





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

# Synthesis Report

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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.

**QOLIVET Partnership:** The project partnership is led by the <u>European Platform for Rehabilitation - EPR</u> (Belgium).

# The QOLIVET partners are:

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

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More info on the project is available here: <a href="http://www.epr.eu/qolivet/?page\_id=4072">www.epr.eu/qolivet/?page\_id=4072</a>

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#### Rationale

It is important from the outset to establish the lens that this project has adopted. The focus of the QOLIVET project is upon the quality of life (QoL) impacts of programme and delivery mechanisms and the scope covers health and social care and vocational education and training. The target audience is any one working in, or receiving, services, across the spectrum, from social care, independent living and rehabilitation to services focused on developing pre-vocational and vocational knowledge and skills. The measurement tool is designed to capture the perceptions of both staff and participants of the extent to which a service or program has enhanced QoL as a means of enhancing the relevance and effectiveness of service or program components and methods of delivery.

The QOLIVET project builds on a benchlearning 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 EPR process utilised a framework for QoL which was based in the work of Robert Schalock (1996). He identified eight critical components of quality of life: emotional well-being; interpersonal relations; material well-being; personal development; physical well-being; selfdetermination; social inclusion; and rights. This informed the work of a research working group of the International Association for the Scientific Study of Intellectual Disabilities (IASSIDD) (Schalock et al., 2002). The group worked in three teams over a period of 24 months to develop a multi-element framework of quality of life that was intended to be relevant at the levels of public policy, evaluation of services, innovation and the identification of support need of individuals. The group proposed a set of principles and guidelines to guide researchers and professionals in implementing initiatives relating to QOL.

The purpose of the research and analysis action in the QOLIVET is to ensure that the state of the art in a number of domains is available to inform the development of the innovative tools. While a substantial amount of endeavour has been expended through previous initiatives in which the partners were involved, this project expands the scope beyond services designed specifically to support people with disabilities to include mainstream VET services and inclusive community services. This required that a broader review of the QoL across these domains.

The outputs of the research and analysis action are intended to provide a basis for:

- Developing a training program for VET professionals and community support staff,
- Creating a good practice resource and portal,
- Producing a set of guidelines for enhancing the QoL impact of both mainstream and specialist services,
- Designing assessment tools to allow organisations to develop key performance indicators reflecting the perceptions of staff and participants about the impact of a service on QoL.

At the outset the aim of the systematic search strategy adopted 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,
- Explored by researchers.

The decision was made to take a relatively narrow sample of the available policy, practice and research to establish the salience of QoL in the discourse of formal documentation about disability and QoL relating to services such as community care, vocational and occupational rehabilitation, vocational education and training.

Broadly, two separate searches were carried out. One focused on VET and the other explored health and social care services.

The searches adopted the IASSIDD model of QoL as a lens to identify the domains and dimensions on which health and social care and VET overlap. Thus, the framework comprises three domains which are broken down into eights dimensions.

- Personal development is segmented in two dimensions: Interpersonal Relations: and Selfdetermination and refers to the range of relationships that shape competence in the sphere of human activity. These processes allow a person to acquire competence and exert control and influence over significant issues in a range of life contexts and moderate the influence of other people on choice. The domain includes personal competence in an interactional situation, in the context of interpersonal relationships an in the exercise of selfdetermination.
- 2. Wellbeing is segmented into three dimensions which cover important life conditions: emotional; physical; and material wellbeing. These dimensions provide an indication of how a person views their own life circumstance and how satisfied they are with the extent to which their aspirations are being fulfilled by in terms of mobility, leisure, daily life activities, property, and income, health and security.
- 3. Social inclusion is segmented into three dimensions: employability; citizenship; and rights, and refers to the opportunities a person has to control their interaction with the environment and to influence the decisions which have an impact on their life projects. It is about the extent to which a person can access the resources to achieve their goals in the labour market, the community and society,

#### QoL as an Outcome Indicator

While Quality of life (QoL) is intuitively attractive as an outcome measurement for social services and has been the focus of research for many years (Guillemin et al., 1993; Mathias et al., 1994), it can be challenging to define and measure (Wolfensberger, 1994; Barcaccia, et al., 2013). Nevertheless, both objective and subjective measures of QoL have been adopted as part of the system of social indicators (Cummins, 2000; Rapley, 2003) to complement economic analyses (Evans 1994). However, many social indicators are relatively general and not useful at the individual level.

Many conceptions of QoL have been compiled through a synthesis of elements valued in terms of comfort and wellbeing in a culture or community which reflect collective or personal experiences, values and knowledge at a particular point in time and in a specific location. These can be influenced by historical, economic, social factors including social status and ethical ethos. It is widely accepted

that conceptions of QoL it cannot be separated from the cultural ethos in which a person lives (Keith, Heal & Schalock, 1996). A person's subjective experience of positive QoL will be influenced by their values which are in turn influenced by their interaction with family, school and community.

Despite the long 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). It is generally accepted that there are two primary types of QoL measures. Objective QoL indicators are concerned with the external and easily established conditions of life that many observers can rate identically (Ventegodt et al., 2003; p. 1031). 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. QoL has been defined in the disability field in many ways, but there tends to be a shared assumption that it is best viewed as a subjective perception of individuals. An optimistic view is that even without agreement on a single standard definition, QoL research can contribute to understanding and comparing the outcomes of interventions (Post, 2014).

This distinction was acknowledged by the IASSIDD expert group (Schalock et al., 2002). The group noted the objective and subjective components of QoL measurement. On the one hand, QoL can be estimated on the basis of generally accepted features of a life of quality including material possessions, social connectedness and participation. On the other hand, QoL is the degree of satisfaction a person experiences in key domains of life including family life, friendships, work, housing, health, education and standard of living. The IASSIDD framework has been benchmarked against the requirement of the UN Convention on the Rights of Persons with Disabilities (CRPD). A strong association between the core domains of the QoL model and many articles of the Convention was identified (Verdugo et al. 2012).

The IASSIDD approach reflects the view that a person knows what is of value to them and that perceptions of QoL are neither right nor wrong. What is important is how satisfied that person is at a certain point in time. The expert group drew attention to the distinction between an individual's perceptions and those of significant others such as carers or family members. As a result, being able to facilitate non-verbal methods of expression for those who are challenged by language is important. In the event that this is not feasible, then a proxy view (the perspective of a significant other) can be used.

It has been documented that perceptions of QoL are impacted by a variety of personal variables including age, age at which a health conditions emerges, the nature and severity of the condition, employment status, income, and relationship status (Mehnert, Krauss, Nadler & Boyd, 1990). Chubon (1985) described a number of different QoL domains relevant across a range of health conditions. These included: work; leisure; nutrition; sleep; social support and network; income; health; love/affection; environment; and self-esteem. Pain et al. (1988) identified 4 domains: emotional health; interpersonal relations; maximisation of one's potential; and meaningful and gratifying life project.

Bowling (2014) cited the WHOQoL Group's definition of QoL as a useful starting point for her review of QoL measurement. It is:

"... 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." (Cited in Bowling, 2014; p. 4).

The WHOQOL Group (1998) identified six domains: physical health; psychological wellbeing; level of independence; social relations; environment; and spirituality/religion /personal beliefs. While the clarity of this definition is undeniable, operationalising it in a way that it can be measured and for that measurement to be useful in enhancing the relevance and quality of services is no easy task.

QOLIVET sets out to provide a number of resources to support the development of more responsive and effective means to ensure that the QoL of participants in social care and vocational education and training is enhanced by that participation. This requires that QoL impact is considered in determining the quality of a service, intervention or programme. There are a number of challenges that need to be addressed to achieve this objective.

- Using objective measures of QoL to evaluate QoL impact is complicated by the fact that many of the indicators often used to assess objective QoL depend on a wide range intervening factors other than the service or intervention such as family income, geographical location, economic conditions and community facilities.
- Particularly in the case of vocational education and training, the QoL impact can only be perceived after an extended period of time. An example of this is the impact of skills and qualifications on income and employment.
- Subjective QoL perceptions can be influenced by many factors beyond the service, intervention or program being delivered. The way a person feels about their QoL can be influenced by how they are feeling about themselves at the time they are completing the self-assessment form. A substantial challenge in determining the QoL impact of any intervention is disentangling the contribution that it has made in addition to, or in spite of, other factors that have little to do with the effort or excellence entailed in the service (Malley, & Fernández, 2012).
- Measuring the actual QoL impact of an intervention requires that QoL is measured pre- and post-delivery (repeated measures) of QoL. Apart from the cost and effort required to assess QoL prior to receiving the service, directly afterwards and in a follow up survey after at least 12 months, there is the ambiguity created by the potential influence of response shift bias. 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 change life or health circumstance, particularly when pre-post- ratings are used.

Perry and Felce (2002) proposed four standards that need to be met in measuring QOL. These related to

• Consistency which refers to the proportion of respondents who can answer an item regardless of the accuracy of the response;

- Test-retest reliability which is the extent to which the ratings of respondents are stable over time;
- Correspondence of responses that have the same meaning which relates to the sensitivity of items to response bias or acquiescence (the tendency to choose ratings that are believed to be expected by the administrator of the assessment tool;
- Agreement of responses with information from other sources such as the degree of agreement with the views of staff or family members.

Many of these challenges can be addressed by designing a QoL rating tool that allows participants to link their ratings directly to the service, intervention or programme in which they are participating; gathering ratings while respondents are still actively participating in a service; ensuring that the questionnaire has been evaluated for reliability in measuring the perceptions of participants; and designing a parallel form which provides respondents with limited language competence or abstract thinking with a simplified version of the scale to express their views.

#### The Status of QoL in Health and Social Care Services

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. Three important trends were revealed at an early stage. Firstly, there were a number of terms used to refer to health and social care services including community care, independent living, social care, community living, and community integration. Secondly, it was clear that the meaning of QoL was strongly influenced by the characteristics of the target participants and the types of service which were the focus of a report or article. For example, it emerged that health-related quality of life (HrQoL) (Makai et al, 2014) and social care related quality of life (SrQol) (Bowling, 2014) needed to be distinguished. In addition, the age of the intended beneficiaries of services influenced the conceptions of QoL that were considered relevant (National Health Executive, 2017; Turid Midjo, & Ellingsen Aune, 2018; 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; Mental Health Commission, 2007; Bowling, 2014). Thirdly, many services were aimed at facilitating transition be that from congregated settings to the community, from school to work, from youth to adulthood or from care to independent living, while other services, particularly for older people, were designed at maintaining people in their current circumstances.

A number of terms are in use to refer to the proactive and responsive interventions and services required to enable participants to progress towards their aspirations for an enhanced QoL (NDA, 2010). These include 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 approached 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 (p. 33).

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 here cover a wide range of contexts, participant characteristics and service types with a view to bringing together thinking that can be used to develop an appropriate tool to be used across sectors and service types.

#### **Characteristics of Effective Mechanisms to Monitor QoL**

Quality of life (QoL) outcomes and impact have been brought to the fore in the health and social care sectors for a variety of reason, not least of which is the strong impetus towards deinstitutionalisation and away from congregated settings. This has fuelled a substantial interest in exploring the meaning of QoL and the most appropriate approach to measuring outcomes and impact.

There are many service providers that strive to achieve more than basic compliance who require relevant national standards on QoL improvement for persons accessing health and social care services (Health Information Quality Authority, 2018). This requires that the meaning and domains of quality of life are clearly specified even at a policy level. 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. The QoL domains included well-being and social inclusion.

Bowling (2014) explored the meaning and ways to measure QoL in social care research with a specific focus on older people. She concluded that a lack of widely accepted measure of QoL and the diversity of approaches creates a challenge for service evaluation and determining their cost effectiveness.

Pierce, Kilcullen and Duffy (2018) noted the Health Service's Transforming Lives Programme and highlighted its aim to achieve a society in which persons with disabilities participated both economically and socially and could access the quality personal social support and services needed to enhance their quality of life and well-being. They recommended 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 clearly highlighted the role of community activities in promoting better health and wellbeing for people with learning disabilities and thus improve their quality of life. It 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).

QoL covers multiple life activities and domains and this needs to be reflected in the types of client outcome measures that are used. For example, HrQol measures are often based on a negative conception about the gap between present health and functioning and a desired state. However, it is important to gather information about wider life experiences, capturing data on the extent to which a person is experiencing a life lived well. On the other hand, if a measure is too general, it may not be sensitive to the outcomes of specific social care services. A potential response to this is to develop patient-reported outcome measures (PROMS) with the involvement of service users in the development and evaluation of the tool. This can result in higher response rates and a greater clarity in monitoring outcomes. Bowling (2014) explored a number of approaches that had potential for monitoring QoL, which are described later in this report.

QoL figured prominently in the recommendations of an expert review group established to advise on Irish disability policy as part of a review of value for money. It noted that, in many jurisdictions, the starting point for responsive, person-centre services was an assessment of what a person needed to participate independently in the community. This often included an assessment of recreational, social and personal development needs, training and education needs, vocational and employment needs and, where it was appropriate, the needs of family and carers (Keogh, 2010). It also noted the link between health and enhanced wellbeing.

The vision proposed by the expert group envisaged a society in which persons with disabilities had access to the supports and interventions required to achieve economic and social participation and enhanced QoL. The overarching goals were full inclusion and self-determination and a cost-effective, responsive and accountable system of support. The underpinning principles and values put forward included citizenship, self-determination inclusion, participation, equity and person-centredness.

The report commented on the lack of adequate information on the overall QoL status of persons with disabilities or the QoL of persons using services and suggested that the assumption that access to services resulted in a better QoL was not supported by the facts. It proposed that the system should endeavour to achieve more positive outcomes as defined by persons with disabilities themselves including 'meaningful' measures of quality of life and independence. (p. 145). For example, the registration of residential services should require evidence that they meet specified criteria including QoL impact.

The Irish National Economic and Social Council addressed QoL in its opinion on the quality of disability services (2012). It viewed the lack of critical review of the disability sector as an area that needed significant improvement. It suggested that QoL was a useful basis for quality assurance beyond measures of service delivery. It cited the Department of Health characterisation of quality organisations, in its value for money review, as those that used information on individual progress against standards in a continuous improvement process aimed at improving QoL outcomes for service participants (Department of Health, 2012).

One conclusion of that report was that persons with disabilities needed access to a range of quality individual supports and services to improve QoL and wellbeing. These supports and services needed to be focused on inclusion and self-determination and community living and be based on the principles of QoL; safety; rights; anti-discrimination; person-centredness; community integration and responsive services. The NESC report acknowledged the lack of a standard tool for measuring QoL for people with intellectual impairments that was universally accepted. As a result, it was recommended that a variety of quality indicators s, both subjective and objective, be included in a comprehensive approach.

A study carried out by the School of Health and Related Research (ScHARR) at Sheffield University explored the perceptions of patients, social care and carers of the QoL and wellbeing impact of the health, social care and public health interventions they were receiving. HrQoL was characterised as including physical functioning, coping, positive emotions, meaningful activities, and social

relationships (School of Health and Related Research, 2017). The researchers noted that QoL and wellbeing were at times used as equivalent terms to describe 'a good or desirable life' (p. 2). In this regard, 'wellbeing' could be viewed as synonymous 'subjective wellbeing'. However, the concept of overall life satisfaction needed to be broken down into a variety of other aspects such as fulfilling relationships, being in control, doing the things one desires, and feeling positive emotions,

The NDA report on outcome measurement for evaluating quality in disability services posed three questions that needed to be answered by service evaluation measures (2019):

- Are persons with disabilities who use disability services making progress towards attaining personal outcomes and a good quality of life?
- What are disability services contributing to progress towards personal outcome attainment where the person themselves has defined the personal outcomes?
- Are outcome predictors evident in the disability services under evaluation? (p. 6)

It is essential that the assumptions underpinning outcome measures are made explicit so that potential conflicts between individual personal outcomes, service provider outcomes and systemwide outcomes are identified (NDA, 2019). Ultimately, the function of outcome measurement must be to make sure that the person served 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 the progress that each person is making towards their personal goals across a range of outcome domains. At the level of the individual, this requires outcome indicators that can track the extent to which each service participant is progressing towards their desired QoL goals.

The impact on social integration in the community depends significantly on the extent to which this is supported by staff (McCarron et al., 2019). This finding was supported by another study which (Chowdhury & Benson, 2011 cited in Mac Domhnaill, Lyons, & McCoy, 2020) which concluded that positive QoL outcomes after a move to the community, including enhanced choice and engagement in leisure activities, more interaction with staff and other residents and improvements in material wellbeing and dignity, were dependent on the commitment of community service providers.

Given the importance of staff commitment in achieving effective community integration outcomes noted by Mac Domhnaill and colleagues (2020), staff training must be seen as an important service improvement mechanism. The Scottish Joint Improvement Team addressed this at a conference on improving the QoL for persons with learning disabilities in 2005. One strong conclusion of the conference was that staff training was central to linking resource inputs to the quality of outcomes (Felce, 2005). It was considered essential that staff be trained in how to provide active support (Joint Improvement Team, 2005: p. 8). Both service participants and their carers can be powerful agents of change. Their aspiration is for better quality services and they can offer practical suggestions for how their own QoL can be enhanced. Organisations need to create opportunities for carers and people with learning disabilities to participate in staff training.

The conference concluded that research does not inform practice to the extent that it should. The evidence base for good practice in responding to the needs of people with learning disabilities is limited in availability and restricts its impact on the implementation of evidence-based effective treatment for persons with learning disabilities. Participation of users and carers in staff training could be viewed as a 'different form of evidence-based training' (p. 8). Local and regional networks

are an important mechanism for identifying ways to support research and learn from current findings (Joint Improvement Team, 2005).

The QOLIVET project sets out to develop a tool that can be used as part of a suite of indicators to allow service providers to monitor these questions and to provide participants and staff an opportunity to contribute to service evaluation.

Bowling (2014) in her review of QoL measures and meanings in social care research summarised some important methodological challenges in achieving this.

- A broad scope is required in measuring SrQoL 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 and reflect the intended outcomes,
- This can be achieved by including a 'core' measure of QoL which is augmented with additional items to reflect different characteristics of the target group or role of respondent and interventions being provided, for example the partner of an older person may respond differently to other family members,
- When developing a scale, it is essential to start by gaining insight into the perspectives of the intended target group and it supports engagement throughout the process to ensure the relevance of the measure,
- It is crucial that 'response shift' is catered for in any tool and to explain contradictory results (Bowling, 2014; p. 18).

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

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 (NDA, 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.

These factors can impact on the QoL of a person regardless of the effectiveness of the service they are receiving (p. 10). Consequently, it is important 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. It is unlikely that standardised outcome measures can capture the impact of a service on all life areas considered important by an individual and this can result in important changes at the individual level being missed (NDA, 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 (NDA, 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.

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 about the items that were included in a new tool aimed at gathering information from people experiencing mental health challenges. The study identified five criteria that need to inform tool development in the opinion of the people with mental health consulted:

- Relevance and meaning,
- Clarity,
- Ease of responding even when distressed,
- Sensitivity to 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).

The most elaborated explorations of the concept of QoL, and how to measure it, were carried out in relation to to people with certain types of impairments and those moving from congregated settings. Intellectual impairment (learning disabilities) and mental health were the impairments for which the QoL question was 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 an essential criterion in service evaluation. Relevant and appropriate outcome measures need to be developed in consultation with service users (Mental Health Commission, 2007).

Bowling (2014) explored a range of tools including the Schedule for Self-Evaluation of QoL (SEIQoL), the Older People's QoL (OPQOL), ICECAP-A, the Lancashire Quality of Life Profile, the Manchester Short Assessment of Quality of Life and the Adult Social Care Outcomes Toolkit. 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).

She went on to list the criteria proposed by Fitzpartick 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.

#### Domains and Dimensions of QoL for Persons with Disabilities

A Council of Europe review of policy and legislation governing rehabilitation and integration examined mechanisms in eleven member countries. It noted that while QoL was frequently specified as an intended outcome of such services, it was only rarely defined or elaborated in terms of its content and meaning. Norway was the only exception (Council of Europe, 2002).

In customising QoL outcome measures in health and social care services, it is important to take into account the life stage of the person served. For example, young adults can hold a self-concept that they are in control of their own lives. In contrast, carers may view them as young people in need of resources and assistance. Staff in health and social care service need to be educated in the skills and strategies to allow young adults to define who they are and 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).

The Scottish Joint Improvement Team conference report on improving the quality of life for people with learning disabilities (2005) elaborated the wider determinants of health as including disadvantage, choice and autonomy, employment, relationships, spirituality, healthy eating. physical activity.

The UK Care Act provided a useful inventory of intended outcomes for health and social care services (UK Public General Acts, 2015). In setting out the duty of local authorities to promote the wellbeing of individuals, it lists the domains that need to be addressed including personal dignity; physical and mental health and emotional well-being; protection from abuse and neglect; control

over daily life; participation in work, education, training and recreation; social and economic wellbeing; family and person relationships; suitable living conditions and opportunities to make a contribution to society (The Care Act 2014, Part 1, Section 1).

Many young persons with disabilities face challenges in trying achieving a good quality of adult life (Wright, 2010). Successful transition services and supports can help them to be more connected, have more opportunities for social contact and acquire the skills needed to function more independently in life, VET and employment (p. 164). Preparation for adulthood needs to address life skills, education and training, leisure, employment, housing, health and wellbeing, travel and financial support. Consequently, effective transition 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 both the young person themselves and their family or carers in terms of satisfaction with interventions and with their QoL impact. The extent to which services are delivered in a joined-up and coordinated manner needs to be part of the evaluation (Wright, 2010; p. 18).

Bowling (2014) summarised Lawton's multidimensional view of QoL for frail older people published in 1997. This included the following dimension:

- Affect (happiness, agitation, depression, affect state, emotional expression, Spirituality),
- Self-esteem (self-esteem, life satisfaction, morale),
- Appraisal of physical functioning (self-care),
- Social relationships (satisfaction with family and friends),
- Social environment (social engagement, meaningful time use, physical safety, presence of amenities, privacy, stimulating quality, aesthetic quality, satisfaction with spare time and housing (institution) and healthcare; freedom from barriers),
- Health (behavioural symptoms, psychiatric symptoms). (Cited in Bowling, 2014; p. 5)

Noonan-Walsh et al. (2007) referenced the domains of the Schalock QOL-Q (Schalock & Keith, 1993). These are choice and control (personal freedoms and dignity of risk); community inclusion (employment, meaningful activity, social connectedness and relationships); equity (equitable access and resource allocation; holistic health and functioning (individual health and functioning); human and legal rights (freedom from abuse and neglect) and person-centred planning and coordination (Rehabilitation Research and Training Centre on Home and Community-based Services Outcome Measurement, n. d.).

The model proposed by Lim and Zebrack (2004) involves physical health and functioning, socioeconomic status, psychological, emotional, and social well-being (Citied in Noonan-Walsh et al., 2007).

The authors summarise the QoL indicators that had been used in evaluating the implications of moving from a congregated to a community setting.

- Independence,
- Personal skills,
- Material wellbeing,
- Choice & self-determination,

- Civic participation/social inclusion,
- Social relationships,
- Community activities,
- Employment,
- Physical Wellbeing,
- Emotional Wellbeing,
- Life satisfaction.

The table below presents a three-dimensional model of QoL as discussed in the report.

Quality of Life: Core Domains (Noonan-Walsh, 2007; p. 20)			
Independence	Civic Participation /Social Inclusion	Well-being	
Personal skills (e.g. adaptive behaviour) Material well-being (e.g. income, possessions) Choice and self-determination Other	Social networks and friendships Community-based activities Employment Other	Emotional wellbeing/mental health (including challenging behaviour) Physical health Personal life satisfaction Other	

In 2010, the NDA produced a synthesis report on developing services for persons with disabilities. The report highlighted the need to continue to strive for services that promoted social inclusion, supported independent living and enhanced QoL. It linked these outcomes to community services and accommodation which were based on inclusive responses to individual needs based on user outcomes and which addressed QoL. A close relationship between independent living and QoL was drawn out by the report which was conceived of as consisting of three core domains: *independence* or *autonomy* covering personal skills, material wellbeing, choice and self-determination; *social inclusion* and *civic participation* which entailed social networks, friendships, community based activities and employment; and wellbeing which was specified as including emotional wellbeing/mental health, physical health and personal life satisfaction. Three statements about the requirements of a person were elaborated each domain.

- A person can/has the opportunity to access life-long learning, income, resources required to have a good diet, housing and participation in family and community life and can choose and control services and manage risk in personal life.
- A person can/has the opportunity to develop range of friendships, activities, relationships; take part in local affairs and decisions; vote; volunteer and access equal opportunities for education, training and employment.
- A person can/has the opportunity to receive protection from abuse and exploitation and access support in managing long-term conditions; experience clear and ordered living environment; undertake physical activity and access health screenings and care; access leisure; experience security at home and enjoy a full, purposeful life (NDA, 2010; p. 35).

The report proposes that QoL indicators and tools must reflect all aspects of life and not solely focus on the outcomes of a specific service, programme or the mission of individual organisations and provide indicators of the extent to which progress has been made towards meeting QoL goals.

Nevertheless, in relation to health and social care services, it is important to strive to estimate the extent to which the service made a contribution to improved health and functioning; met needs

arising in daily life; protected a person's safety and security; ensured a clean and orderly environment; assisted the person to be active and alert; facilitated social contact; supported the person to exercise control over life decisions; fostered independence, self-esteem, confidence and optimism; and helped a person to find ways to live with reduced functioning. These service goals can be summarised as user-informed outcomes in the domains of:

- Improved health and emotional well-being,
- Improved quality of life,
- Making a positive contribution,
- Choice and control,
- Freedom from discrimination,
- Economic wellbeing,
- Personal dignity (Department of Health, 2006; cited in Malley, & Fernández, 2012).

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; <u>http://www.plenainclusion.org/</u>). 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. In Portugal, the Education Act (Law No. 46/86, 14 October) specified appropriate goals:

- Developing physical and intellectual potential,
- Assistance in acquiring emotional stability,
- Developing communication possibilities,
- Reducing limitations caused by disability,
- Support for family, school and social inclusion,
- Developing independence at all levels,
- Preparing for adequate vocational training and integration into working life (Ellul, 2020; p. 285-286).

#### The Status of QoL in Vocational Education and Training

While QoL has been identified as a clear outcome benefit of successful completion of vocational training and education (Cedefop, 2011; 2013), it cannot be taken for granted by VET providers and policy makers that this impact is achieved by all those participating in further education on an equal basis. This is particularly a question that needs to asked about those who fail to complete a program successfully. From this perspective, 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.

There is an argument to be made that reducing withdrawals from formal VET and increasing the effectiveness of participation of learners with additional needs can play significant role in enhancing QoL outcomes for a diversity of vulnerable individuals and groups. A major implication of this argument is that there is an onus on mainstream VET providers to create more accessible and inclusive learning environments and approaches.

This section of the report begins by exploring the policy imperative for VET systems to move beyond technical, professional and academic learning objectives to address social outcomes for participants and wider society. Some approaches to how this can be achieved are described. Then the focus changes to how mainstream VET providers can put in place policies, practices, resources and supports to create a genuinely inclusive learning environment.

# Policy Imperatives for a Broader Role for VET Systems

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. These included:

- Lisbon European Council, March 2000
- Declaration of the European Ministers of Vocational Education and Training, November 2002
- Draft Conclusions of the Council and the Representatives of the Governments of the Member States, October 2004
- Communiqué of the European Ministers of Vocational Education and Training, December 2006
- Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions. Delivering lifelong learning for knowledge, creativity and innovation, November 2007
- Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions – New Skills for New Jobs – Anticipating and matching labour market and skills needs, December 2008 (European Agency for Development in Special Needs Education, 2013; p. 9).

High quality VET, as a means of promoting social inclusion, cohesion, mobility, employability and competitiveness, has a fundamental part to play to achieving the objectives of the Lisbon strategy (2000) (Lasonen, & Gordon, 2009; p. 20). However, there is a view that many VET programmes are aimed at occupational qualifications and/or progression to further or higher education (Hrvoje, 2014). Too great an emphasis on employability as the primary outcome of education could impact on quality and reduce the educational dimension of VET (Šcepanović, & Artiles, 2020).

Bearing in mind the multidimensional nature of social exclusion, a concentration by VET providers on employment competences at the expense of social competences can reduce the likelihood that participants will be successful in gaining access to life domains other than economic wellbeing such as cultural and political resources. The limited participation in VET of people with a higher risk of exclusion, such as persons with disabilities, can further reduce the impact of VET on social inclusion (European Commission, 2000).

Learning is viewed as a means of creating access to a 'satisfying and productive life' beyond employment (European Commission, 2000, p. 9). This is congruent with the view of the International Labour Organisation (ILO) that technical and vocational training needs to prepare people for personal and social life in addition to participation in the economic life of a society.

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 that is adapted to both the needs of countries and latest technological developments. VET is an important part of a system designed to improve QoL. It creates learning contexts that allow learners to broaden their 'intellectual horizons', attain and continually develop occupational skills and knowledge and positively engage in society (p. 9). Programmes need to include opportunities for young people and adults, including those already working, to acquire skills relevant to enhanced involvement in the community and home in order to positively impact on QoL and the use of leisure time (p. 20).

The ILO organised a conference on improving the QoL of persons with disabilities in 2003 (International Labour Organisation, 2004) which adopted a human rights perspective on disability. It explored areas where action was required to achieve a holistic approach to promoting full participation and citizenship through policy and services. It recommended a '...move from a medical approach to a human rights-based approach, from charity to rights...' (p. 13). At a follow up conference in the same year, the strong link between level of education and employment was highlighted. There was a view it could be viewed as an indicator of employability.

Preston and Green (2008) put forward the view that, while VET had an important role in promoting participation in the labour market, this was a narrow view of what social inclusion entailed. They questioned whether VET ought to be viewed as having a contribution to make to a broader conception of social inclusion such as citizenship. They suggested that VET models that solely focus on competences and employment were not fit for purpose when viewed in the context of social inclusion as aspired to in EU Member State's policy (p. 9).

At EU level, there is a view that lifelong learning and VET can play a central part in promoting social cohesion (Preston, & Green, 2008). For example, conclusions of the Lisbon European Council 2000 reaffirmed lifelong learning as a core mechanism in developing citizenship, social cohesion and employment (Preston & Green, 2008; Sklias, et al., 2017). Paragraph 9 of the conclusions maintained that "every citizen must be equipped with the skills needed to live and work in this new information society. Different means of access must prevent info-exclusion. The combat against illiteracy must be reinforced. Special attention must be given to disabled people..."

Cedefop (2013) noted in its report on the benefits of VET that its role as a mechanism to promote social inclusion and equity and its potential to enhance other aspects of life including improved health outcomes, job satisfaction and wellbeing, must not be underestimated (p.41). It proposed a number of outcomes for VET that extend beyond the narrow 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).

Cedefop has emphasised the need to make certain that VET is a positive factor in a person's life not only in terms of being able to pursue a fulfilling career but also in terms of achieving a decent QoL (Cedefop, 2015; p. 4).

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). Over time adult learning policies need to be coherent. This requires a long-term strategic vision, and flexibility to respond to emerging trends and challenges. An evidence-informed approach is needed to ensure that adult learning policies and interrelations are effective.

There is a need for a clear and robust policy imperative towards creating more accessible and inclusive VET systems to promote both economic and social QoL 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). This reflects the aspirations of the QOLIVET project. The sections below explore how VET providers and educators can ensure that the policy objectives that support a QoL role can be implemented at the front line of delivery and in the interpersonal interactions between learners and teachers.

# VET and Quality of Life VET and Personal Development

Learning has been accepted as an integral aspect of personal development and innovation and to be crucial in being able 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).

There is a strong consensus among researchers and practitioners that linking and integrating formal, non-formal and informal learning opportunities is essential to achieve a holistic approach to personal development. Systems must operate in synchrony with a balance between academic and technical competences, social and emotional development, wellbeing and preparing learners as effective workers and citizens (Cedefop & Lifelong Learning Platform, 2019).

The International Labour Organisation (ILO) described how a number of national VET systems addressed the challenge of engendering life, personal and social skills in addition to labour market competences (Preston & Green, 2008). For example, German policies acknowledge the importance of VET in fostering social identity and a motivation to actively shape both personal and public life.

In exploring the contribution of VET to the Lisbon Goals, Leney and Green (2005) concluded that VET needs to provide individual learners with opportunities to optimise performance and progression in work in order to enhance personal identity, participation in communities and QoL more generally (p. 8).

The Council Recommendation on Key Competences (2018) recognised the efforts invested by the European Commission in collaboration with EU Member States to promote key competences, knowledge and perspectives and facilitate lifelong learning. According to the European Council, important outcomes of effective learning systems include personal fulfilment, healthy and sustainable lifestyles, employability, active citizenship and social inclusion. Interpersonal skills and the ability to adopt new competences (learning how to learn) are also recognised as important outcomes.

The role of non-formal and informal learning opportunities and processes in fostering essential interpersonal, communicative and cognitive skills was highlighted by the Council. For example, the transition to adulthood, active citizenship and work can be facilitated by competences such as:

- Critical and analytical skills,
- Creativity,
- Problem solving,
- Resilience.

The Council Recommendation described personal, social and learning to learn competences as being able to:

- Self-reflect,
- Manage time and information,
- Work constructively with other people,
- Maintain resilience in the face of challenges,
- Manage learning and career pathways and aspirations,
- Cope with uncertainty and complexity,
- Learn how to learn,
- Maintain physical and emotional well-being and positive physical and mental health,
- Lead a health-conscious, future-oriented life,
- Empathize and manage conflict in an inclusive and supportive context.

The framework also elaborated the basis for successful interpersonal relations and social participation which requires an understanding of the codes of conduct and rules of communication and sensitivity to how these can be shaped by different societies or contexts

Effective personal, social and learning to learn competences require a knowledge of:

- The components of a healthy mind, body and lifestyle,
- The best ways to enhance learning,
- Personal learning and development needs,
- Relevant and appropriate education, training and career opportunities and guidance or supports.

Personal, social and learning to learn competences require a positive attitude to personal, social and physical well-being and to learning throughout life. The attitudes supporting this include:

- Collaboration, assertiveness and integrity,
- Respect for the diversity of others and their needs,

• Willingness to overcome prejudices and to seek compromise (The Council of the European Union, 2018).

The skills and strategies to support personal, social and learning to learn competences include being able to:

- Identify aspirations and select goals,
- Stay motivated,
- Maintain resilience,
- Be confident to engage in, and understand how to succeed in, learning over the lifespan,
- Engage in positive problem solving,
- Dealing with challenges or change,
- Use existing knowledge and previous experience in a constructive way,
- Explore new learning opportunities and life activities (The Council of the European Union, 2018).

The Council Recommendation elaborates on 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 include:

- Cross-discipline learning:
  - Partnerships between different education levels, training and learning actors, including the labour market;
  - Whole school approaches with its 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,
  - 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.

#### **VET and Social Inclusion**

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Social inclusion is considered to be an important transversal issue in Europe. 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).

Social inclusion has a central position within the discourse about QoL. 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 conceived as a condition in which people are participating in the economic, social and political processes of a society, the definition is not always elaborated in policy (Oxoby, 2009). There is an argument that because it is a generic term which can be interpreted in multiple ways, it has gained a wide acceptance. There have been suggestions that the term be discarded in favour of more specific terms. Nevertheless, social inclusion is associated with a number of life circumstances that are generally accepted including economic wellbeing, employment and political involvement. While it may seem intuitively satisfying, viewing inclusion as the opposite of exclusion can create some conceptual challenges. For example, a person may actively to opt to exclude themselves from political participation on the grounds of a principle. So, exclusion is not so much about a state but about lack of access to the means to attain that state. In this regard, social exclusion needs to be related to 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 which can help to 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 is 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).

He proposes a more subjective characterisation of inclusion in terms of the perception that an individual has of the extent to which they can access institutions and resources in the decision-making environment. This can impact on the motivation to invest effort in attempting to gain socially valued goals (p. 7). He refers to the five domains of 'social rights' that are integral to inclusion proposed by the Council of Europe (2001; citer 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 and that creating opportunities for participation in formal and informal education services can be supported by ensuring equality of access, enhancing quality, fostering lifelong learning skills and preventing withdrawal from formal education through necessary supports.

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In order to understand the VET mechanisms that are effective in promoting social inclusion at the level of an individual learner, it is important to develop a detailed description of what it entails. It is clear that social inclusion is multidimensional and can occur over a range of life domains from which a person can be excluded such as economic success, cultural acceptance and participation in the mainstream political sphere. If VET is to impact across these diverse domains, a clearer focus is required upon the 'social functions of VET' (Preston & Green, 2008; p. 161).

While there is little doubt that job creation and economic growth are important prerequisites for achieving social inclusion, a complementary investment in active social inclusion, equality and non-discrimination policies is required (Rodriguez, et al., 2010). They recommend assigning a higher priority to active social inclusion measures in parallel with investment in growth and jobs (p. 80).

There is a broad consensus that raising the competence levels of European Union's (EU) labour market participants can be an important mechanism to promote social inclusion in addition to improving economic performance, growth and employment. People participate in learning for economic, personal or social reasons. Learning can improve the chances of getting a better job, enhance social standing in the community, foster positive self-esteem or increase participation in the political life (Cedefop, 2009).

This can be linked to the view that educational provision needs to address a wider range of themes such as values, behaviour and citizenship. It creates an imperative to provide greater choice and more flexibility in access routes and modalities of delivery. It supports the argument that the system must recognise both informal and non-formal alongside formal provision (p. 28). VET has an important role in overcoming the challenges to the development of innovative strategies for lifelong learning which can impact positively on the social and economic wellbeing at individual and community levels. (p. 22). In this regard, an increased research emphasis on the VET contribution to the promotion of equal opportunities and social inclusion is desirable (Bureau and Marchal, 2005; cited in Cedefop, 2009; p. 46).

#### **VET and 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). It was initially adopted a pillar of the European Employment Strategi in 1997. Employability 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 condition, 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 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).

#### **VET and Active Citizenship**

It is acknowledged at a policy level that active citizenship requires enhanced cognitive and communication skills and that these can be facilitated though both social and educational activities. This requires that the ways in which VET can contribute to active citizenship be elaborated in more detail (Preston & Green, 2008). The challenge is to move beyond the necessarily generalised language of many reports to explore how different national VET systems are designed to provide the knowledge and competences needed to achieve a 'satisfying and productive life quite apart from a person's employment status and prospects' (p. 136).

The implication of this is that while developing employability i.e., the capacity to participate effectively in a competitive labour market, is a critical goal of education and training, a narrow focus on employability can limit the impact on other social goals such as active citizenship (European Commission, 2000).

The Bruges Communiqué on enhanced European Cooperation in VET reinforced the dual objectives of VET: contributing to employability and economic growth; and responding to broader societal challenges, specified in terms of promoting social cohesion. Although little emphasis was placed on social inclusion, it addressed active citizenship in more detail. Specifically, it called for a reduction in the proportion of learners exiting education at an early age through prevention and remediation. 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). According to the European Commission, inclusive VET needs to be addressed through mechanisms to 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 is recommended (p. 16).

Citizenship is one the eight dimensions of the IASSIDD model of QoL. It is also a recurring theme in European policy documents on VET and Lifelong learning over many years. In this regard, it is usually referred to as 'active' citizenship. It is generally 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.

According to European University College Association, active citizenship is about promoting the QoL of a community through political and non-political processes and acquiring the knowledge, skills, values and motivation to support the endeavour of making a difference in the society (EucA. n. d.; Paragraph 2). The European Commission (2007; Cited in Zepke, 20017) acknowledged the key role that active citizenship played within lifelong learning, education and training. It helps to promote economic development and wellbeing in a global knowledge society (Zepke, 2017).

Consequently, it is important to explore whether active citizenship can be regarded as a QoL benefit for learners or whether it is a mechanism for creating greater social cohesion. Citizenship within the IASSIDD model refers to participation in the social, cultural and political life of a community. There are a number of meanings of active citizenship in the discourse of the EU which include a 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 indicial who strives to reform existing systems to achieve enhanced QoL for all. Zepke (2017) provides a number of characterisations of active citizenship which that have implications for QoL including:

- Working collectively to develop communities in times of social change,
- Participation in the community to create wealth,
- Collective action to improve society,
- Connecting to the structures of social, political and economic activity,
- Participation in social and political life,
- Taking part in service learning at university and in the community,
- Working within local, national and international structures,
- Responding constructively to government policies,
- Participating in learning communities and environmental and political protests
- Obeying laws, conventions and respecting the rights of other citizens,
- Generating, adopting and adapting commitments and obligations to the community,
- Strengthening civil society through democratic participation.

The knowledge and skills that are useful in developing active citizenship are specified by the Council of the European Union (2018) and include:

- Critical and analytical skills,
- Engage in positive problem solving
- Maintain resilience,
- Empathize and manage conflict in an inclusive and supportive context.
- Collaboration, assertiveness and integrity,
- Respect for the diversity of others and their needs,
- Willingness to overcome prejudices and to seek compromise
- Dealing with challenges or change (The Council of the European Union, 2018).

Zepke (2017) proposes additional competences;

- Understanding the nature of democratic processes and their procedural values,
- Networking, collaborating, arguing, researching issues, and advocating positions,
- Embracing and being embraced by one's community

VET can contribute to developing active citizenship through:

- Establishing personal and community identities,
- Facilitating social and/or community development,
- Fostering formal democratic behaviour,
- Stressing individual and/or collective economic development,
- Developing learners' knowledge to suit a variety of social purposes,
- Disseminating a formal statement of rights and responsibilities/duties.

VET can encourage learners to work towards a sustainable life, seek social justice, support and oppose government policies and work towards positive change. Strengthening active citizenship in civil society through democratic participation has the potential to engender in learners a personal sense of well-being and impact positively on other people (Zepke, 2017).

#### **Designing VET Inclusive Learning Environments**

The European Economic and Social Committee (EESC) issued a call to the European Commission and the Board of Governors of the European schools 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). 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. A mandatory inclusive educational exchange quality framework could be put in place to guarantee educational mobility for all learners in second and third level education and vocational training.

VET is acknowledged to have a central role in supporting equitable and sustainable economic and social development, contributing to the realisation of human rights; and to developing the productive capacity of people, their societies and their economies (Wheelahan, & Moodie, 2016; p. 9). This is particularly the case for individuals who are vulnerable or more at-risk of socio-economic exclusion. To enhance the impact of VET on inclusive and equitable quality education and lifelong learning opportunities, key components need to be integrated into VET that assist participants to learn how to learn and attain literacy and numeracy, transversal and citizenship skills.

The value of effective VET for individuals who have acquired an impairment in childhood or early adulthood cannot be underestimated. It can provide them with opportunities in life and sustain their social and economic participation. It is also considered to be critical to individual health and well-being (Goss Consultancy Ltd, 2018).

VET transition programmes have a particularly important role to play for youth with additional learning needs in terms of fostering personal attributes such as personal effectiveness, career readiness, employability skills and social capital and in preparing them for progression to further and higher education and employment (Goss Consultancy Ltd, 2018). The effectiveness of such programmes can be enhanced by adopting inclusive teaching approaches, removing barriers to learning, providing personalised support and preparing learners to transition to adulthood.

In order to design and deliver effective transition programmes, VET providers need to put a number of strategies into place including:

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

The European Commission (2014) proposed that VET systems could achieve a more active participation by people at risk of exclusion by involving them in a consumer-orientated design process, perhaps through focus groups or other means of gaining feedback. 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. Given the diversity among persons with disabilities, it would be unwise to develop VET responses on the basis of assumed characteristics of persons with disabilities as a homogenous group but rather to create more responsive methods of facilitating participation and learning by engaging with each person with additional learning needs to design a context that meets their needs.

The Helsinki communiqué on Enhanced European Cooperation in Vocational Education and Training, issued after the meeting of European Ministers of Vocational Education and Training, the European Social partners and the European Commission in 2006, advocated that VET systems needed to be both efficient and equitable with no compromise between the two values. This requires 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).

It needs to acknowledged, given the diversity of challenges that can face learners with different capacities, that VET must not be viewed as the most effective or even the sole mechanism to address social exclusion. A distinction needs to be made between targeting VET for these learners and tailoring mainstream VET to respond more effectively to meet the needs of such learners. The concept of targeting VET can imply that a separate stream of VET programs for learners with different capacities is required, whereas tailoring VET means that learners with different needs (such as persons with disabilities or immigrants) are involved in the design of VET to meet their needs (Preston & Green, 2008; p. 180).

The capabilities approach is a methodology that warrants consideration within the context of inclusive learning in a mainstream VET context. The approach emphasises the capabilities that enable people to be successful in both economic and personal terms. This conception is broader than the profile of capacities needed for work and covers the capacity and strategies required to reach personal goals in life, employment and education (Cedefop, 2009; p. 39). An important mechanism that can support this approach is 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.

The capabilities approach adopts the position that in order to thrive as an individual, access to a wide range of social, economic, cultural and technological resources are required. Capabilities are specified as social and personal resources that people can access so that they can live the type of life they value. It comprises of a broad framework that can be applied in evaluating and assessing individual well-being and social arrangements and to designing policies for societal change (Wheelahan, & Moodie, 2016). For example, productive capabilities refer to the resources and arrangements of work and the range of knowledge, skills and attributes that a person requires to be productive and successful in their work and career and to be able to influence decisions which impact on work.

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 providing guidance and support services, using new technologies and more effective monitoring systems. Other measures recommended included financial support, mechanisms to validate non-formal and informal learning gained through voluntary activities and offering more flexible learning pathways. The role of VET in promoting active citizenship could be enhanced by collaboration with civil society organisations or increasing learner representation in the governance of VET institutions (Council of the European Union, 2010).

The proportion of persons with disabilities who are restricted in their participation in the labour market is significantly higher than the general population. This is particularly the case for those with learning or intellectual impairments. This constitutes a substantive concern for the management and staff of VET providers, learners with additional needs and their representatives and employer and work representative organisations (European Agency for Development in Special Needs Education, 2013). High-quality VET is viewed as a critical factor to redress this domain of social exclusion. EU policy on VET requires that all citizens are given the opportunity to acquire the skills to live and work in an information society and that special attention is paid to persons with disabilities. This means that VET must address the needs of all learners including those with additional learning needs such as learners with special educational needs (European Agency for Development in Special Needs Education, 2013).

In a monitoring report on vocational education and training policies 2010-14, Cedefop (2015) concluded that VET needed to balance the dual objectives of employability and economic growth while, at the same time, responding positively to the individual needs and aspirations of learners and addressing the wider challenge of promoting social inclusion and active citizenship (p.121). It was acknowledged that substantive progress had been made in increasing VET participation of 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 and practical 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).

The European Pillar of Social Rights confirms the right to quality and inclusive education training and life-long learning for every EU citizen (Europe Commission, 2017). The aspiration is that this will support people in maintaining existing skills and acquiring new ones that empower full participation in society and to navigate a successful transition to the labour market (1). Further, the right to equal treatment and opportunities in the domains of employment, social protection, education, and access to goods and services is underpinned regardless of an individual's personal characteristics including disability (3). Specifically, persons with disabilities are guaranteed a right to the income support they need to live a life of dignity, services that promote participation in employment and society and work conditions that are adapted to their needs (17).

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, 2015p. 163). To respond to this call, VET provision needs to move away from a narrow view of its role in training to meet the technical and vocational demands of the labour and be conceived as a human right which needs to be integrated into everyone's professional and personal development throughout life (p. 197). In addition to broadening its scope, VET needs to reform to become more inclusive of the diverse learners who need a different approach to learning in order to cater for all participants regardless of gender, ethnicity, age, disability or location (p. 161).

This requires that diverse experiences of learners are included in learning materials and strategies for teaching and learning that respond to the needs of an increasingly diverse population of learners. To achieve the goal of inclusive VET, changes will be required to VET institutions and practices to open them up to people from at-risk populations. This can involve 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.

Such changes in the VET system must be supported by a policy commitment in which the needs of learners with specific learning needs are acknowledged, commitments specify particular groups, such as young people, women or people living with disabilities. It needs to cover all types of learning including non-formal learning that takes place at work, whether this be formal or informal work.

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 which identified a set of success factors for inclusive VET (2013). It published a report (2013) which 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 (pp. 7-8).

The recommendations are structured into three categories: Input; Process; and Outcomes. A full list of successful factors identified in the review of practice in 26 countries are presented in Annex 6 and the following strategies have been adapted from the report.

- Develop an inclusive policy which deems difference among learners as the norm in the organisational culture,
- Create an ethos that encourages motivation and commitment,
- Adopt a distributed leadership style that empowers a teamwork approach and collaborative problem solving,
- Ensure that roles within each multi-disciplinary team are clear,
- Provide effective channels for both internal and external communication to support collaboration,
- Encourage cooperation between individuals and teams through peer coaching, informal discussions and collaborative problem solving,
- Utilise learner-centred approaches in the VET learning process to set goals, develop learning plans and design programme content,
- Implement a tailored approach to curriculum development, learning methods, materials and assessment procedures to respond to individual learner needs,
- Be flexible in approaches to the development and implementation of individual learning plans,
- Produce 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,
- Involve learners from the initial stages of individual planning and ensure that their voices are listened to throughout the learning process,
- Undertake preventative educational actions in collaboration with the local social services to support learners at risk of withdrawing or dropping out,
- Where necessary, seek out alternative learning options for those who disengage,
- Subject VET programmes or courses to regular internal and external to ensure relevance of content to current competence requirements,
- Train all staff in the skills and attitudes required to:
  - 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,
- Respect the wishes and expectations of learners and integrate them into the evolving transition process to ensure a successful transition to the open labour market,
- Work 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 employment outcome.

In 2020, the 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 which was sustained through public funds and agreed by the social partners and civil society.

It called for greater ambition to be reflected in the targets and indicators for lifelong learning in the workplace and in education and training settings. This could be informed by an inclusive Key Competences framework which extended beyond secondary education addressing adult learning needs such as learning how to learn, citizenship skills and life competences. This requires that learners are empowered to make an active contribution to developing learning pathways to ensure that they are adopted to their needs.

It noted the position of the European Commission set out in the European Skills Agenda (2020) for sustainable competitiveness, social fairness and resilience. This recognised the priority to increase the participation of adults in learning opportunities and the ambitious targets to be reviewed in 2025. Some of the strategies to progress towards those objectives include:

- Dismantling discriminatory stereotypes,
- Increasing learning participation by adults with low qualifications or who are unemployed,
- Monitoring the increases 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 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.

#### VET and Universal Design for Learning

Universal Design for Learning is an approach to programme design and delivery that espouses the view that a "one-size-fits-all" curriculum will not achieve success for all learners regardless of their personal preferences and learning needs. 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&u tm\_content=aboutudl). These are:

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

The underpinning policy basis for adopting a UDL approach it set out in Article 24 of the UN Convention on the Rights of Persons with Disabilities which holds that 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). Quirke and McCarthy (2020) elaborated a conceptual UDL framework for further education and training sector in Ireland which brings together many of the most useful and relevant concepts and strategies to designing and delivering 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 describe 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 or a workplace, or whether it is virtual or physical.

The conceptual framework for further education and training described the UDL approach in detail (Quirke & McCarty, 2020). The principles of UDL are:

- The 'Why' of Learning Provide Multiple Means of Engagement
- The 'What' of Learning Provide Multiple Means of Representation
- The 'How' of Learning Provide Multiple Means of Action and Expression

A UDL approach is likely to be more effective when it is informed by the values of inclusion. (p. 45). 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, available to fellow learners, can be accessed 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 ensured through the learning process in terms of conditions and outcomes.

To accommodate the increasing diversity of learners entering further education and training, UDL must be applied not only in the design of a curriculum or programme but must encapsulate teaching and learning practices and materials, methods of assessing progress and 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 VET.

- Education is no longer about ensuring that learners accumulate content because this is virtually universally available. It is about learning how to learn. When a person graduates, they do so as 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 or course rather than having to adapt it retrospectively (Johnson & Fox, 2003; Cited in Quirke & McCarthy, 2020; p. 46).

# Selecting Indicators of the QoL Impact of VET

Some important trends that are shaping the future of work and skills include the impact on QoL physical and mental health and the role of lifelong learning (European Training Foundation, 2020; p. 57).

It is challenging to reach definitive conclusions with regard to the social and economic impact of VET, given the variation in types of data and methodologies that have been used across studies (Griffin, 2016). This makes it difficult to judge the returns on investment which have been reported. However, a number of indications are evident. For example, a low level of qualification is associated with less financial return. In interpreting this finding, it is important to keep in mind that there well may be other benefits associated with an entry level qualification such as improved self-esteem, self-confidence and wellbeing. Clearly, these can also be experienced by those with higher qualifications. VET has the potential to assist learners to accrue social capital by developing new networks, and gaining confidence and self-esteem through the respect they receive from teachers and classmates. VET instructors have the capacity to adapt their teaching approaches so that these benefits are more likely (Griffin, 2016).

The benefits that have been attributed to VET range from increasing social cohesion to strengthening social capital, encouraging active citizenship and improving health and wellbeing However, one of the challenges in demonstrating and monitoring the social benefits of VET is the fact many of them are intangible in that they are not easily measured. Nevertheless, learners can provide feedback on the benefits that they experienced such as problem solving, awareness of opportunities to progress, communication skills, networking, access to support groups and increased confidence and wellbeing (Deloitte Access Economics, 2011; p. 46). Education providers listed the intangible benefits that they perceived including psychological wellbeing, increased confidence, self-esteem, feelings of control and socialisation including social interaction, friendship and a supportive environment (p. 44).

It is important to explore the extent to which the social benefits of education in general are deemed relevant to VET (Deloitte Access Economics, 2011; p. v)

- Improved self-esteem, self-confidence and communication skills,
- Higher levels of life satisfaction and happiness,
- Increased engagement or reengagement (being given a 'second chance'),
- Improved problem-solving skills,

- Improved understanding of the concepts of 'lifelong learning' and a stepping stone into further education and training,
- Improved health, life expectancy and quality of life for the learner and their offspring,
- Increased consumer choice efficiency,
- Increased personal status,
- More hobbies and increased participation in leisure activities,
- Intergenerational benefits through greater support for children's learning.

There is evidence that some of these are applicable to VET. For example, VET providers can actively seek to increase learners' confidence and self-esteem and the diversity of their networks alongside developing specific vocational competencies. (p. 44) and undertaking vocational education and training, can enhance the trust a learner has in their beliefs and in their interrelationships with other people (p. 43).

Important learning outcomes for transition programmes, which can be fostered through enrichment activities and work experience, include:

- Personal, social, employability and independent learning skills,
- Excellent punctuality, attendance and behaviours,
- Protecting and maintain both physical and psychological safety and health. (Goss Consultancy Ltd, 2018; p. 36).

A relationship has been found between adult learning and improved health and more active citizenship (ET2020 Working Group on Adult Learning, 2015). Adults that continue to learn earn more, are more employable, enjoy better health and are more active citizens.

The working group recommended that Member States put in place systems and tools that would allow them to anticipate the skills and learning needs to success in employment and in other life domains such has health. The acquisition of basic skills has an important contribution to make in this regard.

A study to explore the relationship between VET and health and wellbeing identified a positive relationship (Stanwick et al, 2006). However, this was not a simple or direct relationship because other factors and intervening variables influenced the relationship. For example, education enhanced the chance of being employed which is an important determinant of health. A path analysis was used on indicators of physical and mental health outcomes using the SF-36 questionnaire (This is described elsewhere in this report) to explore the indirect effects of education. It was posited that many of the benefits were associated with the learning environment rather than the learning process.

Some of the positive relationships with health and wellbeing highlighted were:

- Interacting and networking with others,
- Highest level of education and mental and physical health,
- Increased confidence, self-esteem and feelings of control,
- Social interaction, friendship, concepts of family, solidarity, a sense of belonging and a supportive environment and a sense of wellbeing,
- Improved life coping strategies,

- Gaining a sense of purpose and hope, gaining competencies, and social integration,
- Personal development, social integration, improved capacity for self-direction and an increased capacity to relate well to others.

It must also be acknowledged that failure to succeed in education can have negative impacts including stress, anxiety and mental ill health.

Improved basic skills can impact on both an individual in terms of personal development, improved mental and physical health and employment and on a society in terms of economic competitiveness, reduced social inequality, increased inclusion and active citizenship. Both formal and non-formal adult education, training and basic skills acquisition have equally important roles to play in promoting active citizenship, employment and social inclusion.

The positive impact of participation in learning effective basis skills can be seen across many important life domains and can reduce the 'wellbeing gap' for vulnerable individuals and groups (ET2020 Working Group on Adult Learning, 2015) including:

- Wellbeing:
  - Improved in self-confidence,
  - o Better physical and mental health,
- Social participation:
  - o Positive attitudes to voluntary and community activity,
  - Participation in political and civic life,
- Social equality and inclusion.

Positive physical and mental health outcomes requires that individuals are able to:

- Make healthy choices,
- Manage health conditions,
- Search for health information,
- Select and understand its relevance.

For example, an individual lacking the necessary level of literacy and numeracy skills will be challenged in learning how to manage a chronic health condition such as diabetes. A positive relationship between participation in adult learning and increased optimism, self-efficacy and better self-rated health has also been documented. Adult learners were found to be more likely to develop new and better health behaviours and to sustain these into the future.

#### Learning in Real Life Contexts

It has become increasingly important for people to acquire interpersonal, entrepreneurial and career management skills to prosper in the current labour market. Success can depend on being able to combine them in complex ways (Cedefop & ETF, 2020). This requires that workplaces evolve into learning-friendly environments that stimulate people to develop their professional and personal skills. Substantial progress is required to create learning opportunities to develop personal and social competences, learn how to learn, citizenship skills, cultural awareness and effective communication.

Cedefop summarised the components of facilitating learning in real life contexts (Sonntag & Stegmaier, 2006; Cited in Cedefop. 2009; p. 156), many of which could be useful in a VET context.

- Approaches in a problem-oriented, authentic context
  - Behaviour modelling:
    - Communication,
    - Coping with conflicts,
  - Team building:
    - Comprehension of group processes,
    - Communication,
    - Cooperation,
- Counselling- and supervision-oriented approaches:
  - Mentoring and coaching:
    - Personality development,
    - Career advancement,
  - Leader/member-exchange:
    - Leadership behaviour,
    - Attitude towards employees,
- Simulation:
  - o Simulation:
    - Explorative learning,
- Personality centred/experience-oriented approaches
  - Group-dynamic approaches:
    - Self-image (view of oneself),
  - Outdoor training
    - Self-confidence,
    - Self-concept,
    - Problem-solving,
    - Cooperation,
- Task oriented approaches:
  - Job assignment:
    - Planning,
    - Shaping relations,
    - Self-concept,
    - Values and attitudes,
  - Work-imminent qualification:
    - Planning,
    - Problem-solving,
    - Interpersonal behaviour,
    - Self-esteem.

### Selecting an Appropriate QoL Measurement Strategy

Concern has been raised about the use of QoL questionnaires to evaluate the effectiveness of services over diverse populations (Kober, & Eggleton, 2002). The authors found that one of the four factors in the Schalock QOL-Q could not be considered stable. A systematic review of QoL measures for persons with intellectual disabilities and challenging behaviours concluded with a caveat that needs to be taken into account when selecting a suitable instrument to measure QoL (Townsend-White, Pham, & Vassos, 2012). While acknowledging the relevance of QoL as an outcome indicator,

the authors refer to the 'tyranny of quality of life' and recommended that it be used as one of a variety of performance indicators in a comprehensive evaluation scheme. An overemphasis on QoL has the potential to ignore the subjective experience of the person served and miss out on other areas in which a person may be experiencing deprivation. It is also important that comparative measures are used which reveal the extent to which the QoL of service participants fall short of what is acceptable for the general population even where their QoL has been documented to be improving. They recommended that both researchers and evaluators encourage the use of a 'holistic' approach to QoL which includes participatory action research and evaluation to make sure that the characterisation of QoL is influenced by the subjective experiences of persons with intellectual disability (Townsend-White, Pham, & Vassos, 2012; p. 281).

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 and community services culminating in a review of the international literature on specialist support of persons with disabilities living in the community (Mac Domhnaill, Lyons, & McCoy, 2020). The report concluded that community settings impacted positively on wellbeing, freedom and independent decision-making.

The report gave support to aspiration that outcome measurement supported the building of effective person-centred disability services. It noted the risk that a reductionist and linear approach could reduce the possibility of conversations between staff and the persons they support about the quality of services (Cook & Miller, 2012: cited in NDA, 2019: p. 3).

The Economic and Social Research Institute (ESRI) produced a report which made reference to the NDA (2016) framework of nine QoL domains for measuring outcomes in person-centred disability services and the United States (US) National Core Indicators (NCI) which are used to measure service impact across a variety of service types including employment, rights, service planning, community inclusion, choice, and health and safety (Mac Domhnaill, Lyons, & McCoy, 2020).

Guidelines that need to be taken into account by those responsible for developing or identifying quality indicators for community services when developing indicators of service outcomes (Schalock et al., 2006; cited in Noonan-Walsh, 2007) 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).

The 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 note that QoL had an appeal as an

indicator of the effectiveness of community supports. They noted a consensus on the multidimensionality of the construct and the view that QoL domains were relevant to all people regardless of ability and emphasised that both subjective and objective components were implicated. The relevance of objective components was that they allowed a comparison between QoL impacts for diverse individuals and groups. Subjective measures provided an insight of an individual's perception of QoL reflecting the extent to which each domain was considered important at a particular time.

A number of critical questions that need to be answered when selecting an appropriate QoL tool to gather data on service impacts were proposed by the authors.

- 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)

One contributor to the Joint Improvement Team (2005) conference expressed the concept of the 'same as you' in terms of seven statements which need to be kept in the forefront when considering how service can best promote enhanced QoL.

- 1. It's about my dream to grow up with the same choices as everyone else.
- 2. It's about me being able to grow up with my family.
- 3. It's about me having a home of my own.
- 4. It's about me being treated as an adult.
- 5. It's about getting a bit of support to do ordinary things.
- 6. It's about living my life the way I want to.
- It's about me being able to see the world and all its glories. (Joint Improvement Team, 2005; p. 27)

The NDA summarised outcomes for disability service as covering nine domains of QoL (2016; p. 5). Persons with disabilities are:

- Are living in their own home in the community,
- Are exercising choice and control in their everyday lives,
- Are participating in social and civic life,
- Have meaningful personal relationships,
- Have opportunities for personal development and fulfilment of aspirations,
- Have a job or other valued social roles,
- Are enjoying a good quality of life and wellbeing,
- Are achieving best possible health,

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• Are safe, secure and free from abuse.

### Tools for Monitoring QoL Outcomes in Health and Social Care Services

The EPR benchlearning process reviewed a variety of tools designed to evaluate the outcomes of health and social care interventions. These are presented in Annex 5. This review set out to identify the views of researchers and authors on the tools available for evaluating QoL service impact.

The NDA report on outcome measurement (2019) described a number of approaches to measuring individual outcomes including:

- Using customised person-centred planning and assessment tools. One example described was I-Planit, a person-centred planning software that can be adapted to the purpose of a particular service, the preferences of the person served and the views of staff and other stakeholders and can provide data to assist in evaluating outcomes,
- Deploying the Council on Quality and Leadership's Personal Outcomes Measure Tool (POMS) to assess needs, develop individual plans and monitor individual outcomes. POMS generates indicators of supports and interventions used to identify personal goals and outcomes achieved,
- Using Goal Attainment Scaling (GAS) to monitor progress towards personal goals, particularly where the person served has been actively involved in setting goals, can enhance the relevance of the indicators generated. For this to be achieved, both staff and participants must engage in dialogue about the goals to be achieved and the ways in which this can be measured and evaluated.

The standardised outcome measurement tools explored in the NDA report on outcome measurement included a number of approaches that have been used to assess the impact of services on QoL (NDA, 2019: pp. 37-59).

- The National Core Indicators (NCI) Instrument, deployed in the United States uses surveys alongside other forms of assessment and quality assurance, is focused at organisation, State and Federal levels. 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,
  - Staff stability and competence outcomes,
  - System performance outcomes.

Details of domains, indicators and questions addressed by the NCI are presented in Annex 1.

• Observations have been used 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 QoL model to assess the quality of residential service for people with severe intellectual impairments. The framework adopted was based on the IASSIDD model of QoL. The domains and indicators used are presented in Annex 2.

- Generic patient-reported outcome measures (PROMS) have frequently been used to assess QoL for persons with disabilities. The NDA quality outcomes report (2019) described a number of these.
  - The Short Form-36 (SF-36) is a 36-item questionnaire which was originally developed measure health of individuals. The focus was upon clinical practice and research but also relevant to evaluating the impact of health policy or surveys of health in the general population. A Short Form-12 (SF-12) was developed as a valid alternative for larger samples. The domain covered by the tools include health-related physical limitations, social activity or role limitations related to physical or psychological problems, pain, psychological distress and well-being, general health, energy and fatigue and general health perceptions,
  - The WHOQOL-Bref is an abbreviated version of the WHOQOL which consisted of 100 items. It has been used to measure QoL for a wide range of health conditions and had been extensively researched since its development in the 1990s. More information can be accessed at <a href="https://www.who.int/tools/whoqol">https://www.who.int/tools/whoqol</a>. It consists of 26 items covering four domains:
    - Physical health in terms of activities of daily living, requirement for medication or aids, energy and fatigue, mobility, pain, sleep and work,
    - Psychological wellbeing in terms of body image and appearance, negative and positive feeling, self-esteem, spirituality, thinking, learning, memory and concentration,
    - Social relationships in terms of personal relationships, social support and sexual activity,
    - The environment in terms of financial resources, freedom, physical safety and security, health and social care, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation /leisure activities, the physical environment and transport (NDA, 2019: p. 201).
  - According to the EUROQOL website (<u>https://euroqol.org/eq-5d-instruments/</u>) the EQ-5D has been used in clinical trials and population studies for over 30 years. EQ-5D has two versions which differ in the number of levels of rating of perceived problems on each dimension, either 3 or 5 levels. It has been widely used with a range of health conditions and has been validated. It is available in over 130 languages and there are a range of modes of administration. EQ-5D covers five domains of health: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.
  - The Patient-Reported Outcomes Measurement Information System (PROMIS) is a described as '...a set of person-centred measures that evaluates and monitors physical, mental, and social health in adults and children'
     <a href="https://www.healthmeasures.net/explore-measurement-systems/promis?AspxAutoDetectCookieSup=">https://www.healthmeasures.net/explore-measurement-systems/promis?AspxAutoDetectCookieSup=</a>) (Paragraph 1).

It is designed for use in the general population or with people who are living with chronic conditions. PROMIS Global-10 is publicly available and consists of 10 items, adapted from other measures such as the SF-36 and EQ-ED, that HrQoL for a range

of chronic health conditions. The domains it covers are physical, mental and social health and pain, fatigue and overall perceived quality of life.

 The Adult Social Care Outcomes Toolkit (ASCOT) was developed by Personal Social Services Research Unit (PSSRU) in the UK in cooperation with experts and care organisations. It is designed to measure social care related quality of life (SrQoL) outcomes of individuals in care services. It consists of eight domains: control over daily life; personal cleanliness and comfort; food and drink; personal safety; social participation and involvement; occupation; accommodation cleanliness and comfort; and dignity, which relates how a service impacts on the self-esteem of the person served. Descriptions of each of the domains are presented in Annex 3 and a more detailed explanation is available at https://www.pssru40.org.uk/ascot.

McCarron and colleagues (2018) reviewed the evidence on the most appropriate measures of QoL and cost that could be used to evaluate the impact of moving to community living, with a specific reference to persons with intellectual disabilities. The authors referred to the Schalock el (2002) framework as being an 'influential academic QoL framework' (p. 12) and listed its eight domains: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.

Among the quantitative indicators identified as being used in the studies review were:

- The Life Experiences Checklist (LEC) which assesses both objective and subjective quality of life on four subscales: Home, Leisure, Freedom, Opportunities, Relationships,
- The Quality of Life Questionnaire (QOL-Q), a validated tool which assesses subjective quality of life on four dimensions Satisfaction, Competence/Productivity, Empowerment/Independence, Social Belonging/Integration.
- Life Circumstances Questionnaire (LCQ) a measure of objective quality of life in terms of Material Well-Being, Physical Well-Being, Community Access, Routines, Self-Determination, Social-Emotional Well-Being, Residential Well-Being, General Factors.

The authors concluded that the findings of the qualitative studies they reviewed provided evidence that community living impacted positively on QoL specifically in terms of well-being, freedom, and independent decision-making; more careful consideration of housemate compatibility; increased family contact; and social integration opportunities. Studies specifically examining QoL also identified freedom and self-determination to be important outcomes for individuals. (p. 9).

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. They recommended that economic evaluations needed to use the ICECAP-O (<u>https://www.birmingham.ac.uk/research/activity/mds/projects/haps/he/icecap/index.aspx</u>) which is a capability measure or the ASCOT, described elsewhere, in combination with the EQ-5D or SF-6D.

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 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 the people receiving services.

An influential approach to developing more responsive and person-centred services is the Council on Leadership and Quality Personal Outcome Measures (POMS) (see <a href="https://www.c-q-l.org/tools/personal-outcome-measures/">https://www.c-q-l.org/tools/personal-outcome-measures/</a>). POMS allows a person to select the objectives to be addressed in their personal plan. These are transformed into specific, measurable goals to be addressed throughout the year. A survey was carried out in Ireland to explore the potential for POMS to promote a better QoL (McCormack, & Farrell, 2010). The most frequent QoL related outcomes identified included attaining a goal within the previous twelve months, ongoing contact with family and adequate privacy. The least frequent outcomes were choosing where and with whom to live, exercising personal rights and choosing services e.g. dentist or hairdresser. The most often identified priorities were selecting personal goals and choosing where to work and community participation.

In recent years significant progress has been made in developing tools based on the framework for characterising QOL for people with disabilities based on the work of Schalock/IASSIDD Expert Group. These include:

The GENCAT scale wich 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 relevant to personal outcomes by a third-party informant (proxy). The rating needs to be based on systematic observation and a good knowledge of the person. The instrument contains 69 items. Details are publicly available in Research Gate from the authors (Gomez et al., 2013).
 Respondents use a 4-point scale ranging from always to never to rate the extent to which the person concerned engages, or experiences, the theme of each item. 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 items of the GENCAT are presented in Annex 4.

• The San Martin was developed after 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 program evaluator to evaluate 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.

The manual describes the dimensions of the scale in the following terms:

- Self-Determination (SD): Autonomy; goals, opinions and personal preferences; decisions and choices,
- Rights (RI): Knowledge of rights; intimacy; privacy; confidentiality; respect,
- Emotional Wellbeing (EW): Satisfaction with life; concept of self; absence of stress, negative feelings or behaviour problems; basic safety; emotional communication
- Social Inclusion (SI) Integration; participation; support,
- Personal Development (PD): Self-improvement; learning; skills; and motivational abilities.
- Interpersonal Relationships (IR) Family relationships; social relationships; communication,
- Material Wellbeing (MW): Income; pensions; household conditions; work conditions, technical aids,
- Physical Wellbeing (PW) Nutrition; exercise; hygiene; mobility; medication; medical, service; sexuality.

Items are rated similarly to the GENCAT on a 4-point scale from always to never.

The San Martin Scale questionnaire is available at:

http://sid.usal.es/idocs/F8/FDO26729/San\_Martin\_Scale\_English\_(Verdugo\_Gomez\_et\_al\_2 014).pdf

 The Quality of Life Impact of Services Questionnaire (QOLIS) is also based on the Schalock/IASSIDD model. 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 QOL but a measure of the extent to which a person perceives that participating in a program or receiving a support or intervention has enhanced his or her QOL (McAnaney, & Wynne, 2016).

The rationale underpinning the development of the QOLIS was that linking respondents' ratings of QoL directly to a program or intervention would provide beneficiaries with the means to feedback to providers and professionals their perceptions of its impact on his or her QOL.

There are a number of advantages to this:

- Gaining an insight into the perceptions of participants or users is an important strategy in co-production,
- The direct focus on the impact of a specific program 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 program or intervention.

Three versions of the QOLIS are available.

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

The QOLIS 16-1 items are listed in Annex 4 and referenced to the GENCAT. The QOLIS-SR has been administered by proxy.

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### Annex 1 National Core Indicators (NCI)

lable		outcome domains in Irish Disability Services (NDA, 201	
	Outcome Domain	NCI domain indicator- proportion of people who	NCI Questions for indicator
			Did you choose where you live?
			Did you choose who you live with?
		have choice in where they live	In general, do you like where you are living right
1	Living in the Community	have choice in whom they live with	now?
		are satisfied with where they live	What don't you like about where you live?
			Would you prefer to live somewhere else?
			Where would you prefer to live?
			Do you feel in control of your life?
			Do you get up and go to bed at the time you want
		feel in control of their lives	to?
2	Choice and control	make decisions about their everyday lives	Can you eat your meals when you want to?
		make decisions about their everyddy nives	Are you able to decide how to furnish and
			decorate your room/house?
			Are you able to choose who you live with?
			Did you go shopping in the last month?
	Social and civic participation		Did you do errands in the last month?
		shopped in last month – did errands – went out	Did you go out for entertainment in the last
3		for entertainment – went out to eat – went to a	month?
5		religious or spiritual service – went on vacation	Did you go out to eat in the last month?
		in past year	Did you go to religious or spiritual services in the
			last month?
			Did you go on vacation in the past year?
	Personal relationships	have best friend	Do you have a best friend?
4		see their friends when they want	Can you see your friends when you want to?
		are lonely	Do you ever feel lonely?
		have access to self-advocacy	Have you gone to a self-advocacy meeting?
5	Education and personal development	know who to call with a question, concern or	If you have a complaint about the services you are
		complaint about their services	getting right now, do you know whom to call
6	Employment and valued social roles	have employment	Do you have a paid job in your community?

7	Quality of life	like where they work job pays at least the minimum wage would like a job have had job search assistance volunteer are satisfied with what they do during the day are satisfied with the staff who work with them	Do you like where you work? Would you like a job? Has someone talked to you about job options? Do you do any volunteer work? Do you like how you usually spend your time during the day? Do the people who are paid to help you do things the way you want them done? Do the people who are paid to help you change too often?
8	Health and well-being	Exercise have access to healthy foods have ever had to cut back on food because of money can get an appointment to the doctor when they need to have poor health (self-reported) receive the services that they need	Did you go out to exercise in the last month? Do you have access to healthy foods like fruits and vegetables when you want them? Do you ever have to skip a meal due to financial worries? Can you get an appointment to see your GP when you need to? How would you describe your overall health (excellent/v. good/good/fair/poor/very poor)? Do the services you receive meet your needs and goals? If no, what additional services might help you?
9	Safe and secure and free from abuse	feel safe at home feel safe in neighbourhood feel safe around their caregiver/staff feel safe at work or in their daily activities are treated well by staff in public services basic rights are respected by others feel that their belongings are safe	Do you feel safe in your home? Do you feel safe in your neighbourhood? Do you feel safe around the people who are paid to help you? Do you feel safe at your work and day activity? Does your case manager ask what you want? Does your case manager call you back right away when you call? Do your staff at work treat you with respect? Does your case manager help get what you need?

Do people ask your permission before coming into your home?
Do you have enough privacy at home?
Are you ever worried for the security of your
personal belongings?
Has anyone used or taken your money without
your permission

# Annex 2 Qualitative indicators to guide observation of QoL

Quality of Life Domain	Indicators		
Emotional Well-Being	<ul> <li>People appear content with their environment, their activities, and their support; they smile and/or take part relatively willingly in a range of activities (including interactions) when given the right support to do so</li> <li>People appear at ease with staff presence and support</li> <li>People appear comfortable in their environment, including with the level of arousal</li> <li>People appear pleased when they succeed in activities, do something new, or experience interaction with new people in their environment</li> <li>People do not show challenging behaviour or spend long periods in self-stimulatory behaviour</li> </ul>		
Inter-personal Relations	<ul> <li>Staff are proactive and people are supported to have positive contact with their family on a regular basis; family can visit whenever they want to</li> <li>People experience positive and respectful interactions with staff and others in their social network including coresidents</li> <li>People are positively regarded by staff, they are seen as essentially human "like us" and differences related to impairment or health are attended to from a value neutral perspective</li> <li>People have members in their social network other than paid staff and immediate family and are supported to meet new people with similar interests, both with and without disabilities, and to make and maintain friendships with people outside of their home as well as those within their home</li> <li>From most of these contacts, people experience affection and warmth.</li> </ul>		
Material Well-Being	<ul> <li>People have a home to live in that is adapted to their needs in terms of location, design, size and decor within the constraints of what is culturally and economically appropriate</li> <li>People have their own possessions around their home</li> <li>People have enough money to afford the essentials and at least some non-essentials (e.g. holiday, participation i preferred activities in the community)</li> <li>People are supported to manage their financial situation so they can access their funds and use them in accordance with their preferences (preferences are sought and included in decisions about holidays, furniture, or the household budget)</li> <li>People have access to some form of transport in order to access the community</li> </ul>		
Personal Development	People are supported to engage in a range of meaningful activities and social interactions that span a range of the second social interactions that span a range of the second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second social interactions are supported to engage in a range of the second social second soci		

	People are supported to try new things and have new experiences with just enough assistance and support to
	experience success and, thus, to develop their skills
	People are supported to demonstrate what they can do (their competence) and experience self-esteem
	<ul> <li>People are supported to be safe and well in their own home and in the community (without staff being risk averse)</li> </ul>
	<ul> <li>Personalised and respectful support with personal care is provided well and promptly - all aspects of personal care reflect individual preferences as well as specific needs in respect of things such as swallowing are provided</li> </ul>
Physical Well-Being	<ul> <li>The environment is safe and healthy (e.g., environment not too warm or cold, no uneven or dangerous floors); people can move around their environment safely)</li> </ul>
	<ul> <li>People are supported to live healthy lifestyles at least most of the time - good diet, some exercise, etc.,</li> <li>Pain or illness is recognised and responded to quickly</li> </ul>
	<ul> <li>People are supported to access healthcare promptly when ill and preventative care such as regular health checks appropriate to age and severity of disability - are not over/under-weight - specific health issues are managed</li> </ul>
	<ul> <li>People are offered and supported to express preferences and make choices about day-to-day aspects of their lives, which mean people's own agendas, and preferences guide what staff do rather than those of staff</li> <li>Staff use appropriate communication to support choice and respect people's decisions</li> <li>People are supported to understand and predict what their day will be like, based on their own preferences and</li> </ul>
Self-Determination	<ul> <li>agendas</li> <li>People are supported to be part of Person-Centred Planning and other decision making processes as much as possible and to have someone who knows them and who can help others to understand their desires and wishes, such as an advocate or members of circle of support</li> </ul>
	People lead individualised lives rather than being regarded as part of a group of residents
Social Inclusion	<ul> <li>People live in an ordinary house in an ordinary street in which other people without disabilities live</li> <li>People are supported to have a presence in the local community - access community facilities (shops, swimming pool, pub, and cafe) and are recognised, acknowledged, or known by their name to some community members</li> <li>People are supported to take part in activities in the community and not just with other persons with disabilities; for example, they actually do part of the shopping</li> </ul>
	<ul> <li>People are supported to have a valued role, to be known or accepted in the community - membership of clubs, taking collection in church, are viewed respectfully by people in the community (e.g. shopkeeper/bus driver/neighbours makes eye contact with them and call them by name), people are helped to be well presented in public, staff speak about people respectfully and introduce people by their name</li> </ul>
Rights	People are treated with dignity and respect in all their interactions and have privacy

•	People have access to all communal areas in their own home and garden, and are supported to come and go from their own home and garden, and are supported to come and go from their home as and when they appear to want to
•	People have someone external to the service system who can advocate for their interests
	reopie have someone external to the service system who can advocate for their interests
•	People can physically access transport and community facilities that they would like to or need to access
•	People are supported to take part in activities of civic responsibility - e.g., voting, representing persons with
	disabilities on forums, telling their story as part of lobbying for change
•	People and staff are aware of and respect the arrangements in place for substitute decision making about
	finances or other life areas (guardianship, administration)

## Annex 3 Adult Social Care Outcomes Toolkit (ASCOT) Domains

Table 6 The Social Care Related QoL ASCOT measure with its eight domains (NDA, 2019; p. 53).			
Domain	Definition		
Control over daily life	The service user can choose what to do and when to do it, having control over his/her daily life and activities		
Personal cleanliness and comfortThe service user feels he/she is personally clean and comfortable and looks presentable or, at best, is dressed groomed in a way that reflects his/ her personal preferences			
Food and drinkThe service user feels he/she has a nutritious, varied and culturally appropriate diet with enough food he/she enjoys at regular and timely intervals			
Personal safety The service user feels safe and secure. This means being free from fear of abuse, falling or other physical ha			
Social participation and involvement	The service user is content with their social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends, family and feeling involved or part of a community should this be important to the service user		
Occupation	The service user is sufficiently occupied in a range of meaningful activities whether it be formal employment, unpaid work, caring for others or leisure activities		
Accommodation cleanliness and comfort	The service user feels their home environment, including all the rooms, is clean and comfortable		
Dignity	The negative and positive psychological impact of support and care on the service user's personal sense of significance		

## Annex 4 A Comparison of the GENCAT and QOLIS Items

GENCAT*	QOLIS
Emotional Wellbeing.	Emotional Wellbeing.
1. He/she is satisfied with their present life	17. Enabled me to feel more secure about myself.
2. He/she shows symptoms of depression	18. Enabled me to feel more stable emotionally.
3. He/she is happy and in a good mood	19. Enabled me to better deal with situations of stress.
4. He/she expresses feelings of helplessness or insecurity	20. Enabled me to have a better opinion about myself.
5. He/she shows symptoms of anxiety	21. Enabled me to know better my difficulties.
6. He/she is satisfied with themselves	22. Enabled me to know better my capacities.
7. He/she has problems of conduct	23. Enabled me to feel less alone now.
8. He/she is motivated when performing some kind of activity	
Interpersonal Relationships.	Interpersonal Relationships.
9. He/she does things they enjoy with other people	1. Enabled me increase the number of people with whom I have
	regular contact.
10. The relations with his/her family are as they would like them to be	2. Enabled me improve the relationship with those close to me.
11. He/she complains about a lack of close friends	3. Enabled me to better communicate with other people.
12. He/she has a negative view of their friendships	4. Enabled me to feel more satisfied with my family relationships.
13. He/she says they feel undervalued by their family	5. Contributed to me being better able to solve conflicts with other
	people.
14. He/she finds it difficult to start up a relationship with a potential	
partner	
15. He/she gets on well with their colleagues at work	
16. He/she says they feel loved by the people who are important to	
them	
17. Most of the people with whom they interact are in a similar	
situation to their own	
18. He/she has a satisfactory sex life	
Material Wellbeing.	Material Wellbeing.
19. Where he/she lives stops them from leading a healthy life (noise,	31. Enabled me to better manage my financial situation.
fumes, odors, gloom, lack of ventilation, damage, inaccessibility) 20. His/her workplace complies with rules on health and safety	32. Made me more capable of earning a living in the future.
	52. Made me more capable of carming a nong in the rature.

GENCAT*	QOLIS
21. He/she has the material possessions they need	
22. He/she is unhappy with where they live	
23. Where he/she lives is clean	
24. He/she has enough money to cover their basic needs	
25. He/she does not earn enough to be able to afford luxuries	
26. Where he/she lives has been adapted to their needs	
Personal Development.	
27. He/she finds it difficult to cope with everyday situations	
28. He/she has access to new technologies (Internet, mobile phone,	
etc.)	
29. The work they do enables them to learn new skills	
30. He/she finds it difficult to effectively deal with the problems they	
have to face	
31. He/she does their work competently and responsibly	
32. The service he/she attends caters for their personal development	
and the learning of new skills	
33. He/she is involved in the drafting of their own individual program	
34. He/she lacks motivation at work	
Physical Wellbeing.	Physical Wellbeing.
35. He/she finds it difficult to sleep	24. Contributed to the improvement of my health.
36. Technical aids are available if he/she needs them	25. Enabled me to have more healthy eating habits.
37. He/she has healthy eating habits	26. Enabled me to use my leisure time better.
38. His/her state of health allows them to lead a normal life	27. Enabled me to become more mobile within my environment.
39. He/she maintains good personal hygiene	28. Enabled me to feel more capable of performing the daily tasks.
40. The service he/she attends supervises the medication they take	29. Enabled me to feel more capable of taking care of myself.
41. His/her health problems cause them pain and discomfort	30. Enabled me to feel more able to do physical activities.
42. He/she finds it difficult to access healthcare resources (preventive care,	
GP, at home, in hospital, etc.)	
Self-Determination.	Self-Determination.
43. He/she has personal targets, goals and interests	<ol> <li>Enabled me to identify opportunities to participate in my community.</li> </ol>

GENCAT*	QOLIS
44. He/she decides how to spend their free time	7. Contributed to me feeling more capable in taking decisions.
45. The service he/she attends caters for their preferences	8. Enabled me being more independent in my day-to-day life.
46. He/she defends their ideas and opinions	9. Enabled me better defining my personal objectives.
47. Other people decide upon his/her personal life	10. Enabled me to better exercise my rights.
48. Other people decide how he/she spends their money	<ol> <li>Enabled me to feel more capable of standing up for myself and my opinions.</li> </ol>
49. Other people decide what time he/she goes to bed	<ol> <li>Enabled me to understand the consequences of my actions before doing it.</li> </ol>
50. He/she organizes their own life	13. Opened doors for new opportunities in my life.
51. He/she chooses who they live with	<ol> <li>Enabled me to actively engage in my education and learn new things.</li> </ol>
	15. Enabled me to have greater ability to overcome obstacles and difficulties.
	16. Enabled me to feel more capable of solving problems.

# Annex 5 QoL Assessment Tools Review by the EPR Benchlearning Group

Title	Date	Items	Description
WHO Disability Assessment Schedule Version 2.0 (WHODAS 2.0)	2012	Form 36 Long 12 Short	<ul> <li>The WHODAS 2.0 assesses difficulties due to health conditions including diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs. Respondents are asked to think back over the previous 30 days and rate the degree of difficulty experienced in terms of carrying out activities in 6 domains using a 4-point scale ranging from none to complete.</li> <li>1. Cognition – understanding &amp; communicating</li> <li>2. Mobility– moving &amp; getting around</li> <li>3. Self-care– hygiene, dressing, eating &amp; staying alone</li> <li>4. Getting along– interacting with other people</li> <li>5. Life activities– domestic responsibilities, leisure, work &amp; school</li> <li>6. Participation– joining in community activities</li> <li>It is directly linked to the International Classification of Functioning, Disability and Health (ICF).</li> </ul>
https://www.who.int/class WHO Quality of Life Scale (WHOQOL)	1995	Forms 100 Long 26 Short	<ul> <li>The WHOQOL is a quality of life assessment developed by the WHOQOL Group with fifteen international field centres, simultaneously, in an attempt to develop a quality of life assessment that would be applicable cross-culturally. Versions have been developed for older people, persons with disabilities, persons with intellectual impairment and those with HIV</li> <li>Respondents rate how they felt in the previous 2 weeks on a 5-point scale on the following domains.</li> <li>1. Physical health Energy and fatigue Pain and discomfort Sleep and rest</li> <li>2. Psychological Bodily image and appearance Negative feelings Positive feelings Self-esteem Thinking, learning, memory and concentration</li> <li>3. Level of Independence Mobility Activities of daily living Dependence on medicinal substances and medical aids Work Capacity</li> <li>4. Social relationships Personal relationships Social support Sexual activity</li> <li>5. Environment Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and</li> </ul>

Title	Date	Items	Description
			opportunities for recreation/ leisure Physical environment
			(pollution/noise/ traffic/climate) Transport
			6. Spirituality/Religion/Personal beliefs Religion /Spirituality/Personal beliefs
			Permission is required to use it.
https://www.who.int/ment	al_health/publicatio	ns/whoqol/en/	
			The SF 36 assesses functional health and well-being from a person's point of view. It is a measure of physical and mental health and can be completed in five to ten minutes. Respondents rate the degree of limitation that they experienced in the previous 4 weeks on a 3-point scale from not limited to limited a lot. The domains
			are: 1. Vitality
SF 36 Health Outcomes		36	2. Physical functioning
Survey V2	1998		3. Bodily pain
			4. General health perceptions
			5. Physical role functioning
			6. Emotional role functioning
			7. Social role functioning
			8. Mental health
			Permission is required to use it and special software is required to score the
			instrument.
https://www.optum.com/s	solutions/life-science	s/answer-research/p	patient-insights/sf-health-surveys/sf-36v2-health-survey.html
			The IPAQ focuses on autonomy and participation and is targeted at people with
			chronic health conditions. It consists of items asking respondents to rate their
			participation in life activities on a 5-point scale from very good to very poor. It
Impact on Participation			covers 5 domains:
and Autonomy Questionnaire (IPAQ),		39	1. Autonomy Indoors
		55	2. Autonomy Outdoors
			3. Family Roles
			4. Social Relationships
			5. Paid Work and Education
			It can be purchased from the developers.
https://www.sralab.org/rel	nabilitation-measures	s/impact-participatio	n-and-autonomy-questionnaire

Title	Date	Items	Description
Community Integration Measure (CIM)	2001	10	<ul> <li>The CIM is described as a client-centred questionnaire that requests respondents to rate their perceived connections in 4 community domains.</li> <li>1. General Assimilation</li> <li>2. Support</li> <li>3. Occupation</li> <li>4. Independent Living</li> <li>Respondents are asked to agree or disagree with statements using a 5-point scale from always agree to always disagree.</li> <li>The content was developed from the words and ideas of persons with traumatic brain injury</li> </ul>
https://www.sralab.org/reh	abilitation-measures	community-integ	ration-measure
Reintegration to Normal Living Index (RNLI)	1988	11	<ul> <li>The RNLI assesses extent to which people who have experienced traumatic or incapacitating illness manage to reintegrate into normal social activities.</li> <li>1. Indoor, community, and distance mobility</li> <li>2. self-care</li> <li>3. daily activity (work and school)</li> <li>4. Recreational and social activities</li> <li>5. Family role(s)</li> <li>6. Personal relationships</li> <li>7. Presentation of self to others</li> <li>8. General coping skills</li> <li>Respondents rate the extent to which each statement describes or does not describe their situation. There different versions with different numbers of rating options including a 10, 4 and 3 visual analogue scales. A visual analogue scale is a l0 cm line on a page upon which respondents marks the distance from specific descriptors which represent their views. The mark is measured to produce the rating.</li> </ul>
https://www.sralab.org/reh	abilitation-measures	/reintegration-nor	
The Sense of Well-Being Inventory (SWBI)	2004	36	The Sense of Well-Being Inventory (SWBI) is a quality of life assessment instrument developed specifically as an outcome measure for people with disabilities in vocational rehabilitation. It addresses physical wellbeing and associated feelings about oneself. It covers 4 domains.

Title	Date	Items	Description
			1. Psychological wellbeing
			2. Family and social wellbeing
			3. Financial wellbeing
			4. Medical care
			Respondents rate the extent to which they agree or disagree on a 4-point scale
			from strongly agree to strongly disagree.
https://www.researchgate	.net/publication/225	285094_Sense_of_W	/ell-Being_Inventory
			The COPM is designed to be used by occupational therapists in an interview
			setting. Respondents are questioned about daily activities they want to, need to or
			are expected to carry out in the domain of self-care, productivity and leisure and
			the interview lists those in which they are challenged. They also facilitate
			respondents to assign an importance rating on a 10-point scale from very
			unimportant to very important. The respondent can list three challenges in each of
			the following areas.
			1. Self-Care
			a. Personal Care
The Canadian		Space for 27	b. Functional Mobility
Occupational 1991 Performance Measures (COPM)	1001	items;	c. Community Management
	1991	5 Items	2. Productivity
		monitored	a. Paid/Unpaid Work
			b. Household Management
			c. Play/School
			3. Leisure
			a. Quiet Recreation
			b. Active Recreation
			c. Socialization
			The respondent is then asked to select the 5 most and to rate them in terms of
			performance and satisfaction. This can then be used to measure changes in over
			time.
https://www.researchgate	.net/publication/131	86010_The_Canadia	n_Occupational_Performance_Measure_An_Outcome_Measure_for_Occupational_T
herapy			

Title	Date	Items	Description
Satisfaction with Life Scale (SWLS)		5	<ul> <li>The SWLS is a short 5-item instrument designed to measure global cognitive judgments of satisfaction with one's life. The scale usually requires only about one minute of a respondent's time. Respondents rate the extent to which they agree or disagree with each statement on a 7-point scale from strongly agree to strongly disagree.</li> <li>1. In most ways my life is close to my ideal.</li> <li>2. The conditions of my life are excellent.</li> <li>3. I am satisfied with my life.</li> <li>4. So far, I have gotten the important things I want in life.</li> <li>5. If I could live my life over, I would change almost nothing.</li> <li>The total score can then be compared to a table which indicates the extent to which a person is satisfied with his or her life.</li> </ul>
Quality of Life Index (QLI)	1984;1998	33/66	http://labs.psychology.illinois.edu/~ediener/SWLS.html         The QLI has a generic version and a number of other versions targeted at people         with a variety of health conditions. Respondents rate items on a 7-point scale from         very satisfied to very dissatisfied. They then rate the importance of each of the         items on a 7-point scale from very important to very unimportant.         Five scores are produced that measure quality of life overall and quality of life in         four domains:         1. Health and functioning         2. Social and economic         3. Psychological/spiritual         4. Family
Life Satisfaction Questionnaire (LISAT-9/- 11)	2002	9/11	https://qli.org.uic.edu/index.htmThe LISAT has a 9 item and 11 item version It is a quality of life measure intended for clinical and research purposes specifically for people with spinal cord injuries.Respondents rate their satisfaction on a 6-point scale from very satisfying to very dissatisfying.1. Life as a whole 2. Self-care 3. Vocational situation 4. Financial situation

Title	Date	Items	Description
			5. Leisure situation
			6. Sexual life
			7. Partner relations
			8. Family Life
			9. Contact w/ friends
			10. Physical Health
			11. Psychological Health
			The final two items are included in the LISAT 11
https://www.sralab.org/reh	nabilitation-measures	s/life-satisfaction-qu	estionnaire-9
Perceived Quality of Life (PQoL) http://depts.washington.ed		20	The (PQoL) is a measure based on a model defining quality of life as satisfaction with the major categories of fundamental life needs. Respondents rate their satisfaction on each item using an 11-point scales ranging from extremely satisfied/happy to extremely dissatisfied/unhappy. The tool produces an overall score and three sub-scores: 1. Physical Health Satisfaction 2. Social Health Satisfaction 3. Cognitive Health Satisfaction The GQOL is a single scale that directly evaluates quality of life. Respondents rate their percention of quality of life on a scale from 0 meaning 'no quality of life' and
Global QoL (GQOL)	1996	1	their perception of quality of life on a scale from 0 meaning 'no quality of life' and
	hant/alabal avality lit		100 meaning 'perfect quality of life'.
http://www.midss.org/cont	lent/giobai-quality-iii		MLSS is a structured interview schedule primarily intended to explore the life
Multifaceted Life Satisfaction Scale (MLSS)	1993	NA	<ul> <li>MLSS is a structured interview schedule primarily intended to explore the life satisfaction perceptions of individuals with intellectual impairment. The domains that are explored in the interview are: <ol> <li>Living situation</li> <li>Social/love relations</li> <li>Leisure/creativity</li> <li>Community/ productivity</li> <li>Self-esteem/well-being. Subjective</li> </ol> </li> </ul>

Title	Date	Items	Description
https://www.researchgate.net schedule_for_assessing_perso			ceted_Lifestyle_Satisfaction_Scale_MLSS_Psychometric_properties_of_an_interview
Comprehensive Quality of Life Scale (Com-QOL-ID)	1997	35	The ComQol has versions suitable for the general adult population, adolescents and persons with intellectual impairments. It consists of two scales an objective QOL (OQOL) and a subjective QOL (SQOL) scale. It addresses 7 domains:1. Material Wellbeing2. Health3. Productivity4. Intimacy5. Safety6. Place in Community7. Emotional Well-BeingEach item is rated in terms of satisfaction and importance. Subjective QOL is calculated by multiplying these together. It the version for persons with intellectual impairment, the 5-point importance scale is represented by blocks of different sizes and the satisfaction scale uses faces representing feelings. There is a training stage before the administration of each subjective scale. Confirmatory data is 
http://sid.usal.es/idocs/F5/EVA	A66/ComQol_I5.pc	lf	
Quality of Life Questionnaire (QOL-Q)	1993;2004	39	<ul> <li>The QOL-Q is designed to allow persons with intellectual impairments to assess their quality of life. Respondents rate the frequency with which they engage in each activity on a 5-point scale ranging from always to never. It has 4 dimensions: <ol> <li>Social support</li> <li>General satisfaction</li> <li>Physical/psychological wellbeing</li> <li>Absence of excessive workload/free time</li> </ol> </li> </ul>
https://benthamopen.com/cor	ntents/pdf/TOPSYJ	/TOPSYJ-2-49.pdf	

Title	Date	Items	Description
Personal Wellbeing Index 5 <sup>th</sup> edition (PWI-ID) <sup>1</sup>	2013	7 (8)	<ul> <li>The PWI-ID was developed as a replacement for the Com-QOL. A number of changes were made to strengthen the psychometric properties of the tool. One of these was to introduce an 11-point scale, which only has end descriptors – 'no satisfaction at all' and 'completely satisfied', to replace the original 7-point scale.</li> <li>The domains addressed by the PWI-ID are: <ol> <li>Standard of living</li> <li>Personal Health</li> <li>Achieving in life</li> <li>Personal Relationships</li> <li>Personal Safety</li> <li>Community-connectedness</li> <li>Future security</li> </ol> </li> <li><i>Spirituality/religion (optional)</i></li> </ul>
http://www.acqol.com.au/	uploads/pwi-a/pwi-a·	english.pdf	
Quality of Life Interview Schedule (QUOLIS) <sup>2</sup>	1993	48	The QUOLIS is a semi-structured interview with a proxy who knows the person with the intellectual impairment well. It addressed 12 domains with are elaborated into 4 dimensions (availability of support, accessibility of support, chosen level of participation for or by the disabled individual, and the disabled person's 'apparent' level of contentment with the current situation). The respondents rate each dimension on a 7-point scale. The domains are: 1. Health Services 2. Family and Guardianship 3. Income Maintenance 4. Education, Training and Employment 5. Housing and Safety 6. Transportation 7. Social and Recreational 8. Religious and Cultural

<sup>1</sup> Cummins R. A. & Lau A. (2005) *Personal Wellbeing Index – Intellectual Disability, 3rd edition*. Melbourne, AU: Deakin University.

<sup>2</sup> Ouellette-Kuntz H. (1990). A pilot study in the use of the Quality of Life Interview Schedule. Social Indicators. *Research*, 23; 283–98.

Title	Date	Items	Description
			9. Case Management
			10. Advocacy
			11. Counselling
			12. Aesthetics
https://www.jstor.org/stable	e/27520846?seq=1#	page_scan_tab_cor	itents
Evaluation of Quality of Life Instrument (EQLI) <sup>3</sup>	2006	18	<ul> <li>The EQLI was designed to elicit from staff of health and social care services assessments of the level of satisfaction experienced by adults with intellectual impairment. It can be used to identify participants who are at risk of or feeling dissatisfaction with a service. The tool covers many of the domains specified in the ICF.</li> <li>Learning and applying knowledge</li> <li>Communication</li> <li>Mobility</li> <li>Self-care</li> <li>Domestic life</li> <li>Interpersonal interactions and relationships</li> <li>General tasks and demands (carrying out single or multiple task, organising routines and handling stress</li> <li>Major life areas (engage in education, work and employment)</li> <li>Community, social and civic life</li> <li>The final tool has been demonstrated to assess three factors.</li> <li>Quality of service received</li> <li>Satisfaction with opportunities for social interaction</li> <li>Satisfaction with living environment</li> <li>Respondents rate level of disability on each of the areas on a 5-point scale from 0 meaning for 'no difficulty to 4 'ability only occasionally present. A second set of items is rated in terms of the satisfaction the person concerned feels with life areas on a 5-point scale from very much satisfied to not satisfied at all.</li> </ul>

<sup>&</sup>lt;sup>3</sup> Nota L., Soresi S. & Perry J. (2006). Quality of life in adults with an intellectual disability: The Evaluation of Quality of Life Instrument. Journal of Intellectual Disability Research, 50: 371–85.

Title	Date	Items	Description
https://www.researchgate.	net/publication/7150	606_Quality_of_life	_in_adults_with_an_intellectual_disability_The_Evaluation_of_Quality_of_Life_Instr
ument			

#### Annex 6 Input, Structure and Process Factors Identified in VET Practice in 26 Countries

Extracted from Annex 2 of the European Agency for Development in Special Needs Education Report on European Patterns of Successful Practice in Vocational Education and Training Participation of Learners with SEN/Disabilities in VET. (2013; pp. 40-46).

All the factors identified during the study visits are listed in this Annex. The explanations (provided below each factor) are based exclusively on the visits and the experts' view of the examples. The factors do not refer to theoretical concepts, but rather to observations made in some or all of the 26 participating countries. The numbering of the factors will assist in identifying the factors more easily in this report. Factors observed in many of the study visits that became part of the VET system model are marked with an asterisk (\*).

#### 1 Having high-quality infrastructure (e.g. building, transport, teaching and training materials)

The physical environment of the school/VET setting and the companies where learners carry out their practical training has been adapted to the needs of people with SEN/disabilities. High-quality equipment and training materials (up-to-date technology, use of IT) are available.

- 2.1 Having head teachers/directors and staff who are motivated and committed\* Head teachers/directors and staff are highly motivated, committed, dedicated and sometimes open in expressing their enthusiasm.
- 2.2 Having a school director with effective leadership\*

Leadership from the school director is effective and both appreciated and respected. Distributive leadership is visible and works well.

- 2.3 Having highly qualified teachers, staff and support personnel\* Staff are highly qualified, i.e. they have formal university-level qualifications, a vocational qualification and/or industry-based experience, with on-going/in-service or further training possibilities and human resources/professional development.
- 2.4 Having teachers qualified in SEN pedagogy

Teachers are qualified to teach learners with SEN/disabilities, in addition to having a formal qualification in specific subjects/technical vocations.

2.5 Having further training/education opportunities for all staff, including teachers\*

On-going/in-service or further training opportunities are offered to all educational and support staff, including teachers.

2.6 Having multi-disciplinary teams\*

Multi-disciplinary teams are set up to include professionals such as teachers, trainers, social workers, psychologists, occupational therapists and support staff.

2.7 Having a suitable teacher-learner ratio\*

Small class sizes are used because they are positive for learning. There are additional staff in the classroom, besides the class teacher, where necessary.

2.8 Having a suitable support staff-learner ratio\*

Sufficient support staff are available, co-ordinated at school level, to provide a broad range of support, e.g. assistants, carers and managers, as well as professionals who assist and support learners during their practical training in the workplace.

2.9 Having staff with labour market experience

Staff that work in the school/VET setting have previous work experience in companies, industries, etc.

2.10 Having continuity of staff/low turnover rate.

A stable and permanent team of staff with a low turnover rate helps to build sustainable networks and connections to employers.

3.1 Having established/formalised partnerships, co-operation and networking structures with stakeholders and services\*

Partnerships are established/formalised and co-ordinated (as opposed to ad-hoc, coincidental and fully dependent on contact between a few individuals). There are cooperation and networking structures with stakeholders and services, including employment services, financial providers, youth guidance centres, youth care, local community, voluntary organisations, etc.

3.2 Having collaboration/co-ordination/partnership structures between the VET institution, ministries and employers (national/local level)

A co-ordination service/unit operates: at ministry level to co-ordinate the school/VET setting with the ministry and employers (e.g. by providing job coaching support); at municipality level to monitor and co-ordinate activities; and at the school/VET setting level to co-operate with, for example, a Vocational Training Board for practical training.

3.3 Having a formal and strong co-operation strategy between VET institutions and parents, including parent participation\*

There is a strategy to encourage parents' active involvement in their children's learning process, based upon formal co-operation and dialogue with parents as equal partners, to ensure that parents have a say in which company their child attends.

3.4 Having collaboration structures between special and mainstream VET schools (e.g. special teachers teaching/supporting teachers in mainstream, mutual activities)

Special VET schools and mainstream VET schools collaborate with each other and with training organisations to provide VET for learners with SEN/disabilities, e.g. through special teachers teaching/supporting mainstream teachers or vice versa.

3.5 Having established collaboration structures among VET services, support services and ministries at national level

Co-operation and partnership between service providers and different ministries concerned with feedback on policy development at national level is established.

- 4.1 Having pre-vocational preparation at school Pre-vocational programmes are available at lower-secondary school level.
- 4.2 Having established co-operation structures with local companies for practical training and/or employment after graduation\*

There is a networking structure with a pool of employers for close co-operation with regard to learners' practical training and finding employment after graduation.

4.3 Having established structures and procedures that ensure courses, assessments and certificates are tailored to current and future labour market needs\*

VET programmes/courses are reviewed periodically, both internally (e.g. by validating them against recent labour market analyses) and/or externally (e.g. national agencies) in order to adapt

to future skills needs. This potentially entails the involvement of labour market representatives in school procedures (e.g. examinations) and/or structures (e.g. school boards).

4.4 Having staff (e.g. job coaches, career counsellors, mentors) and resources permanently available throughout the transition and work\*

Formal job coaching programmes, career guidance or support services, including after-care and preparation of employers, are permanently available for learners searching for a job in the open labour market and when they first find employment.

- 4.5 Having financial compensation available to employers on a permanent basis, i.e. as long as necessary, to account for the reduced work ability of employees with SEN/disability Financial compensation is permanently available, e.g. through wage subsidies by national or local authorities.
- 4.6 Having special systems that lead learners (at least temporarily) back to mainstream systems to avoid permanent tracking

Learners with SEN/disabilities are led by the special system back to mainstream at certain points (e.g. the labour agency assesses their readiness for apprenticeship or their need for a pre-vocational course), to avoid being permanently fixed in one educational track.

5.1 Having implemented a national/federal legal framework on inclusive education in secondary/uppersecondary education\*

A national/federal legal framework on inclusive education in secondary/upper secondary education has been implemented with: national goals on inclusive education; provisions relating to learners with SEN/disabilities; decentralisation of responsibilities (regional, local level); more learner-centred approaches and flexibility to deal with diversity and learners with SEN/disability across the country.

5.2 Having implemented a system that ensures the right of learners with SEN/disability who cannot follow mainstream upper-secondary/VET education to tailor-made or special upper-secondary education (legal framework on 'education for all')

Policies developed on the basis of 'education for all' give learners with SEN/disabilities (who cannot follow mainstream upper-secondary/VET education) the right to tailor-made or special upper-secondary/VET education.

5.3 Having implemented a legal framework on disability that ensures civil rights and delegation of respective responsibilities to local and regional level, allowing innovation and co-operation between the relevant stakeholders in VET

The legal framework on disability, equal opportunities and/or anti-discrimination ensures civil rights (with regard to employment, education, accessibility, citizenship, etc.) and delegation of respective responsibilities to local and regional level, allowing innovation and co-operation between the relevant stakeholders in VET.

5.4 Having implemented a legal framework on employment for people with SEN/disabilities (directive, national strategy) in which the inclusion of learners with SEN/disabilities in the labour market is the priority to ensure: emphasis on support for the employment of people with SEN/disabilities; focus on stakeholder co-operation; active policies to promote employment at local level Policy gives priority to the inclusion of learners with SEN/disabilities in the open labour market with an emphasis on additional support; active policies promote employment at the local level; policy promotes the link between VET, practical training of learners in companies and support for employment after graduation.

5.5 Having implemented a legal framework for required support to schools (that take learners with SEN/disabilities) and/or to learners and parents\*

Policy provides for adequate support (e.g. additional funding, higher staff–learner ratios, support staff, multi-disciplinary teams, adapted educational materials, school companions, tax relief, access to support services, etc.) to schools that take learners with SEN/disabilities and to learners with SEN/disabilities and their parents.

- 5.6 Having implemented a legal framework allowing the VET institutions to offer different levels of apprenticeships with different curricula, leading to different qualification levels\*
   Flexibility in policy allows the VET settings to offer different levels of VET programmes with different curricula, leading to different qualification levels, in order to respond to individual needs. This includes opportunities to switch between prolonged and reduced versions of apprenticeships and/or to a different VET programme.
- 6.1 Maintaining an authentic atmosphere of commitment, caring and belonging that, together with positive attitudes, contribute to the creation of equal opportunities\*
  Staff believe in learners' abilities and see opportunities rather than challenges. Their aim is to make all learners feel more confident and assertive in what they do. They empower the learners in order to raise their self-esteem and develop their personalities.
- 6.2 Safeguarding the positive effects of multi-disciplinary teams and of co-ordinated teamwork\* Multi-disciplinary teams have clear roles (teachers, physiotherapists, psychologists, school counsellors, speech therapists, trainers, career guidance, etc.) and a teamwork approach and cooperate with a high level of internal communication (peer coaching, informal discussions, collaborative problem solving, etc.) and external communication with other services.
- 6.3 Offering further training opportunities and staff development to ensure quality in education\* The VET setting offers in-service training for all teachers and support staff in an ongoing process in the context of professional development, including peer teaching, seminars on SEN, subject-based seminars, etc.
- 6.4 Adapting pedagogical methods and techniques at school and in companies\* Teachers/trainers are able to adapt their pedagogical methods to match the employers' needs and have enough resources for innovative individual work and support.
- 6.5 Staff maintaining contacts with companies for practical training and jobs Staff build good relationships and networks with employers at local level for learners' practical training and finding employment after graduation.
- 6.6 Providing sufficient support to educational staff to match the learners' needs\* Sufficient methodological, technical and psychological support is provided to educational staff to adapt the curriculum and materials to learners with SEN/disabilities.
- 7.1 Maintaining a good balance between theoretical/academic subjects and practical training\* The VET programmes provide a good balance between theoretical/academic subjects and practical training/learning-through-doing.
- 7.2 Focusing on hands-on/practical/life-like learning approaches that also include theoretical/academic subjects\*

The focus is on learning-through-doing/learning-on-the-job approaches (as opposed to theoretical approaches), with core subjects integrated into projects.

7.3 Safeguarding learner-centred approaches\*

A learner-centred approach tailors pedagogical methods and materials, the curriculum, assessment methods and goals, etc., to individual needs.

- 7.4 Using individual plans for education, learning, training and transition\* Individual curricula, individual education/learning/training plans, individual transition plans, etc., are developed and implemented.
- 7.5 Accounting for the development of social skills and well-being\* Appropriate attention is given to the development of social skills and well-being, e.g. personal and social skills, rights, duties of citizenship, activities of daily living (ADL).
- 7.6 Using innovative teaching methods and approaches\* Innovative teaching methods and approaches are implemented, e.g. peer learning, role-plays, learning through authentic tasks, using games for certain topics (e.g. maths).
- 7.7 Safeguarding flexibility in VET opportunities/courses to allow progress from one level to another\* There is flexibility in VET opportunities/courses, so that learners can start in a lower level programme and move to a higher level programme either before or after graduation.
- 7.8 Supervising practical training in companies and offering supported employment models with progressively decreasing support intensity\*

Learners are assisted/supported by staff (teachers, trainers, assistants, job coaches, mentors, etc.), both during their practical training in companies and also after graduation. Young people who have found a paid job are supported at work by job coaches/assistants through the supported employment model, with a progressive decrease in support intensity.

- 7.9 Supporting learners and employers during the transition phase into the open labour market\* Career counsellors/officers inform and guide learners regarding employment possibilities, facilitate and support contact with employers, provide support with job applications, provide information and support to employers and provide additional support needed by young people, etc.
- 7.10 Providing follow-up activities to maintain learners' employment in companies\* Follow-up support activities address the needs of young people and employers in order to maintain a learner's employment once they find it.
- 7.11 Offering vocational training (courses, programmes and work experience) that involves real work with real customers/clients

Work is carried out in the VET programme on clients' orders, etc., with real contact with clients and customers.

7.12 Focusing on learners' capabilities\*

Learners with SEN/disabilities are empowered, focusing on their abilities: what they can do, NOT what they cannot do. This is based upon the strong belief of both learners and teachers in the learners' strengths and possibilities, as a means of increasing self-esteem and self-confidence.

- 8.1 Joint working, strong collaboration, good networking, an open spirit of co-operation\* There is good networking and collaboration with different stakeholders at local level, including: municipality, employment service, support services, chambers of commerce, non-governmental organisations, voluntary organisations, parents, trade unions, etc.
- 8.2 Exchanging and co-operating with parents on an equal footing\*

Good links exist and parents are actively involved as equal partners.

8.3 Showing positive attitudes of stakeholders and learners/teachers\*

Employers have positive experiences with the trainees and employees with SEN/disabilities; parents have positive experiences with the VET and employment providers; learners are satisfied with and conscious of the support they receive; funding providers recognise value for money.

8.4 Safeguarding connections with local employers/companies for practical training and job opportunities based upon trust and past experiences\*

Resilient (i.e. long-standing, well-established and stable) connections result in a high percentage of learners obtaining a job with the company in which they carried out their practical training, because the companies feel confident from past experience that they can receive the required support.

*9.1 Developing a differentiated range of qualification levels* 

Different VET programmes and certificates are available, targeting the acquisition of different skills and competences, with options for accreditation of achievement of individually defined goals.

- 9.2 Compiling portfolios and awarding certificates/documents on achievements and skills\* Documents/portfolios are kept on the skills and achievements and sometimes also on the support required in the workplace.
- 9.3 Awarding the same certificates as for non-SEN/non-disabled peers Learners receive an equivalent education; certificates are the same as for non-SEN/non-disabled peers, even if the duration was longer or additional help was granted.
- 9.4 Certifying work- and life-related skills in addition to official certificates Different levels of certificates can be achieved by individual learners, with the support and acknowledgement of local employers.
- 9.5 Developing and implementing individualised and flexible curricula\* A flexible approach allows for the development and implementation of individual curricula.
- 9.6 Implementing reverse inclusion

VET courses and services and the VET centre's facilities are open to non-SEN/nondisabled peers.

- 9.7 Focusing on needs-based instead of diagnosis-based provision Special needs are defined in a flexible and open way and provision is based upon particular needs (e.g. reducing dropout).
- 9.8 Strength-based co-operation between mainstream and special provision Special schools and mainstream schools collaborate and support each other to reduce dropouts.
- 9.9 Providing different pathways and options that allow for exploration (i.e. horizontal) or progression (i.e. vertical)\*

There are: options to improve a qualification, but also to improve grades; opportunities for learners to change their mind and to switch to a different programme; options to choose between different professions and to have an academic and/or professional certificate; options to make use of an adapted curriculum.

9.10 Dropout reduction strategy\*

The school takes preventive educational action against dropouts in close cooperation with the local social services and develops measures so that dropouts find new alternatives.

- 9.11 Committing all stakeholders to quality assurance and improvement strategies\* Programmes are implemented and certified to improve VET quality and continuously improve learners' preparation for the real labour market.
- 9.12 Ensuring that learners, families and all other stakeholders are aware of and understand learning possibilities

Information on learning possibilities is effectively presented and disseminated, e.g. by providing easy-to-understand information sheets with various internet links to job portals, information on finding other opportunities and key dates for the year.

9.13 Ensuring that schools have clear inclusive policies in practice

Equality is an integral part of practice and can be observed in the interaction between teachers and learners, based upon a clear inclusive policy at school level with strategies for implementation and monitoring of progress.

9.14 Implementing a no-risk policy/return policy

Learners can return to the VET setting if their experiences of work do not go as hoped (no-risk policy).

9.15 Implementing policies in each school equally

National policy regarding VET quality is implemented equally in each school.

9.16 Changing the structure and duration of the VET programme if required\*

The VET setting is flexible, ensuring that the structure and duration of the VET programmes respond to learners' needs, e.g. via an extension of the course duration, longer internships in preparatory classes, an emphasis on practical courses rather than theoretical courses, etc.

- 9.17 Assessing learners prior to the start of courses in order to tailor a VET programme to the individual\* Learners take part in assessment schemes prior to starting the VET programme so that the most appropriate VET programme is selected, which matches learners' abilities and wishes.
- 9.18 Supervised practical phases that take place sufficiently in advance of school leaving are obligatory/mandatory for all learners\*

All learners take part in obligatory/mandatory and supervised exposure to work; short practical training in the open labour market; long-lasting (e.g. 24 weeks) practical training to check their capabilities and establish connections with future employers.