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## TEN NOTEWORTHY REFERENCES ABOUT:

### Current trends in disability: a psychological approach

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#### INTRODUCTION

From prehistoric times, we have been witness to both favourable and unfavourable happenings that have decisively marked our understanding of intellectual and other disabilities. However, the first studies differentiating *deficiency and madness* appear in Spain only at the beginning of the twentieth century. (Fierro, 1984; Ingalls, 1982; Muntaner, 1995).

The advances in the field of disability have been innumerable in the course of the twentieth century, but we needed to wait till its last years to detect an attempt to overcome failures in the guidelines followed with people with disability, in contrast to what could be observed in our neighbouring countries. We are referring to the delay in incorporating the terminology proposed by the WHO, the translation mistakes of some texts from the United Nations, the misuse of some terms, and the slow development of the 1982 *Ley de Integración Social de los Minusválidos (LISMI)*—Act for the Social Integration of People with Disabilities, to give some examples.

At an international level, the transition to the twenty-first century, called *the century of diversity*, is associated with a new approach to the field of disability which addresses three key objectives, namely enhancement of independent functioning of handicapped people, the demand for efficient services and for improvement in long-term or indefinite treatments. This entails *support*,

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*self-determination and quality of life*, concepts which were the themes of the IV Jornadas Científicas de Investigación sobre Personas con Discapacidad (IV Congress of Scientific Research on Handicapped

People), held in Salamanca, Spain, in March 2001 (Verdugo and Jordán de Urríes, 2001).

This change does not derive only from the scientific development of medicine, psychology, or education. It alludes instead to a change in the way of thinking about the people who suffer from some disability, and it also extends to the service and support provided (Schallock, 2001).

In addition to the above we need to point out that the change of century and millenium unifies criteria for the new terminology on disability, which culminates in the publication of the *International Classification of Functioning, Disability and Health*. In this new project, the WHO abandones the former focus on *consequences of the illness* in order to direct attention to health and health-related states from a clearly bio-psycho-social perspective. Other initiatives, such as proclaiming the year 2003, the *European Year of People with Disabilities*, are directed at shaping this new perspective on the approach to disability.

In order to end this brief look at the latest international achievements, we can't overlook the important support gained by the UN during the Convention on the Rights of People with Disabilities, held at the UN headquarters in New York on March 30, 2007. The Convention was the the first human rights treaty agreed upon in the twenty-first century and according to the High Commissioner for Human Rights, Ms. Louise Arbour, the support received by eighty countries constitutes an unprecedented backing in the history of the UN and its defence of human rights (EFE, 2007a).

According to the UN expert on disability issues, Mr. Thomas Schimdlmayr, there are an estimated 650 million people with disabilities in the world, which represents the biggest minority there is, that is, ten percent of the world population (EFE, 2007b).

Our country, Spain, has also been willing to participate in this new general approach to disability; first, with the promulgation of *Ley 51/2003, de 2 de diciembre, de Igualdad de oportunidades, No discriminación y Accesibilidad universal de las personas con discapacidad* (Act 51/2003 of December 3, on Equality of opportunities, no discrimination, and universal accessibility for people with disabilities), and, more recently, with *Ley 39/2006 de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia*”, (Act 39/2006 on promotion of personal autonomy and attention for dependent people), which came into effect on January 1, 2007.

The debate on the elaboration and passing of the Dependency Act has been followed by the *Consejo General de Colegios Oficiales de Psicólogos* (General Council of the Official College of Psychologists) with enormous attention, both because of the general interest that it has created in the society, and because of its specific importance for our profession. In this sense, one of the biggest concerns of the Council has been the limited presence of psychological aspects in the aforementioned law.

Without any doubt, the new theoretical approaches and the latest social and political events are increasingly distant from the paternalist view about the disabled person, which used to advocate the traditional model based on the deficiency. Taking this fact as a starting point, we should ask ourselves about the main contributions that can be expected from psychology and, in particular, clinical psychology, in the field of disability. In this sense, we agree with Professor Aguado (2006) in that the emphasis should be placed on intervention processes, more specifically, on evaluation, treatment planning and programme appraisal.

The selection of studies made for this analysis tries to reflect some of the main contributions to the field of disability made by clinical psychology and health psychology. To do that, studies of locally and internationally prestigious professionals published over the last five years are taken as points of reference. Nevertheless, in spite of relying on four works by foreign authors, contributions made by Spanish authors predominate, since, as Verdugo (2006) shows, politics, research, and services function differently in each country. Hence we turn to our nearest context, with the aim of understanding the current state of affairs on the work that is being done in relation with disabled people.

The path taken uses as a reference, Professor Verdugo's work published in 2003, in an attempt to cover conceptual, methodological, evaluation, and planning aspects of intervention in the field of disabled people. In this study he critically analyses the latest definition of intellectual disability put forward by the prestigious American Association on Mental Retardation, at the beginning of this decade and by outlining support models, he links up with the study published in the same year by Thompson and collaborators, who make use of a systematic approach to set out the best way to attend to the support needs of people with mental retardation and with associated developmental disabilities. This first block of works, centred on conceptual issues, finishes with a

representative selection from a recent paper by Schalock about quality of life, which is always a highly topical subject in clinical psychology. On this occasion it is not set out so much as a desire but rather as a challenge for the disabled, due to their personal limitations and to the social and cultural attitudes in relation to their worth as people.

The second block of commented-on reports, also made up of three works, is a commitment on the part of psychological research to attend to an important demand for knowledge about the new needs of this population. The increase of life expectancy of disabled persons compels us to carry out follow-up studies, such as the one by Keogh, Bernheimer and Guthrie (2004); that patterns to facilitate young disabled peoples' transition to adult life are established (Martínez Rueda, 2002) and to start attending to the ageing process of this group (Aguado and Alcedo, 2004).

From our point of view, Bermejo's work (2006) is a clear example of how it is possible to carry out empirical research with real methodological rigour, using groups of psychically disabled people as subjects of a study.

This selection finishes with a set of works that try to show a wider vision of disability, which reveal the strengths and weaknesses of the attention given to disabled people. In the first case, we are referring to the role played by the families and the society in the integration of persons with disabilities. As regards the weak points in this area, we are not forgetting some of the deficiencies still to be found, such as the insufficient development of research regarding disabilities in Spain, and the limited specialised education or training still received by professionals of psychology in disabilities.

**Verdugo, MA (2003). Análisis de la definición de discapacidad intelectual de la AAMR de 2002. Siglo Cero. Revista Española sobre Discapacidad Intelectual, 205, 5-19.**

The work by Miguel Ángel Verdugo can be regarded as a critical analysis of the latest definition of mental retardation, which the prestigious American Association on Mental Retardation (AAMR) has given in their tenth edition. Ever since its foundation in 1876, it has oriented itself, like no other organisation or association, to the understanding, definition and classification of this phenomenon.

As regards the terminology, the article by Miguel Ángel Verdugo disagrees on maintaining the use of the expression *mental retardation* instead of the increasingly accepted and widespread *intellectual disability*. As García, Cobacho, Berruezo, and Gosálbez (2002) defended, Verdugo argues that the main reason for proposing a change in the terminology derives from the “*pejorative character of the meaning of 'mental retardation'*”, which, in addition, reduces the understanding of people with intellectual limitations to a diagnostic category born from psychopathological perspectives.” (p. 6) In the same way, the study highlights the large number of European countries and institutions which have used the term ‘intellectual disability’ for some years now. Such is the case of the

International Association for the Scientific Study of Intellectual Disabilities itself, which includes it in its name. In Spain, at an organisational level, this change is endorsed by FEAPS (Spanish Federation of Associations of Psychotherapists), whose name changes into *Confederación Española de Organizaciones a favor de Personas con Discapacidad Intelectual* (Spanish Confederation of Organisations in favour of people with intellectual disability).

The development of the tenth edition devised by the Committee on Terminology and Classification of the AAMR (Luckasson et al., 2002) cannot be understood without the proposal made by this organisation itself in the former edition (Luckasson et al., 1992), which, as Verdugo points out, brought about a radical change in the traditional paradigm, by moving away from the conception of mental retardation as a feature into a conception based on the interaction of the person and the context (Verdugo, 1994). It was, without any doubt, the first multidimensional approach towards intellectual disability addressed to eliminating the reductionism of the exclusive use of tests for the diagnosis of IC. Furthermore, the evaluation process developed greatly, by proposing the search for information about individual needs in different dimensions which had to relate to further suitable support levels. In this sense, in the author's opinion, the tenth edition might be regarded as a revision and improvement of the approach included in the ninth edition. So, as Verdugo states, once the change of paradigm had been accepted, the current version is committed (you bet on the geeges) to two objectives, namely, to operationalise the multidimensional nature of mental retardation with more clarity, and to provide guidelines of good practice to diagnose, classify and plan support.

The new edition maintains the three criteria proposed in the 1983 and 1992 definitions; namely, significant limitations in intellectual functioning, limitations of adaptive behaviour, and these limitations are manifest in the developmental period. The specific terms that the definition finally sets out are the following:

*Mental retardation is a disability characterised by significant limitation of intellectual functioning and adaptive behaviour, as manifested in practical, social and conceptual abilities. This disability starts before eighteen years of age (Luckasson et al., 2002, p. 8).*

As for the diagnosis, classification and planning issues of intervention, the current system includes a fourth dimension, the so-called *participation, interaction and social roles*. This system develops planning of support, it demands greater precision in measuring intelligence (especially, in adaptive behaviour) and finally, it makes an effort to relate the proposed system to other systems of classification, such as the *International Classification of Functioning, Disability and Health*.

Hence, Verdugo goes through the five dimensions proposed by the new system, namely, intellectual abilities; conceptual, social and practical adaptive behaviour; participation, interaction, and social roles; and health and context. In each dimension, the new

features and the differences in relation to the former editions stand out.

As for the first dimension, that of *intellectual abilities*, the author argues that, in spite of the constraints, the current system keeps regarding the IC as the best representation of the intellectual functioning of a person. Although, it is essential that the IC is obtained from adequate evaluation tools, which need to be standardised in the general population. Apart from that, the criterion to establish the diagnosis of mental retardation is still that of "two typical deviations below the average." This criterion is also extrapolated and so the restrictions on the evaluation of *adaptive behaviour* are also considered significant, which entails the further use of standardised measures in adaptive behaviour, applied to the general population. Without any doubt, this is one of the attempts to specify the evaluation of adaptive behaviour, which was a rather neglected issue in the former versions. In this sense, the AAMR proposes a series of tools with appropriate psychometric properties to evaluate this dimension. (You left this out) However, Verdugo admits that there are not any suitable adaptations of these instruments in the Spanish language, in spite of the increasing number of publications pointing in this direction (Gilman et al., 2002; Morreau, Bruininks y Montero, 2002; Verdugo, 1989/1997, 1996, 2000).

As already stressed, the dimension of *participation, interaction and social roles* is one of the most important novelties of this new classification system. Furthermore, it is a clear commitment to getting closer to the WHO proposal in the *International Classification of Functioning, Disability and Health* (WHO, 2001). In this way, both systems highlight the role of analysing and bearing in mind the opportunities and restrictions of the individual to participate in the community. This is the dimension most concerned with interactional aspects, differently from the rest, which independently focus on personal or environmental aspects.

It also supposes an important advance in the multidimensional conception of this model, as well as an approximation towards other classification systems, the definitive commitment to the assumption of the concept of health proposed by the WHO in 1980, where health is understood as being a state of physical, mental and social well-being. As Verdugo states, the AAMR had so far been criticised for excessively psychopathologising their conception of health, proposing in this new version that this dimension "should widen their approach and include non pathological aspects of emotional well-being." (Verdugo, 1999, pp.29-30).

According to this author, it has been wise to place psychological and emotional aspects in this dimension. However, he thinks that the AAMR's proposal "is limited in its development, on simply concentrating in placing the problems of mental health in this dimension and formulating a general proposal of the concept of health of the WHO" (p. 12).

The fifth and last dimension, *context*, includes the new idea that not only should we attend to the environment in which the person performs, but also the culture, as many values and assumptions about

behaviour are affected by it. As argued in earlier versions, the evaluation of context is not carried out with standardised measures, but is a component which should be included in the so-called clinical judgement.

The last section focuses on the analysis of the three functions of the evaluation process, namely, diagnosis, classification, and support systems. First of all, it states that this version is much more explicit than earlier ones when relating the diagnostic process to the planning of support, that is, to intervention proper in the field of intellectual disability.

In short, what the AAMR explicitly proposes is that the evaluation process should focus not only on the limitations of the individual but also on their abilities, the essential thing being obtaining data which allow for a suitable profile of support which may improve a person's individual functioning. In this sense, Verdugo points out that the instruments used should be able to help to establish diagnosis criteria previously pointed out, and, most importantly, these instruments should be useful in showing which abilities a person may need to develop. From his point of view, the tools which might meet this requirement are the *Curriculum for Adaptive Skills (CALs)* (Gilman et al. 2002); the *Inventario para la Planificación de Servicios y la Programación Individual* (Inventory for the Planning of Service and Individual Planning) (ICAP) (Montero, 1993), and the *Programas Conductuales Alternativos (PCA)* (Alternative Behaviour Programs) (Verdugo 1996, 1989/1997, 2000).

As for the third function of the evaluation processes, the support systems, the AAMR states that "*Supports are resources and strategies that attempt to enhance the development, education, interests, and well-being of a person, and that improve individual functioning.*" (Luckasson et al., 2002, p. 145).

According to this approach, the ultimate objective of evaluation should be to establish a *support needs profile* for each person with intellectual disability. In this sense, nine areas of support are established, namely, human development, teaching and education, life at home, life in the community, employment, health and safety, behaviour, social, protection and defence. For each area it would be necessary to identify the type of support necessary, the degree of support, and the person responsible for providing the support.

In conclusion, the author considers that "*the support model is a key aspect in the present-day conception of intellectual disability, and its functioning depends to a great extent on the existence or not of real changes in the system of attention to the population with intellectual limitations. The current approach to support is directly related to the incorporation of planning focused on the individual.*" (p. 17)

**Thompson, J.R., Hughes, C., Schalock, R.I., Silverman, W., Tassé, M.C., Bryant, B., Craig, E.M. y Campbell, E.M. (2003). Integrando los apoyos en la evaluación y la planificación. (Integrating supports into Assessment and Planning.) Siglo Cero. Revista Española sobre Discapacidad Intelectual, 34 (2), 36-55.**

The study carried out by these authors presents, from a systematic focus, a proposal to attend to the support needs of people with mental retardation and associated developmental disabilities. They propose the definition of 'support' as being resources and strategies which enhance the interests and well-being of individuals, which improve personal and productive independence, and which increase participation in an interdependent society, in community integration and/or in the quality of life. Among the challenges they put forward are that the objectives should start from the needs and aspirations of the people directly concerned; to include improvement in personal development, empowerment, inclusion, and valued social roles; an evaluation of a wide range of individual support needs that are centred on the people should be flexible and adaptable, and to evaluate the changes in state and needs.

The authors start from a focus of four components in order to be able to establish the support needs, and to develop plans which attend to those needs (identifying vital experiences and achievements desired by the person, establishing the degree of individual support in a wide range of environments and activities, developing an individual plan for support, monitoring the results and evaluating the effectiveness of the plan).

These four components are developed within five suppositions on the nature of the support needs of people with mental retardation and associated developmental disabilities.

The first supposition considers that the types of support should depend on the needs and preferences of the individual. The second one states that provision of support should be flexible, responding to the needs of people, who change in function of the circumstances, and they need periodic revisions. The third supposition suggests that some supports are more important to some people than to others; that is to say, we should allow for the prioritizing of some support needs. The fourth one states that systematic evaluation of support needs should guide the development and revision of individual support plans (ISP). Finally, the fifth supposition focuses on the multiple factors necessary for the evaluation of support needs.

All four components focus on the identification of vital experiences and achievements desired by the person, and on the appraisal of the degree of support necessary in various environments and activities. In order to determine this support, the authors propose a scale created by themselves, the "Escala de Necesidades de Apoyo" (*Support Intensity Scale (SIS)*, Thompson et al., 2002).

The authors consider that the SIS is suitable to use at any moment when the support needs of an adult person have to be assessed. For this reason, it can be used independently of the focus of the four components in order to attend to the support needs described in the article.

Following, they reflect on putting this type of intervention into practice. Thus, they consider that the ISP should bear in mind all the sources of support



available for the individual, and the contexts in which they will be given. In this sense, cooperation and communication between the support providers and the planning team is crucial to assure that all support will be provided at the highest possible degree, and without any duplicity or interruption. Likewise, the individual's satisfaction at the support received, and the areas of support which require modification or accomodation are believed to be necessary.

As for identification of the degree of support necessary for each individual, they consider that the evaluation of young children with mental retardation should be focused on the identification of the types and the intensity of support needed by the children's families, who are especially relevant and useful in this age group (Luckasson, Schalock, Snell y Spitalnik, 1996). They state that if people are identified according to the level of support they need or according to their level of personal competence, this should neither hide the need to assess both areas, nor distract attention from the importance of developing reliable and valid evaluation tools to measure both areas. They argue that the SIS seems to have the potential to identify both a person's support needs in specific areas, as well as a global score.

There is also some reflection on the financing of support. In this sense, they think that the disabled person, their family, and other members of the support team should be prepared to make choices about support priorities, since resources are limited.

Finally, they raise a series of themes and challenges associated to the assessment and the planning of support needs. First of all, there is the need for greater acceptance of this work proposal and/or the lack of a clearly defined procedure for measuring support needs. (Polloway, Chamberlain, Denning, Smith y Smith, 1999). The assessment process needs to provide the structure and sufficient uniformity to allow for objective, unbiased, dynamic and realistic development of the ISP.

The work finishes with the authors' statement that their ultimate aim is to provide support with the greatest positive impact on the quality of life of every individual and they believe that the approach described in their article will bring about a significant step in that direction.

**Schalock, R.L. (2006). La calidad de vida como agente de cambio: oportunidades y retos. (Quality of life as an agent of social change. Opportunities and Challenges. In M.A. Verdugo Alonso y F.B. Jordán de Urries Vega (Coord.). Rompiendo inercias. Claves para avanzar (Breaking routine habits. Keys for advance) (pp. 15-39). Salamanca: AMARÚ Ediciones.**

The selection of this paper, presented at the "VI Jornadas Científicas de Investigación sobre Personas con Discapacidad" (VI Scientific Conference on Disabled People), held in Spain in 2006, responds to two specific criteria, namely, the analysis of the current situation of the phenomenon carried out by a well-known researcher on disabled people in Spain, and the analysis of a work proposal on the issue. The author

states that, for every one of us, achieving a good quality of life is both a wish and a challenge, but for disabled people this challenge is even greater because of their personal limitations, because of the social and cultural attitudes in relation to their worth as people, and because of their social consideration within their communities. Even though an attitudinal change is taking place, 'quality challenges' still exist, especially as regards their social inclusion, personal development, self-determination and rights.

The author reflects on the opportunities and challenges encountered by the disabled to achieve quality of life, and on how these challenges can be overcome by completely implementing the concept of quality of life in the individual, organisational, and systemic levels.

First of all, the author focuses on the history of the concept of quality of life, and why our field adopted it in the 1980s. The four reasons he points out make reference to the following: the fact that the concept reflected a constant on-going change about people with disability; the fact that it provided a common language which described the programmes' objectives of normalisation, disinstitutionalisation, integration, and responsibility; the fact that it was coherent with the quality revolution, which gave priority to quality results and quality products and finally, the fact that the expectations of the recipients of the service and the support provided had a significant and positive impact on their personal well-being.

Secondly, he discusses the four conceptual and methodological advances that took place in the 1990s, which provided a clear notion of the concept of life, and a firm philosophical and empirical foundation for our present-day measures and for our efforts in applying them. These advances are: operational principles, basic dimensions of the quality of life, approaches for research and measurement, and a systemic perspective.

An internacional group of researchers on the quality of life have validated a total of twelve operational principles related to conceptualisation, measurement, and application of quality of life. These principles allow for the operational definition of the concept of quality of life as a relevant multidimensional concept.

The basic dimensions of quality of life can be individual centred or family centred. Schalock defines them as: "*the set of factors that shape personal well-being, encompass the concept of quality of life, and thus, define quality of life*" (p. 18). The importance of identifying these basic dimensions lies in the fact that they allow our field to move on from a general concept of quality of life to a specific and multidimensional notion, with measurable properties and attributes.

Within the approaches of researchers and of measurement, the basic indicators of quality of life are defined as: "*the specific conditions, behaviour or perceptions of a dimension of quality of life which give an indication of a person's well-being*" (p. 19), a specific and multidimensional notion with measurable properties. According to the author, the methodological approach is characterised by having different

assessment approaches, multi-variable research designs, and evaluation based on results.

As regards the systemic perspective, it starts from the premise that people live in different 'systems' which influence the development of their values, beliefs, behaviour and attitudes, which to a large degree establish the quality of life that they experience (microsystem, mesosystem, and macrosystem).

Finally, the author puts forward the notion that quality of life may act as an agent of social change for people with disability, but in this process we will need to adopt seven opportunities and challenges. Three of them are related to research, namely, confirming the structure of the factors in quality of life, measuring the personal results, and establishing the significant predictors of quality results. Four of the challenges and opportunities are related to organisations and systems in order to emphasise a quality-of-life programme, to put the most suitable methodologies into practice, to get involved in the continuous improvement of the programmes, and to exploit the mechanisms of social change.

He considers that the first of these challenges is materialised in the increase in the studies on quality of life through statistical methods which *confirm the stability of factors* in the basic dimensions of quality of life in more countries and cultural groups.

As regards the *measurement of personal results*, he considers that they contribute to personal well-being from the individual and family points of view. He states that the four essential aspects of the results are that they can be assessed by means of subjective measures, that they are influenced by variables of the process, that these variables are not the same as the social indicators, and that they can be used for various aims, including individual assessment.

According to the author, *establishing the significant predictors of the personal results* would allow for the creation an acceptable model as to how a programme should function, the analysis of the scope and impact of external influences on the programme, the differentiation between the product of the programme and the short-term and long-term personal results, the development of a framework to analyse alternative strategies to achieve the desired personal results, the better understanding of the functioning of the agency by identifying a sequence of events and greater communication, and the analysis of the logic of human service programmes and public policies.

As for the challenge of *the transition to emphasis on quality of life within the programmes*, the organisations should obtain results valued by the individual and oriented to quality of life, and make the concept of quality of life their main objective.

Within the *implementation of the most adequate methodologies*, he thinks that the two most recommended practices are: the one referring to the recommended programme practice (which entails planning centred on the person/family), the strategies for improvement of quality, individualised support and

assistance technologies. The second practice is related to ethics in assessment.

*Involvement in the continuous improvement of the programmes* has the aim of satisfying clients, improving services and support and increasing organisational effectiveness.

Lastly, *exploiting mechanisms of social change* suggests five possible strategies, namely, ethical community (by interrelating human and community development, and by directing intervention activities to the improvement of support resources); social resources (changes in the relationship among people); education and professional training; solid defence (social change starts with the person); and the alignment of research, policies and practice.

Finally, Schalock concludes that the most important issue about the concept of quality of life is that it makes us think differently about ourselves, about marginalised people, and about the means to actually achieve personal, organisational, systemic, community, and social change in order to improve people's well-being.

Even though the three last decades have witnessed great development, new methods and standards are necessary to plan, provide, manage, and assess both quality of service and personal quality results for the disabled.

As this author thinks, if the concept of quality of life is to be a real agent of social change, the real agents of the change should be the disabled people themselves, our main challenge is to align research efforts, skills and educational programmes and public policies which may facilitate the change. To do that, he proposes three dimensions, centred on research, practice, and politics.

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