

DEVELOPING AN OBJECTIVE TOOL TO MEASURE QUALITY OF LIFE
OUTCOMES OF PEOPLE WITH AN AUTISM SPECTRUM DISORDER (ASD)

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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 well being, relationships, material welfare, personal development, physical well being, 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 is developing a U.K. specific instrument, in collaboration with the University of Burgos and Autism Burgos, Spain, who have been working in this field.

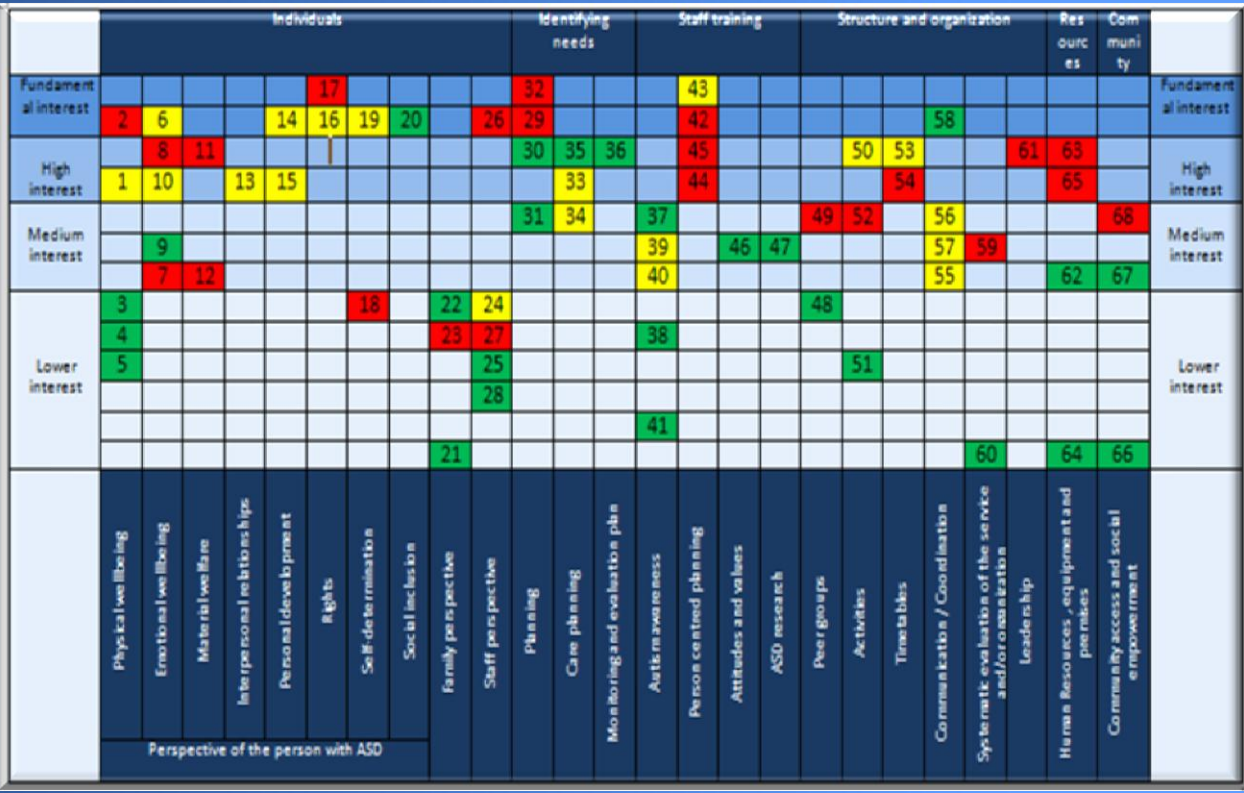
OBJECTIVES

- To design an instrument made up of an objective guide of indicators to assess quality of life outcomes for persons with ASD.
- To adjust and validate this tool to make 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.

SCORE	LEVEL
198 - 246	Excellent
149 - 197	Very Good
100 - 148	Good
51 - 99	Could be better
0 - 50	Could be much better

METHODS

- The original tool 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 is being used to validate the tool. A panel of experts has been selected from across the U.K. with members working in different roles within the autistic spectrum and a series of consultations are being carried out via email over a period of six months.



RESULTS

- The instrument and application manual being developed comprises of indicators which drive outcomes and is grouped into 6 areas:



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

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.

