



EVALUATION OF THE QUALITY OF LIFE IN PERSONS WITH AUTISM

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INTRODUCTION - JUSTIFICATION

The search for quality of life and the trend towards continual improvement has today become a true reference which guides most social organizations. This achievement allows us to find coherence and to bring together practices based on an understanding and on the consideration of the person as the centre of all actions.

The bodies which offer support to persons with Autistic Spectrum Disorder (referred to hereon as ASD) have not gone untouched by the influence of this concept of quality. The serious difficulties which are associated with this disorder affect the main areas of ones personal development: socialisation, communication, comprehension, and adaptation to ones environment, and they require that organizations promote integral networks of resources which guarantee a lifetime of quality services and support. (Barthélemy y cols., 2002.; Plimley, 2007, Cuesta y Hortiguera, 2007).

We have moved away from the traditional organizational model where resources and services were considered as an end in themselves, towards an organization which Schalock y cols. /2007: 53) define as a "*Bridge to the community*". In this model the goal is not only to promote and offer services but to use them to bring about positive personal results. (Schalock and Verdugo, 2008)

The concept of quality of life is not something new rather it is understood as an aspiration pertaining to human nature and is a matter to which references have been made since olden times (Schalock and Verdugo, 2006).

Historically, according to Schalock and Felce (2004) and Gómez- Vela and Sabeh (2001), the conceptualization and measure of the quality of life concept, has encompassed two perspectives:

- In the first stages, the concept identified itself with social indicators, referring to the external conditions, dependant on the contexts of where the people live, such as health, social wellbeing, education, housing... These indicators are generally defined by the State and are formulated into statistics which refer to the population in general, the intention of which is to reflect their living conditions.

Later trends have a bearing on subjective indicators which reflect the perception or level of satisfaction that each person gives to his own life.

As Verdugo states (2006) these two perspectives have been extended to include matters such as expectations, values and personal interests and to take into account the influence that the contexts



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where they usually or occasionally spend their time have on them.

There is much research evidence to show an increase in independence, productivity, inclusion into the community, satisfaction..., when organizations and support services are directed towards objectives of improvement in quality of life (Schalock, 1997a y 1997b).

In the prologue to the book "*How to improve the quality of life of persons with disabilities*" (Verdugo, 2006), Robert Schalock states that within the reference frame for future research lies that of contributing to basing the provision of services and support on the key predictors of quality of life. We need to think about what we measure and go one step further than the subjective measures (satisfaction, personal perception...) in order to grapple with the objective measures which refer to life conditions and circumstances.

In short, according to what Arostegi (2002) states, the evolution of practical concepts and attitudes about disability and the importance that the quality of life concept has today acquired, makes this the paradigm of understanding for the development of actions and good practices.

As suggested by Cuesta and Arnáiz (2001), social organizations these days, including those offering support to persons with disabilities, no longer function independently of the movement towards quality which conventional businesses embarked upon decades ago. Unlike conventional businesses, social organizations are involved in offering services, i.e. its product is not tangible to the client or user, and thus it is difficult to measure or evaluate because it is not something concrete. For this reason, we constantly strive towards making the services as tangible as possible with the aim that those who are at the receiving end of these services are able to assess them and feel satisfied. (Bezosa y cols., 2005)

In the field of disability, the tendency is to evaluate the impact of the services on the person and to assess the personal results. For this, according to Schalock (2004), most recent models favour a multidimensional approach, covering all areas, fields and contexts of the person's life and integrating three perspectives: objective (referring to the measurable conditions of the persons surroundings which in themselves help in improving the person's life), subjective (each person's level of satisfaction) and the aspirations and expectations of the person.

If we look closer at this quality of life concept and relate it to the field of ASD, we find ourselves dealing with persons who show serious difficulties and for whom in many cases it is impossible to express their needs, desires, level of satisfaction, physical and emotional states..., in short, in speaking about and sharing information about themselves which is a basic requirement if our intention is to assess their quality of life (Riviere, 1997a and 1997b).

Different research studies (Baron-Cohen and Bolton, 1998; Frith, 1999; Howlin, 1997, Tamarit, 2005; Plimley, 2007) and guidebooks on good practices in autism (Fuentes, 2006) give information on programmes, strategies and support to compensate for the difficulties shown by persons with ASD, and they serve as a reference for the definition of indicators related to quality of life.

METHOD.

DESIGN AND VALIDATION OF THE QUALITY OF LIFE INDICATORS GUIDE

As stated by Fernández (2001) the design of the Quality of Life Indicators Guide is based on having prior knowledge of the needs of the person with a disability in order to be able to define the conditions that the services and programmes should provide. Only in this way can they directly relate what the organizations offer to the needs and requirements of the persons involved.

The bibliographical update carried out includes a study of existing instruments available to assess quality of life, some of which are appropriate for use directly with the persons with ASD and others to assess the organizations. In addition to the theoretical analysis, the instruments have been



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applied experimentally within organizations and with persons with ASD.

In this search for information process no instrument has been found which is adapted to persons with ASD which can take into account the serious communication difficulties that they have and which deal with specific aspects of this disorder.

Confronted with this reality research suggests that, not excluding the use of scales or instruments to assess the subjective dimension, special importance be placed on looking more deeply into the objective dimension as a way of being able to assess and promote quality of life. Such matters, together with the difficulty of assessing quality of life in persons with ASD from the subjective perspective, make it especially necessary to find valid indicators that help us to favour certain conditions in the ASD persons environment.

This identified need is justification for the objective put forward:

To design an instrument capable of being used to assess the quality of life of persons with ASD, made up of a Guide of Indicators, which organizations and programmes can then use to promote favourable conditions..

In the field of research and in the process of validation, a qualitative method has principally been used. As stated by Bustamante y cols. (2000), quoted by DE La Herrán (2005), these methods have been developed more directly for objectives such as those related to the following work: discovery, checking or confirming theories.

Within the field of qualitative methods the Delphi technique has been chosen to validate the Guide of Indicator which, according to Ruiz (2003), is the technique based on consensus.

It is a sociological research technique which belongs to the type of thorough group interview (Ruiz Olabuénaga, 1999). A group of experts are chosen who, co-ordinated by the researcher and through the successive sending of data, give consensus to the Guide of Indicators.

As advances are made in the research, the initial theory or formula change or are expanded on according to the consensus brought by all those persons involved in contributing to the work (Landeta 1999 and 2002, quoted by DE La Herrán , 2005).

The design of the Guide takes off from its original design, written in 2001, with the aim of making it easier to carry out a general assessment of the services which all professionals in the Burgos Autistic Association carry out yearly. In 2005, following four years of working with the guide, professionals of the Association made further contributions to the guide along with other professionals linked to the field of education and psychology at the University of Burgos (Faculty of Humanities, Department of Science and Education).

In 2006 a third edition of the Guide was started in which a group of professionals and family members of persons with autism were involved. This guide served to give continuity to this research and to embark on a process of validation.

A frequent error in research into quality of life, according to Schallock and Felce (2004) , derives from not having a clear proposal of what it is we want to evaluate and thus not using the most appropriate systems. If we wish to assess personal satisfaction we can design or use specific instruments, or indeed compare with the results of other groups of people. On the other hand, as in this case of this research, if we wish to assess the programmes or services and their appropriateness to the users, it is more applicable to resort to objective indicators.

The Delphi technique, chosen for the carrying out of the validation process, means that a panel or group of experts work towards reaching an agreement by consensus on a design and on the contents of the Guide of Indicators following successive consultation. The panel of experts was formed of 12 professionals of renowned standing in fields related to this research (Autism organizations, University, Quality Management Systems...) and following five successive consultations, a consensus of the contents and of the methodology for the application of the Guide of Indicators for Quality of Life, was reached.



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DESCRIPTION OF THE GUIDE OF INDICATORS

The resulting Guide of Indicators for Quality of Life, following a process of validation, is an evaluation instrument from an objective perspective. It takes into account those contextual factors relevant to organizations and services where persons with ASD are users and which significantly have a bearing, directly or indirectly, on their quality of life.

The instrument is made up of 68 indicators grouped into 6 areas:

- * Quality with reference to the person.
- * Identification of the needs/ Setting up and following through of the personal development plan.
- * Training of professionals.
- * Structuring and organization.
- * Human resources, materials and spaces.
- * Contact with the Community/ Social projection.

Each indicator is made up of four evidences, i.e., four tests which are going to help us to observe and to quantify the indicator. Likewise these tests will allow us to see whether or not the same objective rating scale can be used for all the evaluators.

This instrument is intended as a sort of reference guide for professionals, which can be useful in planning processes and in evaluating programmes and services for persons with ASD.

The Quality of Life Indicator Guide requires objective consensual administration, and even more so if we have the responsibility of putting ourselves in the situation of persons with ASD with serious communication limitations.

The proposal for its application is that it be carried out and assessed by a consultation team, in a consensual way and which take into maximum account not only the objective variables, but also the most relevant subjective variables which influence the contexts where the person is.

Once in the organization, the consultation team accompanied by experts in the different fields to do with the instrument, will check each indicator using the evidences.

Once the collection of information phase is complete, the data obtained will allow for an overall score to be given to the organization. This will give us information on the level of the establishment with respect to the application of the Indicator Guide.

The Guide has an IT programme called "OTEA" into which data is introduced and which then automatically works out the overall score in the form of a graphic chart which makes it easier to interpret the position of the Organization or service with respect to each of the indicators.

The process concludes with the Consultation Team writing and presentation of a Final Report which will include general observations, key indicators which offer guidance on minimum aspects which should be taken into account for improving the level of different areas, improvement guidelines and a proposal review date in cases where this is deemed appropriate.

CONCLUSION

In conclusion, this tool is an attempt to bring a reference frame for those organizations that want to grapple with the challenge of introducing quality of life based models and as an incentive for all those who take on the challenge and hope for advances towards new ways of enriching the quality of support for persons with ASD.

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