

10th AUTISM-EUROPE

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Title

Developing an objective tool to measure quality of life outcomes of people with an Autism Spectrum Disorder (ASD)

Background

Robert Schalock defined quality of life as a concept that reflects the conditions of life desired by a person in connection with eight basic needs: emotional wellbeing, relationships, material welfare, personal development, physical wellbeing, self-determination, social inclusion and rights. Validated and reliable tools to measure the quality of life outcomes of individuals with ASD are in short supply. The difficulty in assessing these outcomes in persons with ASD from a subjective perspective, make it necessary to find valid objective quality of life indicators. Mentaur has developed a U.K. specific instrument, in collaboration with the University of Burgos and Autism Burgos, Spain, who have been working in this field.

Objectives

- + To adjust and validate an instrument made up of an objective guide of indicators to use to assess quality of life outcomes for persons with ASD, making it U.K. specific.
- + To provide this tool free of cost to all professionals and organisations who want to introduce quality of life

based models in advancing and enriching the quality of support for persons with ASD.

Methods

The original Guide of Indicators was translated from Spanish to English and retranslated to Spanish to ensure accuracy. Certain cultural contextual changes were made.

A qualitative research method, the Delphi technique, where a group of experts co-ordinated by the chief researcher and through the successive sending of data reach an agreed consensus, was used to validate the Guide of Indicators. A panel of experts has been selected across the UK from a wide range of fields within the ASD and a series of consultations were carried out via email over a period of six months.

Application of the tool is currently being piloted by Autism West Midlands across their services.

Results

The instrument and application manual developed comprise of indicators which drive outcomes and are grouped into 6 areas:

- + Quality in reference to the individual and needs assessment
- + Setting and following up on personal development plans.
- + Staff training.
- + Structure and organisation of service.
- + Human resources, materials and spaces.
- + Contact with the community and social empowerment.

Each indicator is made up of four evidences or tests which help evaluate and quantify the indicator. The preliminary results show that while there is concurrence

between Spain and the UK with many of the indicators in several areas, there is also divergence which surrounds issues including information provided to users, extent of family involvement, level of choice, staff training and advocacy.

Conclusions

We believe there will be unique features to this tool which will surmount, for example, the serious communication difficulties which persons with ASD often have and will allow a comprehensive and objective overview on quality of life outcomes.

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