

# Seminar: Measuring the Quality of Life of people with disabilities

## Kulttuuritehdas Korjaamo Helsinki, Finland

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Quality of life (QOL) is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life<sup>1</sup>. The World Health Organisation (WHO) defines individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment<sup>2</sup>.

The term QOL has meaning for nearly everyone, and every academic discipline, individuals and groups can define it differently. This makes it challenging to measure is that and although health is one of the important domains, there are other domains as well that add to the complexity of its measurement<sup>3</sup>.

The European Quality of Life Survey provides a means to measure outcomes of progress, such as well-being and social inclusion. The data from the survey can serve to complement the social indicators used to monitor the impact of policy, particularly regarding the implementation of the European Pillar of Social Rights<sup>4</sup>. Many aspects of quality of life are determined at national and local levels, and the survey evidence regarding country differences can be an impetus for further analysis by Member States and, also, for mutual learning<sup>5</sup>. Mutual learning and benchmarking have been at the core of the European Platform for Rehabilitation's work on QOL.



The EPR Service Impacts on Quality of Life (SIQOL), formerly Outcome Measurement in Vocational Rehabilitation (OMVR) Group, has developed a benchmarking procedure and set of tools to measure the perception of service users of the QOL impact of social and vocational rehabilitation programs on their lives. The SIQOL group members, currently in five different countries, have worked together to generate a

<sup>1</sup> The WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL). Development and psychometric properties. Soc Sci Med 1998; 46:1569-1585.

<sup>2</sup> The WHOQOL Group. Measuring Quality of Life. The World Health Organisation Quality of Life Instruments. (the WHOQOL-100 and the WHOQOL-BREF). Division of mental Health and Prevention of Substance Abuse, 1997; 1

<sup>3</sup> Center for Disease Control and Prevention. HRQOL Concepts

<sup>4</sup> Eurofound (2017), European Quality of Life Survey 2016: Quality of life, quality of public services, and quality of society, Publications Office of the European Union, Luxembourg.

<sup>5</sup> Eurofound (2017), European Quality of Life Survey 2016: Quality of life, quality of public services, and quality of society, Publications Office of the European Union, Luxembourg.

consensus list of potential QOL outcomes of social and vocational rehabilitation which can be applied to programs delivered by their organisations.

This seminar examined different models for quality of life of people with disabilities, with a focus on the SIQOL model.

Heidi Anttila, Senior Researcher from the National Institute for Health and Welfare (THL) in Finland, presented some of the latest developments regarding the digitalisation of the functioning outcome measurement database. She also presented the Finnish Committee for Reforming Rehabilitation's report from 2017, suggesting a new rehabilitation action model consisting of counselling, case management and coordination and follow-up phases, forming one joint rehabilitation process.

Furthermore, THL have created an open access free-of-charge tool in Finnish called TOIMIA, designed for experts and professionals interested in how to measure functioning in clinical practice and research. The International Classification of Functioning, Disability and Health (ICF) is used as a framework, and the THL cooperates with over 60 partners from different organisations and about 100 functioning experts from different areas on TOIMIA. Valid and competent assessment of functioning helps the service systems, sponsors and citizens in planning and allocating actions and resources adequately, as well as enhancing equality for citizens through a harmonisation of terms and measures. Professionals can access reliable information in an easily useable format and find all forms in the same place, which saves time and money, in addition to enhancing health equity by reducing the need for repeat documentation.

Using a tool called FunctionMapper, one can edit and distribute functioning outcome instruments with topic and concept linkages for information systems (see presentation for more information). In the future, THL will develop access-management and specify a model for the content population both nationally and internationally, so that users in other countries may make use of the structures in their information systems and data repositories.

Following this presentation, The EPR Service Impacts on Quality of Life (SIQOL) group: Origins of benchmarking group and current development of the SIQOL in Portugal. Donal McAnaney, SIQOL Leading expert (Ireland), António Rilho, Chief Operations Manager at Centro de Reabilitação Profissional de Gaia presented the model, tools and outcomes of the bench-marking group, including the origins and goals of the outcome measurement and cases from Portugal, Ireland. The challenges in defining QOL is that it lacks uniform or consistent definition, and the fact that it is multidimensional in nature. As a result, the QOL conceptual model presents three dimensions; personal development, social inclusion and well-being.

Thus, using subjective and objective indicators of QOL, the SIQOL allows respondents to link their ratings of QOL directly to the service in which they participated or are still participating in. SIQOL has been evaluated for reliability and found to be stable over time, even though measuring the impacts of services in quality of life is different from measuring quality of life itself.

Therefore, the SIQOL has measures to ensure consistency in the proportion of respondents who can answer an item regardless of their capacity, and have simplified answering the survey through easy-read questions and a simplified rating scale. When measuring the impacts of service provision, the results showed a consistency across the years but also a somewhat low rate of answer (around 20 percent). The 'more distant' the client is from the services provided (at the moment of inquiry), the less it seems to be the importance he/she gives to the services received.

The survey found some significant strengths of service impact on quality of life such as improving the client's chances of getting a job, making the clients better at coping with changes and enabling clients to actively engage in their education and learn new things. Simultaneously, it found areas for improvement such as enabling clients to take part in cultural leisure activities, enabling clients to feel less lonely and feeling more stable emotionally.

Anne Tornberg, Development Director, Luovi Vocational College presented how they are using some of the SIQOL tools in assessing the quality of their VET services. *ADD from presentation*



Linda Coone (Ireland), Head of Quality Assurance and Improvement. Quality & Governance Directorate, Rehab Group explained how they use QOLIS to improve the delivery of services in Ireland.

The experts then took part in a panel discussion, discussing their experiences and challenges in measuring quality of life. In Ireland, it is a requirement to measure quality of life but service providers experience pressure from the funders of the services to achieve certain things, qualifications for example, and this can have a negative impact on their quality of life, including their mental health.

The panellists stressed the importance of educating funding authorities in the field of quality of life, as they may have a narrow understanding of this. Funders may look more at simple satisfaction surveys and not the impact of services on the service user, including on their quality of life.



For some organisations, measuring quality of life can be seen as an additional task, which they don't have the time to carry out. Measuring quality of life in a deliberate way means that resources also need to be dedicated to analysing results and the data gathered. Practical tasks may be seen to be of priority over actions that measure quality of life, but measuring quality of life might show that some practical tasks are not the best ones to carry out.

Panellists explained that measuring quality of life should be an essential dimension of providing a service, becoming routine in order to ensure that the service is having the desired impact. A questionnaire to gather information can be integrated into a programme. It may be that staff should be educated more in the concepts and tools related to quality of life, or have that perspective in their daily work. In some organisations, they have an annual day where the staff gather to discuss the results of the quality of life survey and see what may need to change to improve results. Even if it forms a key part of a service, it does involve additional resources, and government funding should take this into account.

Quality of life has a clear link to the empowerment of service users; they should be parallel processes, measuring quality of life and empowering the individual, leading to increased quality of life. Quality of Life, compared to other concepts used in measuring impact on an individual

Geir Moen, representative of the Scandinavian EQUASS License Holder closed the event presenting the EQUAL model, with a focus on the perspective of Quality of Life of service users, and EQUASS, the system developed by EPR to guarantee service users quality of services. The EQUAL model presents a systematic approach focusing on including the perspective of Quality of Life of service users, developing and following up individual person-centred plans when welfare or social services are provided.

EQUASS, another initiative of the European Platform for Rehabilitation (EPR), provides an example of how engaging social service providers in continuous improvement, learning and development, can guarantee quality of services throughout Europe

Laura Jones closed the meeting thanking speakers and participants, and explained that in the coming months EPR would be developing an e-learning module on the theme which would be available to the public.

There are presentations available on the EPR webpage [here](#).

