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The concept of quality of life and its role in enhancing human rights in the field of intellectual disability

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Abstract

Background   The changed societal views of persons with disabilities are reflected in the 2006 United Nations *Convention on the Rights of Persons with Disabilities.* However, what is not specified in the Convention is how to operationalise and measure the Articles composing the Convention, and how to use that information to further enhance the human rights of persons with disabilities.
Method   The authors analyse the relationships between eight core quality of life domains and the 34 Articles contained in the Convention.
Results   There is a close relationship between the core quality of life domains and the 34 Articles contained in the Convention. Furthermore, the current status of these Articles can be evaluated through the assessment of indicators associated with the eight core quality of life domains.
Conclusions   Based on the assessment of these quality of life-related outcomes, three strategies can be used to enhance the human rights of persons with intellectual disability. These three are to employ person-centred planning, publish provider profiles and implement a system of support.

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Introduction and overview

Societal views on the human rights of persons with disabilities have changed significantly over the last 40 years. This change is demonstrated in the development of international conventions intended to guide the policy of states and public authorities. After the Universal Declaration of Human Rights (United Nations 1948), the Declaration on the Rights of Mentally Retarded Persons (1971) specified what equality and fundamental rights mean for person with intellectual disability (ID). Rights, however, are not sufficient if they are not accompanied by opportunities to exercise those rights. The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (United Nations 1993) therefore were an important additional international document defining the societal prerequisites of equality. In 2006, the Standard Rules were replaced by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations 2006). These rules and related Articles state the socio-political conditions for achieving equality, autonomy, non-discrimination, participation and inclusion in society. What is not

specified in the Convention is how to operationalise and measure the Articles and use that information to further enhance the person's life, including their human rights.

We argue in this paper that, whereas these Conventions and Articles focus on the socio-political or macrosystem level, the emerging construct of quality of life (QoL) reflects the dynamics of personally desired subjective and objective conditions of life. This construct has become the link between the general values reflected in social rights and the personal life of the individual. It has also become a vehicle through which individual referenced equity, empowerment and life satisfaction can be understood and enhanced. QoL models capture the essential dimensions of an individual's life situation, including his or her human and legal rights (Schalock *et al.* 2007; Brown *et al.* 2009; Buntinx & Schalock, 2010). We argue further that the concept of QoL might best be viewed as: (1) a relevant concept both to public policy determination and an outcome for social policies; and (2) a process of achieving equal opportunities for people with disabilities (Matikka 2000).

We recognise the importance of other constructs, such as family QoL (see Samuel *et al.* 2012 for a review) for three reasons. First, abuses and violations of rights often occur in and through the family environment (e.g. Craig *et al.* 2010). Second, relatives are usually who require the resources for ensuring inclusive and effective home environments, and most of them have a mediator role in other environments (e.g. Rodríguez *et al.* 2008; Werner *et al.* 2009). Finally, because people with profound multiple disabilities are particularly dependent on family support and care (e.g. Petry *et al.* 2005). However, we will focus on the field of individual QoL given that theories and models of family QoL would need to be the subject of another paper.

This paper has three sections. The first discusses the essential aspects of the QoL concept including its eight domains. The second section summarises the 34 Articles included in the UNCRPD, shows how these Articles are closely related to the eight QoL domains, and discusses briefly how the application and current status of these Articles can be evaluated through the assessment of QoL-related personal outcomes. The paper concludes with a discussion of three organisation strategies that can be used to enhance the human rights of persons with ID.

The concept of quality of life

Over the last three decades the QoL concept has evolved from a sensitising notion to a social construct that guides programme practices and provides a useful conceptual and measurement framework to assess the personal outcomes guaranteed under UNCRPD (Karr 2011). The issue that the concept addresses is the lives of persons and ensuring that citizens with ID experience the same human rights and a life of quality as any other member of society. To this end, the QoL concept reflects the following four principles: (1) QoL is composed of the same factors and relationships for all people; (2) QoL is experienced when a person's needs are met and when the individual has the opportunity to pursue life enrichment in major life activity settings; (3) QoL has both subjective and objective components; and (4) QoL is a multidimensional construct, influenced by individual and environmental factors.

Over the last two decades the authors have developed and validated cross-culturally the QoL conceptual and measurement framework summarised in Table 1. The interested reader can find empirical support for its validity (e.g. Aznar & Castañón 2005; Xu *et al.* 2005; Chou & Schalock 2009; van Loon *et al.* 2010), verification of its factor structure (e.g. Bonham *et al.* 2003, 2004; Wang *et al.* 2010; Gómez *et al.* 2011a), determination of the etic and emic properties of its dimensions and indicators (e.g. Kober & Eggleton 2002; Jenaro *et al.* 2005; Verdugo *et al.* 2005; Claes *et al.* 2010), and the role of mediating and moderating variables (Schalock *et al.* 2010a, 2011). The conceptual and measurement framework summarised in Table 1 is the result of more than two decades of research starting and mainly focused in the ID field, but increasingly applied in other areas such as ageing, physical disabilities, mental health, special education, chemical dependency and with individuals who are at risk for social exclusion (e.g. Woodwill *et al.* 1994; Raphael *et al.* 1995; Brown 1997; Bowling & Gabriel 2004; Caballo *et al.* 2005; De Maeyer *et al.* 2009; Arias *et al.* 2010; Cummins *et al.* 2010; Verdugo *et al.* 2010a; Gómez *et al.* 2012).

Table I Quality of life conceptual and measurement framework

Factor	Domain	Exemplary indicators
Independence	Personal development	Activities of daily living
	Self-determination	Choices, decisions, personal goals
Social	Interpersonal relations	Social networks, friendships
	Participation	Social inclusion/community involvement
	Rights	Human and legal
Well-being	Emotional well-being	Safety and security
	Physical well-being	Health and nutrition status
	Material well-being	Financial status, employment

In the Table 1 framework, QoL indicators refer to QoL-related perceptions, behaviours and conditions that define operationally each QoL domain. Furthermore, psychometrically robust and culturally sensitive indicators are used to assess either the person's perceived well-being ('self report') or an objective indication of the person's life experiences and circumstances ('direct observation'). Other QoL models, which are similar to the one summarised in Table 1, can be found in Cummins (2005), Felce & Perry (1995) and Petry *et al.* (2005).

For consistency and standardisation purposes, indicators and QoL-related personal outcomes are selected on the basis of published research, expert panels, Delphi studies and stakeholder focus groups. Criteria for selecting specific indicators are that those indicator items selected: reflect what people want in their lives, are culturally sensitive, are related to current and future policy issues, are those that the individual (or service provider) has some control over, and can be used for quality improvement purposes (Verdugo *et al.* 2005, 2010a; Walsh *et al.* 2006; Schalock *et al.* 2008). As discussed in the following section, the assessment of these domains and indicators by means of QoL-related personal outcomes is closely related to the assessment of some specific rights, and the eight-domain model becomes a conceptual framework that helps to guide the assessment and application of the rights appearing in the UNCRPD.

United Nations Convention on the Rights of Persons with Disabilities

Initially, the international human rights movement has focussed almost entirely on the activities of the able-bodied and the able-minded (Koh 2004) rather than persons with disabilities and the barriers they face in their daily living (Stein & Lord 2009). The normalisation principle encouraged the development of disability rights legislation during the 1960s, and also served as an instrument for considering what is appropriate (rather than 'normal') consistent with an ethical value theory (Nirje 1985). As Reinders (1999) later pointed out, in the absence of morally defensible caring practice, contemporary rights discourse will not be meaningful.

Prior to the UNCRPD, there were other Conventions [e.g. Declaration on the Rights of Mentally Retarded Persons in 1971; United Nations Declaration on the Rights of Disabled Persons in 1975 (United Nations 1975)] that tried to re-affirm the rights of people with disabilities, but these never became international treaties and were not legally binding. This could be one of the reasons, along with the need of evidence-based practices regarding its application (Schalock *et al.* 2011; Navas *et al.*, in press), why they were rarely applied in practice. To overcome this disregard, Article 1 of the UNCRPD declares the Convention's objective is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. These objectives are reflected in a series of Articles, which are shown in Table 2.

The UNCRPD is consistent with the ecological model of disability proposed by the American Association on Intellectual and Developmental Disabilities (AAIDD; Luckasson *et al.* 1992, 2002; Schalock *et al.* 2010b) and the World Health Organisation (WHO 2001). Thus, the United Nations Convention has been a major quantitative and qualitative step

Table 2 Articles of the UNCRPD

Article	Definition
5	Equality and non-discrimination
6	Women with disabilities
7	Children with disabilities
8	Awareness-raising
9	Accessibility
10	Right to life
11	Situations of risk and humanitarian emergencies
12	Equal recognition before the law
13	Access to justice
14	Liberty and security of person
15	Freedom from torture or cruel, inhuman or degrading treatment or punishment
16	Freedom from exploitation, violence and abuse
17	Protecting the integrity of the person
18	Liberty of movement and nationality
19	Living independently and being included in the community
20	Personal mobility
21	Freedom of expression and opinion, and access to information
22	Respect for privacy
23	Respect for home and the family
24	Education
25	Health
26	Habilitation and rehabilitation
27	Work and employment
28	Adequate standard of living and social protection
29	Participation in political and public life
30	Participation in cultural life, recreation, leisure and sport

UNCRPD, United Nations Convention on the Rights of Persons with Disabilities.

forward in that it in considers both the environment and supports and individual needs. It could be the instrument that many Governments need to develop and implement policies, laws and administrative measures to ensure the rights under the Convention (Harpur & Bales 2010) and, therefore, abolish laws, regulations, customs and practices which constitute discrimination. However, we should keep in mind, as indicated in Article 4, that this is only a Convention – a treaty – which implies no obligations unless the States Parties sign the Optional Protocol. Once signed, States Parties shall submit to the Committee on the Rights of Persons with Disabilities (Articles 33 and 34) a report on the development and implementation of public policies that guarantee the rights

enshrined in the Convention. On the other hand, history has shown that the effectiveness of this type of convention is directly related to the capacity of civil society to promote its implementation. As discussed by Quinn (2009), the UNCRPD is a mirror to society; it makes us face up to our own values and it forces us to acknowledge the large gap that still exists between the 'myth system' (i.e. our own values) and the 'operations system' (i.e. how these values are dishonoured in daily practice).

The UNCRPD builds on the principles of non-discrimination, equality of opportunity and accessibility, and links these to a group of civil (e.g. adequate standard of living and social protection) and political (e.g. participation in political and public life) rights. Most of the Articles are related to fundamental freedoms, but it is especially important that other rights, such as living independently, personal mobility and habilitation and rehabilitation, are addressed since without them, fundamental rights cannot be achieved by people with disabilities (Stein & Lord 2009).

Relationship between quality of life domains and United Nations Convention

The UNCRPD calls for rehabilitation, living independently, education, health, work and employment, and other measures to promote the independence and QoL of people with disabilities. However, although legal reforms are necessary, they may not be enough in and of themselves to bring about social change, and thus we need something more than a treaty to improve QoL of people with disabilities and guarantee that their rights are being respected (Kynlicka & Norman 1994; Rioux & Carbert 2003; Sabatello 2005; Karr 2011). More specifically, we need a framework that allows policy makers, service providers, and the population in general to understand and evaluate how the implementation of these rights are translated into improved human functioning and personal outcomes reflective of one's human rights. In this sense, we need to move from political concepts to evidence-based practices (Council of Europe 2006; Schalock *et al.* 2011).

The conceptual and measurement framework presented in Table 1 can be used to guide the development and implementation of the Articles

Table 3 Relationship between quality of life (QoL) domains and articles in the UNCRPD

Domains of QoL	QoL indicators	UNCRPD articles (directly related to QoL indicators)	UNCRPD articles (indirectly related to QoL indicators)
Personal development	Education status Personal skills Adaptive behaviour	Article 24	Article 27
Self-determination	Choices/decisions Autonomy Personal control Personal goals	Article 14 Article 19 Article 21	Article 9 Article 12
Interpersonal relations	Social networks Friendships Social activities Relationships	Article 23	Article 30
Social inclusion	Community integration/participation Community roles Supports	Article 8 Article 9 Article 18 Article 20 Article 27 Article 29 Article 30	Article 19 Article 21 Article 24
Rights	Human (respect, dignity, equality) Legal (legal access, due process)	Article 5 Article 6 Article 7 Article 10 Article 11 Article 12 Article 13 Article 15 Article 22	Article 14 Article 16 Article 18 Article 21
Emotional well-being	Safety and security Positive experiences Contentment Lack of stress	Article 16 Article 17	Article 23 Article 25
Physical well-being	Health and nutrition status Recreation Leisure	Article 16 Article 25 Article 26	Article 17
Material well-being	Financial status Employment status Housing status Possessions	Article 28	

UNCRPD, United Nations Convention on the Rights of Persons with Disabilities.

contained in the UNCRPD. That process begins by seeing the close relationship between the eight core domains and the most closely aligned Article(s). These relationships are shown in Table 3. In reviewing Table 3 it is interesting to note that the majority of the Articles relate to the QoL domains of self-determination, social inclusion, rights and physical well-being.

The assessment of the QoL domain-referenced indicators results in valid and reliable measures of the rights and freedoms guaranteed under UNCRPD (Karr 2011). Once assessed, these measures can be reported either by Article (or Article cluster) or for the respective QoL domain/Article cluster. Furthermore, the information obtained from the assessment can be used at the organisation

level to enhance the rights and freedoms as guaranteed under the Convention. Three ways of achieving this are discussed in the following section.

Organisation strategies to enhance the human rights of persons with disabilities

The QoL framework emphasises the need to incorporate the systems perspective (Bronfenbrenner 1979) because people live in a number of systems (micro, meso and macro) that influence the development of their values, beliefs and attitudes (Schalock 2004). The microsystem refers to the immediate social context, as the family, home, peer groups and the workplace, which directly affects the life of the person. The mesosystem includes the neighbourhood, community, service agencies and organisations that directly affect the functioning of the microsystem. The macrosystem reflects the larger cultural patterns of culture, socio-political and economic systems. This section of the article focuses on strategies at the organisation (i.e. mesosystem) level and describes three strategies related to person-centred planning, provider profiles and individualised supports.

Person-centred planning

Focusing on enhancing personal outcomes/human rights encourages organisations to develop person-centred planning, provide individualised supports and involve people in the decision making of their own lives and supports. However, these interventions should be made on the basis of empirically validated conceptual frameworks and by means of assessment instruments that are reliable and valid. Two instruments that meet those criteria (and were developed on the basis of the eight-domains QoL model summarised in Table 1) are the *Integral Scale* (Verdugo *et al.* 2007, 2009a, 2010b) and the *Personal Outcomes Scale* (van Loon *et al.* 2008). The first of these was developed for use in Spain; the second for Holland and Belgium. Both were developed to assess QoL-related personal outcomes in adults with ID, to enable the development of provider profiles to guide continuous programme development and to enhance personal outcomes.

Provider profiles

Provider profiles are used at the organisational level to describe the characteristics of service/support agencies, to report their annual quality assurance and quality improvement activities, and to summarise yearly aggregated QoL outcome measures for their clientele and to compare these scores with those of members of the community. Three such provider profiles are described below.

Maryland

In Maryland, consumers with ID administer a QoL survey (based on the QoL framework – Table 1) to a representative sample of people with disabilities in order to provide feedback to organisations managers on predictors of personal outcomes. The project also includes an annual training session for all participating providers about strategies to enhance QoL, especially personal development, self-determination and rights domains (Bonham *et al.* 2004; Keith & Bonham 2005).

Nebraska

The Nebraska approach assesses the QoL of service recipients with ID on eight core QoL domains and publishes the aggregated results (i.e. total scores obtained by all consumers in an organisation) for each of the eight domains and a total index for persons with and without ID in the provider's city. With these data, providers can compare their results with the ones obtained by similar organisations and with the ones obtained by people without disabilities in their community.

Spain

A third approach to provider profiles has recently been employed in Spain (Catalonia) using the *Gencat Scale* (Verdugo *et al.* 2008a,b, 2009), which is an objective instrument to assess QoL-related personal outcomes. The scale was applied to a representative sample of more than 11 000 social service consumers within 288 organisations. Among them, there were not only people with ID, but also people with other disabilities, people with mental health problems, older people, persons with drug dependences (i.e. adults with prescribed drug

problems) and people with HIV/AIDS. In this way, data based on the eight-domain model may be used not only to compare results among organisations, but also among different groups in order to develop evidence-based practices (Schalock *et al.* 2011). Furthermore, data may be used for the development of policies at the macrosystem level aimed to improve results in those domains with the lowest scores (i.e. personal development, social inclusion and self-determination).

In addition to these three profiles, a recent study illustrates how the assessment of QoL-related personal outcomes may be used to explore the knowledge and exercise of human rights. Gómez *et al.* (2011b) show how the eight-domain model allows key agents to monitor and assess different human rights. The research uses a double perspective: self-report of the persons with ID by means of the *INTEGRAL Scale*, and observations of the staff working with them by means of the *GENCAT Scale*. The results found that there are still many situations involving abuse and neglect, and that there is an urgent need for assessing the Convention implementation in a systematic way.

Individualised supports

Since its introduction into the ID field in the mid-1980s, the concept of supports has been expanded to a framework on the systematic assessment of an individual's support needs, and are individualised to provide a structure for enhancing personal outcomes and human rights. In this sense, the Support Intensity Scale (Thompson *et al.* 2004) has become a useful tool to answer the question regarding the supports that are needed to help people participate in their community, assume valued social roles, and experience greater satisfaction and fulfilment (Thompson *et al.* 2002).

Such a system of supports includes (Schalock & Verdugo 2012): (1) developing a system of supports based on a QoL conceptual framework leading to the provision of individualised support; (2) involving consumers through the knowledge of their rights and empowering them to be effective self-advocates; (3) increasing support staff competencies and effectiveness through the use of evidence-based practices; and (4) expanding to new programme options and opportunities that involve community living,

employment, educational and natural supports. As an example, the Gipuzkoa Autistic Society (Spain) is a not-for-profit parents' organisation with the mission of informing and creating awareness among society and offering the appropriate services to people with autism. This organisation is improving rights in daily work by using a QoL framework to individual assessment and programming. The main characteristics of its work are: the use of an ethical framework, which specifies the values that underpin the idea of person, and including the exercise of rights in each individual support plan, and a new organisational policy that defines how to manage self-determination of people in planning their life projects, emphasising support for communication.

A second example is that of FEAPS, the Spanish member organisation of Inclusion International, which is composed of 891 organisations and more than 100 000 persons with ID. FEAPS has published a 'best practices guide' to help people with ID to learn, evaluate and defend their rights for improving their QoL. Organisations are using this guide for training persons with ID to be active self-advocates. The guide has been developed with the involvement of people with ID who, according to the eight dimensions of QoL, have analysed situations in which their rights have been somehow violated, encouraging them to analyse consequences of these events, and providing them with information about how to avoid these situations and improve their behaviour.

Conclusion

Human and legal rights are essential components to a life of quality and equality. We argue in this article that human rights extend across a wide range of human activities that involve each of eight QoL domains listed in Table 1. The UNCRPD and its related Articles articulate well the rights of people with disabilities. However, the Convention does not specify how to operationalise and measure the Articles so as to develop a metric that can be used to evaluate the progress and changes in peoples' status regarding their human rights and a life of quality and equality. The QoL conceptual and measurement framework presented and discussed in this article provides that template and allows

organisations and systems to implement QoL-related enhancement strategies that impact the desired results of the Convention. The three strategies discussed in this article were person-centred planning, provider profiles and individualised supports.

The UNCRPD encourages a strong monitoring mechanism to ensure accountability for appropriate programme and policy planning. States Parties' legislative and programmatic progress are tracked through Article 35, which requires states and non-governmental organisations to submit comprehensive reports on measures taken to give effect to [their] obligations under the Convention and on progress made. We have argued in this article that the reliable and valid assessment of QoL-related domains and indicators that are aggregated according to the Convention's Articles will allow states and organisations to fulfil that requirement.

References

Arias B., Gómez L. E., Verdugo M. A. & Navas P. (2010) Evaluación de la calidad de vida en drogodependientes mediante el modelo de Rasch. *Revista Española de Drogodependencias* **35,** 206–19.

Aznar A. S. & Castañón G. G. (2005) Quality of life from the point of view of Latin American families: a participative research study. *Journal of Intellectual Disability Research* **49,** 784–8.

Bonham G. S., Basehart S. & Marchand C. B. (2003) *Ask Me! FY2003 Report: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA Funded Support.* The ARC of Maryland, Annapolis, MD.

Bonham G. S., Basehart S., Schalock R. L., Marchand C. G., Kirchner N. & Rumenap J. M. (2004) Consumer-based quality of life assessment: the Maryland Ask Me! Project. *Mental Retardation* **42,** 338–55.

Bowling A. & Gabriel Z. (2004) An integrational model of quality of life in older age. Results from the ESRC/MRC HSRC quality of life survey in Britain. *Social Indicators Research* **69,** 1–36.

Bronfenbrenner U. (1979) *The Ecology of Human Development.* Harvard University Press, Cambrigde.

Brown R. I. (1997) *Quality of Life for People with Disabilities: Models, Research and Practice,* 2nd edn. Stanley Thornes, Cheltenham.

Brown R. I., Schalock R. L. & Brown I. (2009) Quality of life: its application to persons with intellectual disability and their families: introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities* **6,** 2–6.

Buntinx W. H. E. & Schalock R. L. (2010) Models of disability, quality of life, and individualized supports: implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities* **7,** 283–94.

Caballo C., Crespo M., Jenaro C., Verdugo M. A. & Martínez J. L. (2005) Factor structure of the Schalock and Keith quality of life questionnaire (QOL-Q): validation on Mexican and Spanish samples. *Journal of Intellectual Disability Research* **49,** 773–6.

Chou Y. C. & Schalock R. L. (2009) Survey outcomes and cross-national comparisons of quality of life with respect to people with intellectual disabilities in Taiwan. *Journal of Policy and Practice in Intellectual Disabilities* **6,** 7–10.

Claes C., van Hove G., van Loon J., Vandevelde S. & Schalock R. L. (2010) Quality of life measurement in the field of intellectual disabilities: eight principles for assessing quality of life-related personal outcomes. *Social Indicators Research* **98,** 61–72.

Council of Europe (2006) Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006–2015. Available at: http://www.coe.int/t/e/social_cohesion/soc-sp/Rec_2006_5%20Disability%20Action%20Plan.pdf (retrieved 12 January 2011).

Craig L. A., Lindsay W. R. & Browne K. D. (2010) *Assessment and Treatment of Sexual Offenders with Intellectual Disabilities: A Handbook.* Wiley-Blackwell, Chichester.

Cummins R. A. (2005) Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research* **49,** 699–706.

Cummins R. A., Lau A. L. D., Davey G. & McGillivray J. (2010) Measuring subjective wellbeing: the Personal Wellbeing Index – Intellectual Disability. In: *Quality of Life for People with Intellectual Disability* (ed. R. Kober), pp. 33–46. Springer, Dordrecht.

De Maeyer J., Vanderplasschen W. & Broekaert E. (2009) Exploratory study on drug users' perspectives on quality of life: more than health-related quality of life? *Social Indicators Research* **90,** 107–26.

Felce D. & Perry J. (1995) Quality of life: its definition and measurement. *Research in Developmental Disabilities* **16,** 51–74.

Gómez L. E., Verdugo M. A., Arias B. & Arias V. (2011a) A comparison of alternative models of individual quality of life for social service recipients. *Social Indicators Research* **101,** 109–25.

Gómez L. E., Verdugo M. A., Arias B. & Irurtia M. J. (2011b) Evaluación de los derechos de las personas con discapacidad intelectual: estudio preliminar. *Psicología Conductual [Behavioral Psychology]* **19,** 207–22.

Gómez L. E., Arias B., Verdugo M. A. & Navas P. (2012) An outcomes-based assessment of quality of life in social services. *Social Indicators Research* **106,** 81–93.

Harpur P. & Bales R. (2010) The positive impact of the Convention on the rights of persons with disabilities: a case study on the South Pacific and lessons from the U.S. experience. *Northern Kentucky Law Review* **37,** 363–88.

Jenaro C., Verdugo M. A., Caballo C., Balboni G., Lachapelle Y., Otbrebski W. *et al.* (2005) Cross-cultural study of person-centered quality of life domains and indicators: a replication. *Journal of Intellectual Disability Research* **49,** 734–9.

Karr V. (2011) A life of quality: informing the UN convention on the rights of persons with disabilities. *Journal of Disability Policy Studies* **22,** 66–82.

Keith K. D. & Bonham G. S. (2005) The use of quality of life data at the organization and systems level. *Journal of Intellectual Disability Research* **49,** 799–805.

Kober R. & Eggleton I. R. C. (2002) Factor stability of the Schalock and Keith (1993) Quality of Life Questionnaire. *Mental Retardation* **40,** 157–65.

Koh H. (2004) Different but equal: the human rights of persons with intellectual disabilities. *Faculty Scholarship Series* 1779. Available at: http://digitalcommons.law.yale.edu/fss_papers/1779 (retrieved 20 April 2011).

Kynlicka W. & Norman W. (1994) Return of the citizen: a survey of recent work on citizenship theory. *Ethics* **104,** 352–81.

van Loon J., van Hove G., Schalock R. L. & Claes C. (2008) *Personal Outcomes Scale*. Arduin Steichlich, Middleburg.

van Loon J., Claes C., Vandevelde S., van Hove G. & Schalock R. L. (2010) Assessing individual support needs to enhance personal outcomes. *Exceptionality: A Special Education Journal* **18,** 193–202.

Luckasson R., Coulter D. L., Polloway E. A., Reiss S., Schalock R. L., Snell M. E. *et al.* (1992) *Mental Retardation: Definition, Classification, and Systems of Supports*. American Association on Mental Retardation, Washington, DC.

Luckasson R., Borthwick-Duffy S., Buntix W. H. E., Coulter D. L., Craig E. M., Reeve A. *et al.* (2002) *Mental Retardation: Definition, Classification and Systems of Supports*. American Association on Mental Retardation, Washington, DC.

Matikka L. (2000) The right to be treated as human being: a Finnish perspective on quality of life. In: *Cross-Cultural Perspectives on Quality of Life* (eds K. D. Keith & R. L. Schalock), pp. 291–9. American Association on Mental Retardation, Washington, DC.

Navas P., Gómez L. E., Verdugo M. A. & Schalock R. L. (in press) Rights of people with intellectual disabilities: implications of the United Nations Convention. *Siglo Cero. Revista Española sobre Discapacidad Intelectual*.

Nirje B. (1985) The basis and logic of the normalization principle. *Australia and New Zealand Journal of Developmental Disabilities* **11,** 65–8.

Petry K., Maes B. & Vlaskamp C. (2005) Domains of quality of life of people with profound multiple disabilities: the perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities* **18,** 35–46.

Quinn G. (2009) Bringing the UN Convention on rights for persons with disabilities to life in Ireland. *British Journal of Learning Disabilities* **37,** 245–9.

Raphael D., Brown I., Renwick R., Cava M., Weir N. & Healthcote K. (1995) The quality of life of seniors living in the community: a conceptualization with implications for public health practice. *Canadian Journal of Public Health* **86,** 228–33.

Reinders H. S. (1999) *The limits of rights discourse*. Paper presented to Roundtable of the Special Interest Research Group (SIRG) on Ethics, International Association for the Scientific Study of Intellectual Disabilities. Doorn, The Netherlands, April 16–18.

Rioux M. & Carbert A. (2003) Human rights and disability: the international context. *GLADNET Collection* **316,** 1–14. Available at: http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1318&context=gladnetcollect&seiredir=1#search=%22Rioux+and+Carbert,+2003%22>.

Rodríguez A., Verdugo M. A. & Sánchez M. C. (2008) Calidad de vida familiar y apoyos para los progenitores de personas con discapacidad intelectual en proceso de envejecimiento. *Siglo Cero* **39,** 19–34.

Sabatello M. (2005) The human rights of persons with intellectual disabilities: different but equal. *Human Rights Quarterly* **27,** 737–49.

Samuel P. S., Rillota F. & Brown I. (2012) The development of family quality of life concepts and measures. *Journal of Intellectual Disability Research* **56,** 1–16.

Schalock R. L. (2004) The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research* **48,** 203–16.

Schalock R. L. & Verdugo M. A. (2012) *A Leadership Guide to Redefining Intellectual and Developmental Disabilities Organizations: Eight Successful Change Strategies*. Brookes Publishing Company, Baltimore, MD.

Schalock R. L., Gardner J. F. & Bradley V. J. (2007) *Quality of Life for People with Intellectual and Other Developmental Disabilities*. American Association on Intellectual and Developmental Disabilities, Washington, DC.

Schalock R. L., Verdugo M. A., Bonham G. S., Fantova F. & van Loon J. (2008) Enhancing personal outcomes: organizational strategies, guidelines, and examples. *Journal of Policy and Practice in Intellectual Disabilities* **5,** 18–28.

Schalock R. L., Keith K. D., Verdugo M. A. & Gómez L. E. (2010a) Quality of life model development and

use in the field of intellectual disability. In: *Quality of Life for People with Intellectual Disability* (ed. R. Kober), pp. 17–32. Springer, Dordrecht.

Schalock R. L., Borthwick-Duff S. A., Bradley V., Buntix W. H. E., Coulter D. L., Craig E. M. *et al.* (2010b) *Intellectual Disability. Definition, Classification, and Systems of Supports*, 11th edn. American Association on Intellectual and Developmental Disabilities, Washington, DC.

Schalock R. L., Verdugo M. A. & Gómez L. E. (2011) Evidence-based practices in the field of intellectual and developmental disabilities: an international consensus approach. *Evaluation and Program Planning* **34,** 273–82.

Stein M. & Lord J. (2009) Future prospects for the United Nations Convention on the Rights of Persons with Disabilities. In: *The UN Convention on the Rights of the Person with Disabilities: European and Scandinavian Perspectives* (eds O. M. Arnadóttir & G. Quinn), pp. 17–40. Martinus Nijhoff Publishers, Leiden/Boston.

Thompson J. R., Hughes C., Schalock R. L., Silverman W., Tassé M. J., Bryan B. *et al.* (2002) Integrating supports in assessment planning. *Mental Retardation* **40,** 309–405.

Thompson J. R., Bryant B. R., Campbell E. M., Craig E. M., Hughes C. M., Rotholz D. A. *et al.* (2004) *Supports Intensity Scale (SIS)*. American Association on Mental Retardation, Washington, DC.

United Nations (1948) *Universal Declaration of Human Rights*. Available at: http://www.un.org/en/documents/udhr/ (retrieved 17 November 2011).

United Nations (1975) *Declaration on the Rights of Disabled Persons*. Available at: http://www2.ohchr.org/english/law/res3447.htm (retrieved 10 June 2011).

United Nations (1993) *Standard Rules on the Equalization of Opportunities for Disabled Persons*. United Nations General Assembly, New York.

United Nations (2006) *Convention on the rights of persons with disabilities*. Available at: http://www.un.org/disabilities/convention/conventionfull.shtml (retrieved 10 June 2011).

Verdugo M. A., Schalock R. L., Keith K. & Stancliffe R. (2005) Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research* **49,** 707–17.

Verdugo M. A., Gómez L. E. & Arias B. (2007) La Escala INTEGRAL de calidad de vida: desarrollo y estudio preliminar de sus propiedades psicométricas. *Siglo Cero* **38,** 37–56.

Verdugo M. A., Arias B., Gómez L. E. & Schalock R. L. (2008a) *Formulari De l'Escala Gencat De Qualitat De Vida. Manual D'aplicació De l'Escala Gencat De Qualitat De Vida*. Departamento de Acción Social y Ciudadanía, Barcelona.

Verdugo M. A., Arias B., Gómez L. E. & Schalock R. L. (2008b) *Escala GENCAT. Informe Sobre La Creació D'una Escala Multidimensional Per Avaluar La Qualitat De Vida De Les Persones Usuàries Dels Serveis Socials A Catalunya*. Departamento de Acción Social y Ciudadanía, Barcelona.

Verdugo M. A., Gómez L. E., Arias B. & Schalock R. L. (2009a) *Escala Integral De Calidad De Vida*. CEPE, Madrid.

Verdugo M. A., Arias B., Gómez L. E. & Schalock R. L. (2009b) *Formulario De La Escala GENCAT De Calidad De Vida. Manual De Aplicación De La Escala GENCAT De Calidad De Vida*. Departamento de Acción Social y Ciudadanía, Barcelona.

Verdugo M. A., Arias B., Gómez L. E. & Schalock R. L. (2010a) Development of an objective instrument to assess quality of life in social services: reliability and validity in Spain. *International Journal of Clinical and Health Psychology* **10,** 105–23.

Verdugo M. A., Gómez L. E., Schalock R. L. & Arias B. (2010b) The Integral Quality of Life Scale: development, validation, and use. In: *Enhancing the Quality of Life of People with Intellectual Disabilities: From Theory to Practice* (ed. R. Kober), pp. 47–60. Springer, Dordrecht.

Walsh P., Erickson E., Bradley V., Moseley C. & Schalock R. L. (2006) *Supported Accommodation Services for People with Intellectual Disabilities: A Review of Models and Instruments Used to Measure Quality of Life in Various Settings*. National Disability Authority, Dublin.

Wang M., Schalock R. L., Verdugo M. A. & Jenaro C. (2010) Examining the factor structure and hierarchical nature of the quality of life construct. *American Journal on Intellectual and Developmental Disabilities* **115,** 218–33.

Werner S., Edwards M., Baum N., Brown I., Brown R. I. & Isaacs B. J. (2009) Family quality of life among families with a member who has an intellectual disability: an exploratory examination of key domains and dimensions of the revised FQOL Survey. *Journal of Intellectual Disability Research* **53,** 501–11.

Woodwill G., Renwick R., Brown I. & Raphael D. (1994) Being, belonging, becoming: an approach to the quality of life of persons with developmental disabilities. In: *Quality of Life for Persons with Disabilities: International Perspectives and Issues* (ed. D. Goode), pp. 57–74. Brookline, Cambridge, MA.

World Health Organization (2001) *International Classification of Functioning, Disability and Health (ICF)*. World Health Organization, Geneva.

Xu J., Wang M., Xiang Y. & Hu X. (2005) Quality of life for people with intellectual disabilities in China: a cross-culture perspectives study. *Journal of Intellectual Disabilities Research* **49,** 745–9.