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TITOLO	INDIVIDUAL AND FAMILY QoL IN ID: A CHALLENGING RELATIONSHIP

ABSTRACT

Background: Until a few years ago, outcome measures of care and rehabilitative interventions were based on the traditional medical approach aimed at restoring a person to "normal" morphologic conditions and "normal" functioning status. The reference point here, even for people with ID, was the majority of people in the general population. Even today, most family complaints arising from the quality of care for people with ID refer to this model.

Recently, new patient-oriented outcome measures have emerged in disability research and practice. Among these, Quality of Life (QoL) has gained a central place. Nevertheless, most published articles on QoL refer to Health-Related QoL, which needs to be carefully distinguished from Generic QoL. The QoL approach represents an effort to mobilize and revalue resources that can help a person (and the holistic system that they represent) to embark on or to continue a lifespan curriculum of life skills improvement.

A QoL framework is also useful for understanding the impact of individuals with ID on the life quality of members of their family. Also determination of appropriate conceptualization of family outcomes requires an international level, family QoL is emerging as an important field of research, but the number of studies on it is still quite limited, especially if compared with the substantial literature investigating individual QoL. Still, considerable work has been accomplished conceptualizing family quality of life and determining appropriate family quality of life outcomes.

There is substantial literature investigating quality of life (QoL) of individuals with Intellectual disability (ID). Also QoL of families of people with ID is emerging as an important field of research. Despite this, there's a lack of studies regarding their relationship.

Aim: the present paper aimed at studying the correlation between QoL scores of individuals with ID and members of their families.

Methods: 45 parents or relatives of 30 subjects with ID were recruited by 5 different research centres across Italy to be administered with the Italian adaptation of the Family Quality of Life Survey. QoL of subjects with ID was assessed through the administration of the QoL-IP and the LSF. QoL scores were organised for subgroups, according to background characteristics, and statistically correlated (Pearson and Spearman).

Results: Findings showed that families interviewed perceived a low level of QoL in leisure time, enjoyment of life, support from others and disability-related services, while spiritual and cultural beliefs rated higher. On the contrary individuals had lowest scores in the area of spiritual being and higher scores in the area of physical being. findings showed that families interviewed perceived a low level of QoL in 'Support from others' and 'Community Interaction', while 'Family Relationships' and 'Health of

the Family' were rated higher. Individuals had lowest QoL scores in the area of 'Spiritual being' and higher QoL scores in the area of 'Physical being'.

Family and Individual quality of life were greatly and mutually related. Significant correlations were found between family 'Financial', 'Relationships', 'Support from Service', 'Support from Others' areas and individual 'Becoming' and 'Belonging' areas.

Conclusions: although they present several limits to be overcome with further research, results suggest that QoL has some different characterisations in individual with ID and in members of their families. This difference could negatively impact on QoL of people with ID, especially in those areas with strongest correlations.

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