VET.

The framework consists of eight dimensions (Wang, Schalock, Verdugo, & Jenaro, 2010; Schalock, Verdugo, & Lee, 2016)

1. **Personal Development** which includes educational attainments and status; cognitive, social and practical competences; and performance in terms of success, achievements and productivity.
2. **Self-Determination** which consists of personal control and autonomy; desires, expectations and values; and choices in terms of opportunities, options and preferences.
3. **Interpersonal Relations** which involve social networks and contact; relationships with friends, family and others; and supports.
4. **Social Inclusion** which covers community integration and participation; social roles and contributions; and access to services and supports.
5. **Rights** which include respect, dignity, equality, citizenship, access and due process.
6. **Emotional Wellbeing** which consists of contentment satisfaction, moods and enjoyment; self-concept, self-esteem and worth; and absence of undue stress.
7. **Physical Wellbeing** which covers health and functioning; fitness and nutrition; access to health care; and leisure, recreation and hobbies.
8. **Material Wellbeing** which covers financial status in terms of income and benefits; employment or work status and quality of the work environment; and housing or type of residence.

The components of the Schallock/Verdugo QoL model can provide a framework to help map the pathway to a rights-based approach to VET and community care services. 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).

Background and Context

An important concept that underpins the QOLIVET approach is that services need to be viewed as operating along a pathway to inclusion and autonomy (Lord, & Hutchinson, 2007; Rose, & Shevlin, 2021). For some people, particularly those who are starting out in adult life, this pathway spans across a number of sectors that are frequently viewed from a system perspective as being distinct silos of policy and provision. An aspiration of the QOLIVET partners is that a seamless continuum of supports and interventions can bridge the gaps between the health and social care, and the VET sectors, in particular, in order to enable progression and successful transition. It is also acknowledged that there is an alternative pathway leading to exclusion and dependency which often originates within the VET sector and which can be reversed through collaboration between sectors.

The focus of the QOLIVET project is upon people embarking on adult life, although many of the concepts described are derived from, or equally relevant to, inclusive learning at primary and secondary levels.

It is a prerequisite of an effective cross-sectoral system response that the underpinning framework is compatible with the intended impacts of both sectors and 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, and VET sectors 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 context of the drive towards community care from congregated living (McCarron *et al.*, 2018). 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 (Wheelahan & Moodie, 2016; Duffy, S. (2016).

The good practice guidelines presented here are intended to integrate these two perspectives using the IASSIDD model of QoL, described above. They are intended to reflect the foundational principles upon which a sustainable pathway to inclusion can be built and inform the other system capacity building mechanisms being developed by the QOLIVET project.

Towards a Definition of Quality of Life (QoL)

The World Health Organisation's WHOQOL Group (World Health Organisation, 1998) provided a definition of QoL which reflects the multidimensional characteristics of QoL. It describes QoL as 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' (1998;

p. 2). While the definition makes no reference to how QoL could be measured, the WHO conception of QoL is reflected in the WHOQOL tool (World Health Organization, 2012). It is an individual's perception of their position in life compared to their goals, expectations, standards, and concerns. It is a subjective view that is influenced by the culture and value systems in which they live. The WHOQOL suite of instruments reflect this position and it is fair to question why any additional tools are required? An important aspect of the WHOQOL approach is that it characterises QoL as being a subjective experience of the individual. It is generally accepted that objective measures of QoL are also required. It can be measured objectively using normative indicators and the observations of others using appropriate psychometric instruments.

Another challenge facing those responsible for developing systems or services is the relevance of effective QoL indicators to measuring quality and responsiveness in a way that is compatible with a continuous improvement process (National Disability Authority, 2010).

Consequently, ways to explore the QoL impact of both social services and VET have continued to be explored and debated for more than 20 years since the initial work of the WHOQOL group established its definition. Despite this effort, QoL impact has proved to be an elusive concept to pin down in terms of research and programme evaluation. Although there is an extensive history of the use of QoL indicators to measure the outcome of policies, programmes, and services across a diverse range of sectors, no universally accepted definition or measurement tool has evolved (Bowling, 2014).

The Status of QoL in Community Care

Within the health and social care sector, one factor that has increased the challenge of a commonly agreed definition is the diversity of interventions, supports, and terms used to refer to services including community care, independent living, social care, community living and, community integration. A definition of QoL needs to be able to encapsulate the impact of all of these. The distinction between health-related quality of life (HrQoL) (Makai *et al.*, 2014) and social care related quality of life (SrQoL) (Bowling, 2014) is one example of the challenge facing system and service developers, even within the same sector (Makai *et al.*, 2014). Many HrQoL measures request respondents to rate the gap between their present health and functioning and a desired state. In contrast, SrQoL measures focus on broader concerns such as self-determination, participation in life activities, and security. While HrQoL is important, gathering information about wider life experiences and on the extent to which a person is experiencing a life lived well is also crucial (Bowling, 2014).

While all people with disabilities, the elderly and others have the right to improve their QoL regardless of the place and level of dependency they show, the distinctions in the conceptions of QoL impact can differ within the health and social care sector depending on the intended outcomes of services. Services aimed at facilitating progression, such as transition from congregated settings to the community, from school to work, from youth to adulthood or from care to independent living, aspire to positive changes in a person's life. Other services are intended to maintain participants in their current circumstances and protect their independence, and security. The latter is an example of where the age of the intended beneficiaries or their type and level of impairment can influence the conceptions of QoL that are considered relevant (National Health Executive, 2017; Turid Midjo, & Ellingsen Aune, 2018; Wright, 2010; Connell, Carlton, J. Grundy, A., *et al.*, 2018; Bigby *et al.*, 2014; Mental Health Commission, 2007; Bowling, 2014).

The Status of QoL in VET

A broad consensus can be found in the literature and policy statements on VET that enhanced QoL is a clear outcome benefit of successful completion (Cedefop, 2011; 2013). However, there is a case to be made that, for many years, it was viewed as a subsidiary impact as a result of gaining productive employment and all that that can mean terms of life choices, and wellbeing. As a result, a narrow conception of what was, and was not, within the remit and responsibilities of VET providers predominated. Within the European project, VET was adopted as an important mechanism with broader goals such as fostering shared values, enabling young people to participate more successfully as citizens of Europe and engendering the meaning of good European citizenship (European Commission, 1997, p. 57).

Since the Lisbon Treaty (2000), the role of VET has been broadened still further, in a series of policy statements and documents issued by the European Commission, so that VET outcomes include its role in promoting social inclusion, cohesion, mobility, employability, and competitiveness (Lasonen, & Gordon, 2009; p. 20). More recently, there is a strong indication that the impact of VET on QoL, and physical and mental health, will be considered as significant outcomes in future work, lifelong learning and skills initiatives (European Training Foundation, 2020; p. 57).

It cannot be taken for granted by VET providers and policy makers that this impact can be achieved without the introduction of elements and mechanisms into VET programmes aimed explicitly at enhancing its QoL impact on participants. This imperative is reflected in the European Council's Recommendation on Key Competences for Lifelong Learning (The Council of the European Union, 2018) which is intended as a comprehensive framework for all sectors of education and training. The Recommendation emphasised as important outcomes the development of life skills, citizenship, participation in democracy, and social participation.

The review carried out by the QOLIVET project identified a broad consensus across many European actors, including the European Centre for the Development of Vocational Training (Cedefop, 2015); the International Labour Organisation (2004); the European Economic and Social Forum (2020); the Council of Europe (2018); the European Agency for Development in Special Needs Education (2013); and the European Commission (2000), that there is an onus on VET and other lifelong learning providers to promote personal development, interpersonal skills, citizenship skills, awareness of rights, healthy lifestyles, and wellbeing. These are all dimensions of the Schalock/Verdugo model of QoL developed for persons with developmental disabilities (Schalock, *et al.*, 2002; Schalock & Verdugo, 2012; Gomez, Schalock & Verdugo, 2021).

Creating Pathways to Inclusion

The scope of the inclusion pathway addressed by the QOLIVET project can be described as covering health and social care services, 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. The guidelines are based upon the assumption that greater participation in mainstream community activities, training, and work are valid aspirations to be addressed at all stages of the pathway to inclusion and for all people. It is also assumed that this will have a positive impact on a person's QoL.

A major challenge to be faced by management and staff of community care and VET providers, learners with additional needs and their representatives, and employers is that the proportion of persons with disabilities who are restricted in their participation in work is significantly higher than in the general population. This is particularly the case for those with intellectual impairments or mental health conditions. There is a case to be made that addressing employability or work ability at all stages of the pathway will increase the likelihood of successful transitions. Accessibility does not begin at the threshold to a mainstream training centre. It needs to extend into the community and other sectors to create barrier-free opportunities and bridging programmes to facilitate participation.

There is an equivalent challenge in responding to learners who are currently struggling to cope within the mainstream VET system. The limited participation in VET of people with a higher risk of exclusion, such as persons with disabilities, can reduce the impact of VET on social inclusion and, consequently, its impact on QoL (European Commission, 2000). It is fair to question what the QoL impact is upon those who fail to complete a program successfully. It is essential, at the very least, that VET programs and procedures do not disable learners with additional individual learning needs and, more importantly, that the design of VET programs includes components and mechanisms that are intended to directly enhance personal capabilities, promote social inclusion, and increase wellbeing.

The guidelines proposed here are based on the premise that addressing the additional needs of participants, regardless of whether they are participating in community care, specialised or mainstream VET, requires that organizations adapt and change their values, management processes and evaluation procedures to ensure that:

- Inclusive learning approaches are adopted,
- Personalised learning plans guide the process,
- Active involvement of the person is standard practice,
- Learning opportunities, materials and environments are universally designed,
- Physical and psychosocial barriers are removed or reduced,
- Negative attitudes and stigma have been eliminated,
- Appropriate assistive technologies and accommodations are readily available,
- Staff have been properly trained in the application of flexible approaches,
- The rights of participants are respected,
- Personal assistance is provided when required.

In systems where QoL impact is valued as an intended outcome and measured as a key performance indicator, the above strategies are likely to result in more responsive and higher quality interventions and supports at all stages of the pathway to inclusion.

Generating the Good Practice Guidelines

The guidelines presented here are informed by a systematic search of the peer reviewed and grey literature; research evidence; web resources; training courses; learning resources; QoL assessment tools; and VET evaluation tools. The aim was to identify any relevant evidence that could cast a light on useful ways in which QoL outcomes have been addressed in policy; valued by funders; measured by providers; detailed in programme specifications; included in quality guidelines and explored by researchers. Broadly, two separate searches were carried out. One focused on VET and the other explored community care services.

The documents reviewed in the development of these guidelines span a wide range of contexts, participant characteristics, and service types. The aim is to bring together thinking that can 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. The results and conclusions of this process can be reviewed in the QOLIVET Synthesis Report (QOLIVET Partnership, 2022).

The findings of the research and analysis process were shared with key staff from each of the partners during a three-day seminar. They were facilitated to propose the themes that need to be prioritised in a system of service delivery that aims to enhance the QoL of participants. The outputs of the seminar were circulated to partners and a consensus was reached on 15 guidelines. These were submitted to an expert in the field for review whose feedback guided a final revision. The resulting guidelines are present below.

QOLIVET Good Practice Guidelines

Guideline 1: QoL is a fundamental impact of both community care and VET

A broad consensus has 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. A review of policy documents, research and measurement tools identified a range of indicators that 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 in terms of mechanisms, programme components, qualifications of staff and how they are organised and funded. Nevertheless, the two sectors can be located on a pathway to inclusion in which enhanced independence, social participation and wellbeing are considered important outcomes.

Guideline 2: QoL is multidimensional and influenced by personal and environmental factors

All policies and tools that address QoL are based on models that characterise it as having multiple dimensions. Although there is a wide variation in the terminology and concepts that are proposed, all of the concepts can be assigned to one of the dimensions of the Schalock/Vergudo model developed (Schalock *et al.*, 2002; Schalock & Verdugo, 2012; Gomez, Schalock & Verdugo, 2021). Specifically, QoL impact can be described in terms of:

- Personal Development
- Self-Determination
- Interpersonal Relations
- Social Inclusion
- Rights
- Emotional Wellbeing
- Physical Wellbeing
- Material Wellbeing

It is also broadly recognised that a person's view of what is valued is influenced by their values which are in turn influenced by their interaction with family, school, and community. It is widely accepted that conceptions of QoL cannot be separated from the cultural ethos in which a person lives.

Guideline 3: QoL has the same components for all people

QoL is a universal concept that is relevant to all people regardless of their personal characteristics or socioeconomic status. The QoL of an older person or a person with a disability can be described using the same concepts as those applicable to the rest of the population. Although, specific life concerns and support needs may well differ, the same QoL domains and dimensions can be used to describe the extent to which a person is achieving their aspirations for a life well lived in terms of family life, friendships, work, housing, health, education, and standard of living. Nevertheless, the indicators and items to measure the quality of life of these dimensions can vary according to the population to be worked with (age, type of disability, severity of disability, etc.).

Guideline 4: QoL principles must underpin interventions and outcomes for persons with disabilities

The principles of QoL need to inform the approach adopted to service delivery in both the community care and VET sectors. Quality organisations can be characterised as those that use information on individual progress against standards in a continuous improvement process aimed at improving QoL outcomes for participants. Assessment of needs must explore the aspects of QoL in which a person requires support and identify the barriers to a positive QoL in a person's context. Person-centred planning must aim to remove or reduce the barriers to a better QoL and build the person's capacity to participate more fully in a life well lived. A QoL informed approach is relevant across a wide variety of service performance indicators, mission statements, service contracts, and policy statements, regardless of the sector or the jurisdiction in which an organisation operates.

Guideline 5: QoL needs to be measured using both subjective and objective indicators

QoL impact can be viewed from the perspective of an individual (subjectively) or society (objectively). Both objective and subjective measures of QoL have been adopted as part of the system of social indicators. Objective QoL indicators are concerned with the external and easily established conditions of life that many observers can rate identically including accepted features of a life of quality such as material possessions, social connectedness and participation. Subjective QoL indicators are generally gathered through self-report tools which allow people to rate the extent to which they view life as being good i.e., the degree of satisfaction a person experiences in key domains of life. Both types of indicators are essential to gain an understanding of the QoL impact of a service for participants. One approach is to measure QoL the "subjective" view to the perception a service user, and the "objective" to the opinion resulting from the direct observation of a family member or professional.

Guideline 6: Enhanced QoL impact is an essential key performance indicator for services

Given the wide acceptance that enhanced QoL is a core impact of services and systems, quality management systems need to include key performance indicators (KPIs) to monitor the extent to which this impact is being achieved by participants. It is essential that both types of measurement are used: objective measures of QoL to explore how QoL conditions compare to societal norms and subjective measures to gather information on the perceptions of participants of the QoL impact of the service. Service and system leaders must promote enhanced QoL as a priority impact and ensure that progress towards improved performance is monitored by quality systems, results in continuous improvement and is reported to stakeholders and boards of management.

Guideline 7: Enhanced QoL implies respect, dignity, equality, inclusion, participation and rights

An organisation that is committed to achieving positive QoL impact must ensure that its values and ethos reflect the core principles of ethical and equitable practice. It must guarantee that: individuals are treated with respect and dignity; its processes and procedures support equality of status and access; its practices are inclusive and responsive; participants are aware of their rights and can actualise these; and strenuous efforts are invested in supporting participants to actively participate in the development, design and evaluation of personal plans and programme components.

Guideline 8: Staff need to be equipped with the competences that impact on the QoL of participants through mandatory training

Staff commitment is an essential factor in achieving positive QoL outcomes. Equipping staff with the skills and attitudes required to provide active support is central to linking resource inputs to the quality of outcomes and can result in enhanced choice and participation. The creation of inclusive and enabling environments, and experiences, depends significantly on the extent to which these are supported by staff.

Staff need to be educated in the skills and strategies to provide the active support that participants deserve to define who they are, engage in personal growth, develop a positive self-concept and become agents in their own life change. Given the importance of staff commitment in achieving effective QoL impact, staff training must be seen as a mandatory service improvement mechanism.

The participation of participants and their representatives in staff training is an important form of evidence-based training. At the very least, all staff need to be equipped with the skills and attitudes required to place learners' abilities at the centre of their approaches; see opportunities rather than challenges; focus on what people 'can' do, not what they 'cannot' do and foster confidence and assertiveness in participants.

Guideline 9: Meaningful participant involvement in service development leads to better QoL impact

Systems and services need to be engineered to achieve more positive outcomes as defined by persons with disabilities themselves. Meaningful measures of QoL and independence can provide an indication of progress towards this aspiration. A measure of participants' perceptions of the extent to which the services they receive are positively impacting on their QoL can make an important contribution to co-production and universal design. The experience and insights of participants and their representatives are important evidence to inform innovation, training and practice. More active participation by participants can be achieved by involving them in a consumer-orientated design process, perhaps through focus groups or other means of gaining feedback. Similarly, participation in the governance processes of organisations can create a greater consensus between staff and participants on intended objectives.

Guideline 10: Participants need to be actively involved in setting QoL goals and evaluating outcomes

It is essential to operate on the assumption that a person knows what is of value to them and that their perceptions of QoL are neither right nor wrong. Participants must be confident that their voices are acknowledged and heard by the service provider. This can be achieved by enabling active involvement right from the initial stages of their assessment of needs, through the development and implementation of a person-centred plan to the evaluation of progress towards their goals. This can require mechanisms and assistive devices to facilitate participation or communication and access to independent advocacy or assisted decision making for those who require it. Inequalities of power must be acknowledged and procedures need to be in place to reduce the impact of this on an individual participant's esteem and confidence. Where required, a participant's circle of support/independent adviser can be important co-participants in the process. Person-centred plans must be easy-to-use, available in accessible formats,

considered to be living documents and be reviewed and revised based on the feedback from both participants and staff.

Guideline 11: Collaboration with communities and other agencies enhances QoL impact

From a system perspective, equality of access is not something that operates at the threshold of a service but an objective that needs to inform every stage of an inclusion pathway. The involvement of community actors and organisations that offer opportunities different to those available within a service are prerequisites for enhanced QoL impact and the extension of service outcomes to community (labour market) outcomes. There is a responsibility on inclusive services to plan for transition and offer opportunities to learn from ‘real life’ experiences. This is the case for both community care and VET services. 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. Collaboration with community actors and complementary agencies can bridge the gap between contexts and sectors for people progressing along the pathway to inclusion but equally, it can act as a preventative measure for those who are on a pathway to exclusion and dependency as a result of withdrawal from mainstream services.

Guideline 12: Synergies between community care and VET are central to improving QoL impact

To enhance the impact of inclusive and equitable lifelong learning, key components need to be integrated into community care and VET programs to assist participants to learn how to learn and attain literacy and numeracy, transversal skills, and citizenship skills. Community care services have developed expertise and accrued experience in fostering personal growth, promoting social participation and providing environmental supports. Inclusive VET services have developed a range of methodologies and mechanisms to nurture effective learning skills and design accessible learning environments and processes. An effective inclusion pathway must provide 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. Inter-agency and cross-sectoral collaboration are core building blocks in any pathway to inclusion. Greater participation in community activities, training and work are valid aspirations to be addressed at all stages of the pathway and for all people.

Guideline 13: Community-wide awareness of QoL principles need to be promoted

QoL outcomes and impacts need to be achieved not within the confines and limits of a service but in wider society. From both a community care and VET perspective, this implies increased participation in the life of the community, a valued social status and engagement in productive work. From a biopsychosocial perspective, it is essential that services identify and address the environmental barriers to increased participation in a person’s life. Negative attitudes and stigma represent a significant psychosocial barrier to participation which needs to be addressed. Direct experience of working alongside or relating to persons with disabilities is the most effective way to reduce stigma. There is an onus on service providers to engage with community actors and employers to create opportunities for participants to be involved in promoting positive attitudes and dismantling discriminatory stereotypes. Raising awareness of the importance of personal development, social inclusion, citizenship, and wellbeing can contribute to a community in which both physical and attitudinal barriers are reduced.

Guideline 14: QoL impact must be supported by system policies, processes and training

To achieve enhanced QoL impact, there is a requirement for systems of delivery to strive to create more responsive opportunities for people at risk of exclusion. It is essential to synchronise the individual level (direct support practices), organizational practices, and development of public policies in order to sustain changes or advances achieved in quality of life over time. There is a need to improve the vertical and horizontal alignment of the three levels of the system (Schalock et al., 2018; Schalock & Verdugo, 2013).

The European Pillar of Social Rights can provide a basis for specifying the domains of action that need to be addressed. Specifically, community care and VET systems must address the right, regardless of an individual's personal characteristics including disability, to equal treatment and opportunities in the domains of employment, social protection, education, and access to goods and services.

The goal of a more inclusive society is often specified in global policy objectives. The challenge is to transform this aspiration into responsive person-facing interventions and supports that are adapted to the needs and strengths of each participant regardless of gender, ethnicity, age, disability or location. This requires a unifying conceptual framework that can span the silos of policy and administration and generate impact indicators to monitor progress along the pathway to inclusion at all levels including the system, services, and the individual. QoL impact has the potential to serve as such a framework.

Guideline 15: QoL outcomes can be enhanced through inclusive and person-centred strategies

Proactive and responsive interventions and services are acknowledged as essential mechanisms in enabling participants to progress towards their aspirations for an enhanced QoL. A variety of terms have been used to refer to such approaches including self-directed support; self-directed services; consumer-directed services; person directed services; independent living; consumer control; self-determination; and individualised funding. All of these approaches are based on the fundamental principle that for a person with a disability to participate and contribute as an equal citizen, they must have choice and control over the resources and supports they need to go about their daily lives. 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 families or carers.

This principle is implicit in learner-centred approaches in VET services in which participants are genuinely active participants in setting goals and developing learning plans. Person-centred planning in community care services is based on a similar engagement with participants and is a core mechanism to enable choice and control. The starting point for responsive, person-centred services is an assessment of what a person desires and needs to participate independently in the community.

Inclusive policies are based in the premise that differences among people is the norm and this must be integrated into system and organisational culture. Inclusive systems encourage acceptance of diversity and underpin equality of opportunity. They are based on the principle that services need to be designed and delivered in ways that cater for the widest possible range of abilities through a broad range of flexible and responsive approaches. One effective approach to enhancing inclusivity is a collaborative approach between actors in different settings and sectors.

The strategies described below are widely accepted as being particularly useful in achieving more person-centred and inclusive services and reflect the Quality of Life Supports Model which advocates for inclusive environments, generic supports, and QoL support and facilitating conditions (Gomez et al., 2021; Verdugo et al., 2021).

Person-centred delivery and organisational ethos

Given the diversity among persons with disabilities, it is essential to operate responsive processes that facilitate each person in the design of a context that meets their needs. An important mechanism that can support this approach is the personalisation of progression paths based on individual needs. In a VET context, implementing targeted measures and flexible training formats, based on a personalised plan, can prevent early withdrawal from formal learning, support transition to work and increase the participation of persons with disabilities. In a community care context, creating a set of targeted and customised interventions and supports, based on a person-centred assessment and planning process, can increase the potential for genuine community participation and personal growth.

A person-centred mode of delivery can only be achieved within an organisational culture and ethos which prioritises the person's right to choice, control, respect, dignity, and rights, uses valid indicators to monitor its person-centred processes and strives to enhance them through a continuous quest for improvement.

A holistic and biopsychosocial approach

An importance premise of person-centred and inclusive approaches is that disability is not a state of being nor an individual trait but rather a dynamic process in which the person's interaction with their environment results in restricted participation in life and the community. A biopsychosocial or holistic approach contends that it is possible through effective interventions and supports to reduce the disability experienced by an individual. A biopsychosocial framework can support a holistic assessment of needs and strengths, in collaboration with the participant, to form the basis of a joined up and coordinated plan to build their capacity, introduce supports and assistive devices and remove or reduce barriers to participation.

Creating opportunities to develop self-determination and decision making

Every person needs the social and personal resources that can allow them to live the type of life they value. This can only be achieved if participants are empowered to make an active contribution to developing their own pathway to inclusion. To make a meaningful contribution to the planning process, they need to have certain personal competences. Self-determination, problem solving, and decision making are important personal competences in achieving life goals. These can be developed through direct training but they need to be practiced in real life contexts. Facilitated participation in a person-centred planning process provides an opportunity to foster these skills (Sala et al., 2020).

Fostering personal and interpersonal competences

Interpersonal relationships are at the heart of a life lived well. Being able to develop and maintain positive and constructive relationships with family and friends and to relate effectively with strangers and those in authority are critical competences for successful social participation. In a work context, being able engage in team work and relate to co-workers are valued characteristics. In a social setting, being able to engage

in interactions with others and put them at their ease is a valued skill. Successful intimate relationships are built upon effective personal and interpersonal competences. Experiential learning is more effective than formal instruction as a means of developing and practising such competences. Consequently, the person-centred planning experience must provide participants with the opportunity to explore and understand their personal and interpersonal skills (Sala et al., 2020).

Encouraging empathetic and positive communication

Effective communication skills are an important attribute that can assist participants in the quest for increased social participation. They are also an essential attribute of effective workers and managers. While formal training in communication skills can expose participants to the basic processes, it is essential that staff who interact with participants practice empathetic and positive communication. Not only does this have the potential to enhance participants' sense of identity and self-esteem, it also provides them with models of how best to interact with others and express their needs and desires.

Building resilience in the face of challenges

Being overwhelmed by challenges can be a substantial source of stress for any individual. Over a quarter of all workers identify stress as a significant concern. Failure to cope effectively with stress can lead to both physical and mental health conditions. Resilience in the face of negative stress is a useful personal characteristic. It has two components. The first is having the personal coping strategies to deal with adversity, such as finding healthy ways to reduce tension and negative emotions. The second is being able to adapt the environment so that negative stressors are reduced or support is available. Learning how to manage stress through relaxation and appropriate assertiveness can increase a participant's resilience and have a positive impact on their perceptions of QoL.

Inclusive strategies and settings

There is an onus on service providers in both the community care and VET sectors to create more accessible and inclusive learning environments and approaches. Inclusive lifelong learning is an important mechanism that can redress some of the disadvantages and vulnerabilities faced by persons with disabilities. In a VET context, it can reduce withdrawals and drop outs and increase the participation of learners with additional needs. In a community care setting, it can equip participants to become more independent in managing their own learning and prepare them for participation in formal learning settings. Inclusive strategies and settings are best developed in collaboration with participants and their representatives in a co-production process. They need to address both the physical and psychosocial characteristics of the learning context including the ethos and attitude, the format of content, the accessibility of materials and resources, the flexibility of learning methods and the appropriateness of assessment procedures. A person-centred approach and ethos are the building blocks of an inclusive setting.

Universally designed environments and processes

Universal Design (UD) and Universal Design for Learning (UDL) provide a useful basis for developing inclusive services and settings (Quirke & McCarthy, 2020). The premise upon which they are based is that it is significantly more efficient and economical to incorporate the diverse characteristics of people into settings, services, products and procedures at the design stage rather than having to accommodate them retrospectively. Effective UD and UDL can only be achieved through collaboration and co-production with

current and potential participants and their representatives. In the community care sector, the aspiration is to develop universally designed and accessible public services to support persons with disabilities to gain and sustain optimum physical, mental, and emotional wellbeing. The aspirations of the VET sector are strikingly similar.

Access to appropriate assistive technologies

In the case where physical or psychosocial environmental barriers cannot be removed, the provision of an assistive device can significantly enhance a person's independence. Assistive devices range from low-tech aids, such as a magnifier or a rollator, to high-tech devices, such as augmentative and alternative communication systems (Annicchiarico, 2012; Minnesota's Guide to Assistive Technology, n. d.). With the onset of the digital age, assistive technologies are proliferating and are becoming more affordable every day. It is essential that staff in community care services are aware of the potential for assistive technology to transform a participant's life. It is equally important for VET staff to know about the latest developments in assistive devices to support learning. The effective deployment of assistive devices requires that each person is matched to the technology that meets their needs through a biopsychosocial assessment process and that they, their family and support network receive training in how best to use the technology.

Matching supports and interventions to identified needs

The starting point for responsive, person-centred services is an assessment of what a person needs in order to participate independently in the community or the labour market. The assessment must explore needs and strengths. It must document the personal assets that a person brings to the process and the areas where additional support and interventions will be required to meet their aspirations. In the community care sector, this may include an assessment of recreational, social and personal development needs, learning and work needs and, where appropriate, the needs of family and carers. In the VET sector, this will focus more specifically on vocational aspirations, aptitudes, interests and learning support needs. An important principle in the assessment process is that strengths and needs can be characteristics of the person or exist within their environment. The purpose of the planning process is to build on the person's strengths and introduce interventions or supports to address their needs.

Healthy balance between QoL outcomes 'Important To' and 'Important For' the person

Person-centred and inclusive services prioritise and privilege the goals and aspirations of the participant. However, it is important that they also take a more objective view of a participant's life circumstances particularly in relation to how the person might gain a better QoL in ways of which they are not currently aware. It is also important to acknowledge that services need to achieve the outcomes that have been specified in the service contract. Comparative measures need to be used to reveal the extent to which the QoL of participants falls short of what is acceptable for the general population even where they have rated their own QoL to be improving. Person-centred services will balance outcomes that are 'important to' a participant with those that are 'important for' them. In the community care sector, this could be ensuring that a person develops more effective self-care skills. In the VET sector, it could be insisting that a person learns how to deal with conflict.

References

- Annicchiarico, R. (2012). Enhancing Service Delivering, Improving Quality of Life, Preserving Independence through Assistive Technology. In John Mantas, Stig Kjær Andersen, Maria Christina Mazzoleni, Bernd Blobel, Silvana Quaglini, and Anne Moen (Eds.), *Quality of Life through Quality of Information*. IOS Press Ebooks. <https://ebooks.iospress.nl/ISBN/978-1-61499-100-7>
- Bigby, C., Knox, M., Beadle-Brown, J., & Bould, E. (2014). Identifying Good Group Homes: Qualitative Indicators Using a Quality of Life Framework. *Intellectual and Developmental Disabilities*, 52(5): 348-366. https://www.researchgate.net/publication/265970866_Identifying_Good_Group_Homes_Qualitative_Indicators_Using_a_Quality_of_Life_Framework
- Bowling, A. (2014). *Quality of life: Measures and Meanings in Social Care Research*. NIHR School for Social Care Research. London School of Economics and Political Science. <https://eprints.soton.ac.uk/373668/1/MR16.pdf>
- Cedefop. (2011). *The Benefits of Vocational Education and Training*. Author. Publications Office of the European Union.
- Cedefop. (2013). *Benefits of Vocational Education and Training in Europe for People, Organisations and Countries*. Author. Publications Office of the European Union.
- Cedefop. (2015). *Stronger VET for Better Lives: Cedefop's Monitoring Report on Vocational Education and Training Policies 2010-14*. Publications Office of the European Union. https://www.cedefop.europa.eu/files/3067_en.pdf
- Connell, J., Carlton, J., Grundy, A., et al. (2018). The Importance of Content and Face Validity in Instrument Development: Lessons Learnt from Service Users when Developing the Recovering Quality of Life Measure (ReQoL). *Quality of Life Research*, 27: 1893–1902. <https://doi.org/10.1007/s11136-018-1847-y>
- Council of the European Union. (2000). *The Lisbon European Council: Presidency Conclusions*. Author. https://www.europarl.europa.eu/summits/lis1_en.htm
- 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](https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32018H0604(01)&from=EN)
- Duffy, S. (2016). *Citizenship and the welfare state*. Sheffield, UK: Centre for Welfare Reform
- European Agency for Development in Special Needs Education. (2013). *European Patterns of Successful Practice in Vocational Education and Training Participation of Learners with SEN/Disabilities in VET*. Author. https://www.european-agency.org/sites/default/files/vet-report_en.pdf

- European Commission. (1997). *Accomplishing Europe through Education and Training*. Office for Official Publications of the European Communities. https://www.selpipes.com/uploads/1/2/3/3/12332890/1997_-_accomplishing_europe_through_education_and_training.pdf
- European Commission. (2000). *A Memorandum on Lifelong Learning: Commission Staff Working Paper SEC(2000) 1832*. Author. https://arhiv.acs.si/dokumenti/Memorandum_on_Lifelong_Learning.pdf
- European Economic and Social Forum. (2020). *Opinion on Sustainable Funding for Lifelong Learning and Development of Skills*. EESC 2019/4762 - SOC/629, OJ C 232, 14.7.2020, p. 8–17. <https://www.eesc.europa.eu/en/our-work/opinions-information-reports/opinions/sustainable-funding-lifelong-learning-and-development-skills-context-shortage-skilled-labour-exploratory-opinion-request>
- European Training Foundation. (2020). *Social Inclusion High on EU Policy Agenda*. Author. <https://www.etf.europa.eu/en/news-and-events/news/social-inclusion-high-eu-policy-agenda>
- Gomez, L., Schalock, R., & Verdugo, M. (2021). A quality of life supports model: Six research-focused steps to evaluate the model and enhance research practices in the field of IDD. *Research in Developmental Disabilities*, 119: 104112.
- International Labour Organisation. (2004). *Vocational Rehabilitation and Employment of People with Disabilities: Report of a European Conference*. Author https://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_106627.pdf
- Lasonen, J., & Gordon, J. (2009). Improving the Attractiveness and Image of VET. In, Cedefop (Ed.), *Modernising Vocational Education and Training. Fourth Report on Vocational Training Research in Europe: Background Report, Volume 3*, pp. 15-88. Office for Official Publications of the European Communities. https://www.cedefop.europa.eu/files/3050_3_en.pdf
- Lord, J & Hutchinson, P. (2007). *Pathways to Inclusion: Building a New Story with People and Communities*. Captus Ontario, CA: Press.
- Makai, P., Brouwer, W., Koopmanschap, M., Stolk, E., & Nieboer, A. (2014). Quality of Life Instruments for Economic Evaluations in Health and Social Care for Older People: A Systematic Review. *Social Science & Medicine*, 102: 83-93. <https://doi.org/10.1016/j.socscimed.2013.11.050>.
- McCarron, M., Lombard-Vance, R., Murphy, E., O'Donovan, M., Webb, N., Sheaf, G., McCallion, P., Stancliffe, R., Normand, C., Smith, V. & May, P. (2018). *Quality of Life Outcomes and Costs Associated with Moving from Congregated Settings to Community Living Arrangements for People with Intellectual Disability: An Evidence Review*. Health Research Board. https://www.hrb.ie/fileadmin/publications_files/Quality-of-life__outcomes_and_costs_living_arrangements_for_people_with_an_intellectual_disability_2018.pdf

- Mental Health Commission (2007). *Quality Framework Mental Health Services in Ireland*. Author. <https://www.mhcirl.ie/File/qframemhc.pdf>
- Minnesota's Guide to Assistive Technology (n. d.) *Types of Assistive Technology (AT)*. <https://mn.gov/admin/at/getting-started/understanding-at/types/>
- National Disability Authority. (2010). *Developing Services for People with Disabilities: A Synthesis Paper Summarising the Key Learning of Experiences in Selected Jurisdictions as at October 2010*. Author. <http://nda.ie/Policy-and-research/Research/Research-Publications/Developing-Services-for-People-with-Disabilities/Developing-Services-for-People-with-Disabilities-A-Synthesis-Report.html>
- National Health Executive. (2017). *NICE to Review Quality of Life Measures across Health and Social Care*. Author. <https://www.nationalhealthexecutive.com/Health-Care-News/nice-to-review-quality-of-life-measures-across-health-and-social-care>
- QOLIVET Partnership. (2021). *Measuring the Quality of Life Impact of Care, Education and Training: Summary Synthesis Report*. European Platform for Rehabilitation, Brussels, Belgium.
- Quirke, M., & McCarthy, P. (2020). *A Conceptual Framework of Universal Design for Learning (UDL) for the Irish Further Education and Training Sector*. SOLAS. <https://www.solas.ie/f/70398/x/948bcabcc4/udl-for-fet-framework.pdf>
- Rose, R., & Shevlin, M. (2021). *Establishing Pathways to Inclusion: Investigating the Experiences and Outcomes for Students with Special Educational Needs*. UK: Routledge.
- Sala, A., Punie, Y., Garkov, V., & Cabera, M. (2020). *LifeComp: The European Framework for Personal, Social and Learning to Learn Key Competence*. Joint Research Centre. <https://publications.jrc.ec.europa.eu/repository/handle/JRC120911>
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D. & Parmenter, T. (2002). Conceptualization, Measurement, and Application of Quality of Life for Persons with Intellectual Disabilities: Report of an International Panel of Experts. *Mental Retardation*, 40(6): 457–470. DOI: 10.1352/0047-6765(2002)040<0457:CMAAQ>2.0.CO;2
- Schalock, R. L. & Verdugo, M.A. (2002). *Handbook on quality of life for human service practitioners*. Washington D.C.: American Association on Mental Retardation.
- Schalock, R. L. & Verdugo, M.A. (2012). *A Leadership Guide to Redefining Intellectual and Developmental Disabilities Organizations: Eight Successful Change Strategies*. Baltimore: Brookes.
- Schalock, R., & Verdugo, M. (2013). The transformation of disabilities organizations. *Intellectual and Developmental Disabilities*, 51(4), 273-286 doi:10.1352/1934-9556-51.4.273
- Schalock, R.L., Verdugo, M.A., & Lee, T. (2016). A systematic approach to an organization's sustainability. *Evaluation and Program Planning*, 2016, 56, 56-63. doi: <http://dx.doi.org/10.1016/j.evalprogplan.2016.03.005>

- Schalock, R., Verdugo, M., & van Loon, J. (2018). Understanding organization transformation in evaluation and program planning. *Evaluation and Program Planning*, 2018, 67, 53-60. doi: 10.1016/j.evalprogplan.2017.11.003
- Turid Midjo, T., & Ellingsen Aune, K. (2018). Identity Constructions and Transition to Adulthood for Young People with Mild Intellectual Disabilities. *Journal of Intellectual Disabilities*, 22(1):33-48. DOI: 10.1177/1744629516674066.
- Verdugo, M., Navas, P., Gómez, L. & Schalock, R. (2012). The Concept of Quality of Life and its Role in Enhancing Human Rights in the Field of Intellectual Disability. *Journal of Intellectual Disability Research*, 56(11): 1036–1045.
- Wang, M., Schalock, R. L., Verdugo, M. A., & Jenaro, C. (2010). Examining the factor structure and hierarchical nature of the quality of life construct. *American Journal on Intellectual and Developmental Disabilities*, 115, 218– 233. doi: 10.1352/1944-7558-115.3.218
- Wheelahan, L., & Moodie, G. (2016). *Global Trends In TVET: A Framework for Social Justice*. Education International.
https://www.researchgate.net/publication/310328472_Global_trends_in_VET_a_framework_for_social_justice_A_contribution_by_Education_International
- World Health Organisation (1998) *WHOQOL User Manual*. CH: Author.
<https://www.who.int/publications/i/item/WHO-HIS-HSI-Rev.2012.03>
- World Health Organization (2012). *The WHOQOL Guidance (normative)*. CH: Author.
<https://www.who.int/publications/i/item/WHO-HIS-HSI-Rev.2012.03>
- Wright, K. (2011). *Transition from Children’s to Adults’ Services for Young People Aged 14 to 25 in Westminster*. *Westminster Joint Strategic Needs Assessment*. Westminster City Council.
<https://www.jsna.info/sites/default/files/JSNA%20Westminster%202011%20Transition%20to%20Adult%20Services.pdf>