

Measuring Quality of Life and Quality of Support of Elderly Persons with Intellectual Disabilities: development of two new questionnaires

Aims: Persons with Intellectual Disabilities (ID) age into near normal ranges. Being able to evaluate their Quality of Life (QoL) and the quality of the support strategies they get matters. Research reveals that QoL and Quality of Support (QoS) are coloured by specific age-and-ID aspects.

Methods: We developed an item pool on the basis of a systematic literature review and of focus groups with elderly persons with ID, caregivers and experts. It contained relevant QoL-outcomes, QoL-influencing support strategies and characteristics of the elderly and his environment, specific to elderly persons with ID. Drawing from this pool, we developed two questionnaires.

Results: Both questionnaires are specific to persons with lifelong ID, older than 65 years (older than 50 years when Down syndrome or profound ID / PIMD). The QoL-EPID (Questionnaire on QoL for Elderly Persons with ID) examines the eight QoL domains of Schallock plus an extra domain of Existential Wellbeing. The QoS-EPID (Questionnaire on Quality of Support for Elderly Persons with ID) examines support strategies on macro, meso and micro level.

Contribution: The questionnaires are currently used in a survey in different Flemish care settings. They provide a new, specific way to measure QoL and QoS of elderly persons with ID.