The Concept of Quality of Life as Framework for Implementing the UNCRPD

Marco Lombardi* 1, Hanne Vandenbussche 1, Claudia Claes 2, Robert L. Schalock 3, Jessica De Maeyer* 4, and Stijn Vandeveld随之
*E-QUAL (Expertise Centre on Quality of Life), Department of Special Needs Education, University College Ghent, Ghent, Belgium; 1Department of Special Needs Education, Ghent University, Ghent, Belgium; and 2Hastings College, Hastings, NE

Abstract

Societal views on the rights of persons with disabilities have changed over the last few decades. Evolutions are reflected in international conventions, as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) developed to guide policies and practices. However, knowledge about the implementation of the Convention remains limited. In addition, another important concept, quality of life (QOL), has gained increasing prominence in the field of disability. This construct has evolved from a sensitivity notion to a measurable construct that provides a framework to assess organization and systems transformation.

The present research focused on the implementation of the UNCRPD articles to assist organizations and systems in the support provision practice. The study is a preliminary step toward implementation, looking for consensus on cross-culturally referenced indicators of QOL outcomes. The methodology chosen to find cross-cultural consensus was an international modified Delphi study to determine the relation and alignment among UN Convention articles, QOL domains, and measurable indicators. A total of 153 experts (self-advocates, professionals, family members, academics, and experts in law) from 11 countries evaluated the indicators. The Delphi study resulted in finding at least one indicator per convention article/QOL domain pairing. Thus, an international pool of cross-cultural indicators was identified to assist the implementation of the Convention articles. The study provides a first exploration of using the QOL framework to implement the UNCRPD. Although international indicators have been found per convention article/QOL pairing, challenges exist in regard to the further translation process into practice between policy and research, and vice versa. Efforts should continue to determine not only the relations among convention articles and measurable indicators, but also associated strategies for realizing the aim of the Convention in local policies and practices.

Keywords: disability, human rights, ID, quality of life, UNCRPD

Introduction and Overview

Societal views on the rights of persons with disabilities have changed over the last few decades and are reflected in specific international conventions that have been developed to guide policy and practice (Claes, Van Hove, van Loon, Vandeveld, & Schalock, 2009; Verdugo, Navas, Gomez, & Schalock, 2012).


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Correspondence: Marco Lombardi, Researcher and Lecturer, at E-QUAL (Expertise Centre on Quality of Life), Faculty of Education, Health and Social Work, Department of Special Needs Education, University College Ghent, Valentin Vsewoldeweg 1, 9000 Ghent, Belgium. Tel: +32 9 243 26 73; E-mail: marco.lombardi@hogent.be

As of March 2017, the Convention has been ratified by 172 nations (United Nations, 2017, http://indicators.ohchr.org/). The rights of people with disabilities are included in the general human right convention, but many reports have shown that vulnerable groups, including persons with disabilities, suffer double, triple, or even multiple levels of discrimination (Sabatello & Schulze, 2014). The disability community needs many years to persuade states that a specific convention was required to ensure the full enjoyment of human rights by persons with disabilities (MacKay, 2014). Although the need for the UNCRPD is clear, the translation of the Convention into practice has been difficult. Abstract characteristics of the human rights often make the translation into practice difficult (De Maeyer, Vandenbussche, Claes, & Reynaert, 2017). As Mittler underlined in 2015, there is a need in defining targets and timelines for implementation plans, especially with regard to articles on education, employment, independent living, and equality before the law. Furthermore, a shared perspective on the social model of disability, a greater commitment on the involvement of organizations of persons with disabilities and a focus on the early achievements are highly relevant for

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implementation, especially in the process of supports definition and provision. The necessity to bridge the gap between policy and practice is prominent (Cohen, Brown, & McLilley, 2015; Mittler, 2015).

In the field of disability, the construct of quality of life (QOL) has evolved from being a sensitizing notion to a measurable construct that might proffer a framework to assist organization and systems transformation (Claes, Van Hove, Van de Velde, van Loon, & Schalock, 2012; Karr, 2011; Schalock & Verdugo, 2015; Verdugo, Schalock, Keith, & Stanchfield, 2005). This article proposes that the QOL concept provides a framework for implementing the UNCRPD Articles and Sustainable Development Goals. Our focus is on implementation, defining it as: “a specified set of activities designed to put into practice an activity or program of known dimensions” (Fissen, Naom, Blase, & Friedman, 2005, p. 3), and not on evaluation, since progress is being made by the UN Scientific Committee on developing monitoring indicators (Mittler, personal communication, August 28, 2016).

The conceptual framework for this article, which identifies QOL domain referenced indicators matched to specific UNCRPD Articles, is based on the close alignment between QOL domains and the UNCRPD Articles (Claes, Vandenbussche, & Lombardi, 2016; Vandenbussche, Lombardi, van Loon, & Claes, 2016; Verdugo et al., 2012). By determining indicators for each QOL domain/article pairing, we aim to assist organizations and systems to implement the UN Convention Articles (WHO, 2011). We consider this study to be a preliminary exploration of possible indicators. The present research aspires to find consensus on a minimum of indicators to fulfill the connection for each QOL domain/article pairing to implement the Convention in the everyday life of persons with disabilities. When striving for the enjoyment of human rights, further steps should be taken to define and review specific support activities linked to each item and each indicator of the Convention to achieve QOL outcomes.

This article is divided into two sections. In the first section, we offer an overview of the UNCRPD and explain how the QOL concept provides a framework for assisting organizations and systems in implementing the UN Convention Articles. In the second section, we describe the procedures and results of an international Delphi Study that identified UN Convention Articles/QOL domain pairings. We conclude the article by discussing some of the challenges involved in determining cross-cultural indicators and the need for an interdisciplinary approach connecting several kinds of expertise.

The UNCRPD constituted a paradigm shift in the way people with disabilities are represented and participate in society. The Convention strives for social-political conditions in the implementation of basic rights related to equality, autonomy, nondiscrimination, participation, and inclusion (Sabatello & Schalock, 2014). As such, the Convention focuses on macro sociopolitical conditions, and the need for developing specific regulations and legislation related to people with disabilities (Shogren et al., 2009). These aspirations are translated into 50 UNCRPD-Articles. Articles 5–50 reflect the vision of the UNCRPD by focusing on specific contexts and conditions. For example, Article 19 Living independently and being included in the community strives for full inclusion and participation. The Convention strives for the equal rights of all persons with disabilities to live in the community and to have choices comparable with others. This encompasses a focus on accessibility and support by community services and facilities. Article 24, Education, ensures an inclusive education system at all levels and lifelong learning. Every person with a disability should be able to achieve his/her full potential and sense of dignity and self-worth. People with disabilities should be enabled to fully participate in a free society. Article 27, Work and Employment, focuses on just and favorable conditions of work, whereas Article 29, Participation in political and public life, underscores equal chances concerning public and political participation (United Nations, 2006). Table 1 presents an overview of the articles of the UNCRPD.

The UNCRPD delivers a mechanism for advancing practice and setting a policy agenda (Shogren & Turnbull, 2014). The UNCRPD strives for rehabilitation, independent living, education, health, work and employment, and other endeavors that enhance the rights of persons with disabilities. Although regulation is necessary, some authors argue that it is not enough to create social change to improve the QOL of people with disabilities; there is also a need for a framework to understand and evaluate human functioning and personal outcomes related to human rights (Karr, 2011; Verdugo et al., 2012). Such a framework postulates a way for political concepts to be translated into evidence-based practices (Schalock, Verdugo, & Gomez, 2011). Thus, the assumption underlying the present study is a specific need for a clear conceptual and application framework such as specified by the QOL concept to implement the UNCRPD Articles.

In reference to the QOL construct, four conceptualization principles that “have stood the test of time” (Schalock & Keith, 2016) are presented. First, QOL is multidimensional and influenced by personal and environmental factors and their interaction. Second, QOL has the same components for all people. Third, QOL has both subjective and objective components. Finally, QOL is enhanced by self-determination, resources, purpose in life, and a sense of belonging. Although many QOL conceptual models exist (e.g., Cummins, 1997; Felce & Perry, 1995; Schalock & Verdugo, 2002), several authors agree with those conceptualizing principles (see, e.g., Cummins, 2005; Schalock et al., 2002; Verdugo et al., 2005). The present study employed what is frequently called the Schalock and Verdugo conceptual model that involves eight QOL core domains (emotional wellbeing, physical well-being, material well-being, self-determination, personal development, interpersonal relations, social inclusion, and rights), which present the set of factors that constitute personal well-being. These represent the range over which the QOL concept extends and defines a life of quality in a cross-cultural perspective (Schalock & Keith, 2016). Eleven participating countries applied the same eight-domain conceptual model of QOL. Table 2 presents these eight domains (published in Schalock & Keith, 2016, p. 6).

Considerable research exists on the relationship between the construct of QOL and the UNCRPD. For example, Karr (2011) and Buntinx (2013) demonstrate the universality of QOL and express the usefulness for assessing improvements in the lives of persons with disabilities as underlined by the UNCRPD. In
TABLE 1

Summary of UNCRPD-articles

<table>
<thead>
<tr>
<th>Article number</th>
<th>Article definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Purpose</td>
</tr>
<tr>
<td>2</td>
<td>Definitions</td>
</tr>
<tr>
<td>3</td>
<td>General principles</td>
</tr>
<tr>
<td>4</td>
<td>General obligations</td>
</tr>
<tr>
<td>5</td>
<td>Equality and nondiscrimination</td>
</tr>
<tr>
<td>6</td>
<td>Women with disabilities</td>
</tr>
<tr>
<td>7</td>
<td>Children with disabilities</td>
</tr>
<tr>
<td>8</td>
<td>Awareness raising</td>
</tr>
<tr>
<td>9</td>
<td>Accessibility</td>
</tr>
<tr>
<td>10</td>
<td>Right to life</td>
</tr>
<tr>
<td>11</td>
<td>Situations of risk and humanitarian emergencies</td>
</tr>
<tr>
<td>12</td>
<td>Equal recognition before the law</td>
</tr>
<tr>
<td>13</td>
<td>Access to justice</td>
</tr>
<tr>
<td>14</td>
<td>Liberty and security of the person</td>
</tr>
<tr>
<td>15</td>
<td>Freedom from torture or cruel, inhuman, or degrading treatment or punishment</td>
</tr>
<tr>
<td>16</td>
<td>Freedom from exploitation, violence, and abuse</td>
</tr>
<tr>
<td>17</td>
<td>Protecting the integrity of the person</td>
</tr>
<tr>
<td>18</td>
<td>Liberty of movement and nationality</td>
</tr>
<tr>
<td>19</td>
<td>Living independently and being included in the community</td>
</tr>
<tr>
<td>20</td>
<td>Personal mobility</td>
</tr>
<tr>
<td>21</td>
<td>Freedom of expression and opinion, and access to information</td>
</tr>
<tr>
<td>22</td>
<td>Respect for privacy</td>
</tr>
<tr>
<td>23</td>
<td>Respect for home and the family</td>
</tr>
<tr>
<td>24</td>
<td>Education</td>
</tr>
<tr>
<td>25</td>
<td>Health</td>
</tr>
<tr>
<td>26</td>
<td>Habilitation and rehabilitation</td>
</tr>
<tr>
<td>27</td>
<td>Work and employment</td>
</tr>
<tr>
<td>28</td>
<td>Adequate standard of living and social protection</td>
</tr>
<tr>
<td>29</td>
<td>Participation in political and public life</td>
</tr>
<tr>
<td>30</td>
<td>Participation in cultural, recreation, leisure, and sport</td>
</tr>
<tr>
<td>31</td>
<td>Statistics and data collection</td>
</tr>
<tr>
<td>32–50</td>
<td>Articles 32–50 explain how countries which are bound by the Convention must give it full effect. They also explain the responsibility of countries to report to the United Nations Committee on the Rights of Persons with Disabilities on how they are putting the Convention into effect (Disability Action, 2016).</td>
</tr>
</tbody>
</table>

2012, Verdugo et al. discussed the close relation between the UNCRPD and the QOL construct, arguing that the QOL construct: (1) reflects the dynamics of personally desired subjective and objective conditions of life, (2) captures the essential domains of an individual’s life situation, including his/her human and legal rights, (3) links the general values reflected in social rights and the personal life of the individual, (4) can be the vehicle through which individual referenced equity, empowerment, life satisfaction, and equal opportunities can be understood and enhanced, and (5) is relevant to both public policy determination and a framework for outcomes evaluation. An important contribution comes from the acknowledgement that UNCRPD in itself is not a scientifically validated, but a political construct. Therefore, as suggested by Brown in 2017, there is a need to become practical and concise in terms of QOL recommendations for application in the field, for agency management and for policy development. For these reasons, we found the QOL construct a pragmatic and valid instrument to facilitate the transition from human rights to the practice of support provision and therefore to personal QOL outcomes.

Table 3 provides a summary of the close connection between the QOL construct and the UNCRPD-articles based on the work of Verdugo et al. (2012).

Methods: An International Delphi Study to Identify UN Article/QOL Domain Indicators

Overview and Initial Two Phases

The methodology to find cross-cultural consensus was an international modified Delphi study to determine the relation among UN Convention articles, QOL domains, and measurable indicators. The process entailed a structured research process where several research rounds were utilized to achieve consensus as in the Delphi methodology (Dalkey, Brown, & Cochran, 1969).

The procedure required a modification of the classical structure for Delphi studies, as two generative content phases had
<table>
<thead>
<tr>
<th>Domains of QOL</th>
<th>QOL indicators</th>
<th>UNCRPD articles (directly related to QOL indicators)</th>
<th>UNCRPD articles (indirectly related to QOL indicators)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal development</td>
<td>Education status</td>
<td>Article 24</td>
<td>Article 27</td>
</tr>
<tr>
<td></td>
<td>Personal skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Adaptive behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-determination</td>
<td>Choices/decisions</td>
<td>Article 14</td>
<td>Article 9</td>
</tr>
<tr>
<td></td>
<td>Autonomy</td>
<td>Article 19</td>
<td>Article 12</td>
</tr>
<tr>
<td></td>
<td>Personal control</td>
<td>Article 21</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Personal goals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal relations</td>
<td>Social networks</td>
<td>Article 23</td>
<td>Article 30</td>
</tr>
<tr>
<td></td>
<td>Friendships</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social inclusion</td>
<td>Community</td>
<td>Article 8</td>
<td>Article 19</td>
</tr>
<tr>
<td></td>
<td>integration/participation</td>
<td>Article 9</td>
<td>Article 21</td>
</tr>
<tr>
<td></td>
<td>Community roles</td>
<td>Article 18</td>
<td>Article 24</td>
</tr>
<tr>
<td></td>
<td>Supports</td>
<td>Article 20</td>
<td>Article 27</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Article 27</td>
<td>Article 29</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Article 29</td>
<td>Article 30</td>
</tr>
<tr>
<td>Rights</td>
<td>Human (respect, dignity, equality)</td>
<td>Article 5</td>
<td>Article 14</td>
</tr>
<tr>
<td></td>
<td>Legal (legal access, due process)</td>
<td>Article 6</td>
<td>Article 16</td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>Safety and security</td>
<td>Article 16</td>
<td>Article 23</td>
</tr>
<tr>
<td></td>
<td>Positive experiences</td>
<td>Article 17</td>
<td>Article 25</td>
</tr>
<tr>
<td></td>
<td>Contentment</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Lack of stress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical well-being</td>
<td>Health and nutrition status</td>
<td>Article 16</td>
<td>Article 17</td>
</tr>
<tr>
<td></td>
<td>Recreation</td>
<td>Article 25</td>
<td></td>
</tr>
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<td></td>
<td>Leisure</td>
<td>Article 26</td>
<td></td>
</tr>
<tr>
<td>Material well-being</td>
<td>Financial status</td>
<td>Article 28</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Employment status</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Housing status</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Possessions</td>
<td></td>
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</tr>
</tbody>
</table>

been already conducted (Brown, 1968; Keeney, Hasson, & Mckenna, 2001; Landeta, 2006). The main feature of the modified Delphi technique is an abbreviated initiation process reflected in the first two phases of the present study. The authors determined the first-round agenda, whereas in a classical Delphi study, the agenda arises from the participants’ responses in the first round (Landeta, 2006). The advantages of using a modified Delphi method are that it (1) typically improves the initial round response rate, (2) provides a solid grounding in previously developed work, and (3) saves time by reducing the number of rounds required (Campbell, Cantrill, & Roberts, 2000).

Two initial phases of the current study that were conducted in Belgium and the Netherlands are described in detail in Vandenbussche et al. (2016). The purpose of these initial phases was to: (1) align the UNCRPD articles to the eight core QOL domains, (2) operationalize the articles in reference to measurable QOL domains and indicators, and (3) reach initial consensus on those indicators that could become the basis for policies and practices that enhance human rights and QOL. All the
indicators were generated using a participatory approach. Focus groups, expert panels, and a Delphi study with people with disabilities (including ID/DD) (experts by experience) were used to collect the initial pool of indicators. At this phase, an indicator was defined as an outcome that can be used to measure the quantity or quality of the results achieved when the UN Convention Article or strategy is implemented. For each indicator, the intent of the UN Convention Article and the fitting of the indicator to the respective QOL domain were evaluated. The QOL indicators were considered and generated from an outcome perspective, which aligns with the notion of their assessment and multiple uses for reporting, quality improvement, and research (Brown, 2017; Verdugo & Schalock, 2014). Results of these two initial phases led to a pool of indicators where the experts involved found consensus about. Consequently, 85 indicators (Table 4) were used as a basis for the presently described study to determine cross-cultural perspectives.

Panel Member Selection

The members of this study were recruited through the American Association on Intellectual and Developmental Disabilities (AAIDD) international Special Interest Group (SIG). The authors of the study invited the participants of the SIG to participate in the research during the AAIDD meeting of 2013 in Charlotte, North Carolina. Eleven individuals representing 11 countries (Brazil, Canada, Catalonia, Czech Republic, Germany, Italy, Israel, Portugal, Spain, Taiwan, and the United States) volunteered to participate in the study, and for each country, a coordinator was chosen. The communications and the coordination process were supervised by the authors of the study in Ghent, Belgium. Email was the most common means of communicating with the coordinators.

Participant recruiting and sample composition. Each coordinator was responsible to recruit approximately 15 participants. The respondents were balanced in national groups concerning their expertise by being a member of one of the following categories: self-advocates (individuals with a disability, regardless of age and diagnosis, as ID, DD, aging/dementia or severe mental/behavioral/physical/sensorial health impairments, n = 47), being an important relative of a self-advocate (n = 35), working as a professional with people with disabilities (n = 31), being a scholar researching the concept of QOL (n = 28), and being familiar with jurisdiction and the concept of QOL with people with disabilities (n = 11). The 85 indicators from the two preliminary phases were presented to a group of 153 individuals. Respondents were supported by their national coordinators or professional/natural carer to participate.

Language and culture. The questionnaires were administered in English, or when it was not possible a back-translation process, conducted by a native speaker, was completed for each of the eight languages (Portuguese, Spanish both Catalan and Castilian, Czech, German, Italian, Hebrew, and Chinese). The questionnaires were filled out, depending on the availability of means of the respondents, in paper version or using an online platform (Limesurvey, 2015).

Delphi Process

The indicators were presented to the participants in two rounds. About 6 weeks of response time was allocated for each round. The coordinators distributed the translated or English version to the participants and they personally collected all the results. Once the full sample was collected, the national coordinator sent the results to the authors by email or by filling out the online questionnaire. Reminders were sent to the coordinators of the national groups, after the deadline, every two weeks. Panelists received up to three mailings as a reminder to complete the survey.

Standards for Consensus

Delphi-related literature presents arbitrary and unclear standards for consensus (Diamond et al., 2014). In the present study, the median with the interquartile range and the spread of the responses were used as criteria (Gordon, 1994; Hung, Atschuld, & Lee, 2008; Keeny et al., 2006; Sandford & Hsu, 2007). Seventy-five percent was the lowest cut-off point for consensus chosen, as this aligns with the frequently used standard for consensus in the literature (Mitchell, 1991). All the results from the international sample were imported in an SPSS file and analyzed by the authors. The median response and interquartile range for each item were computed. Consensus was reached when at least 75% of the respondents thought the indicator fitted the article (score 4-5-6) and the median response was 5 or 6 (on a 6-point Likert scale). Following literature suggestions, when consensus was reached, the Delphi study rounds were terminated (Diamond et al., 2014).

Round 1 of the International Delphi Study

Determining consensus. The respondents were asked to indicate on a Likert scale from 1 (strongly disagree) to 6 (strongly agree) how well each indicator fitted the intent of the respective UN Convention Article. In all phases of the study, an indicator was defined as an outcome that can be used to measure the quantity or quality of the results achieved when the respective UN Convention Article is implemented. Respondents had the opportunity to add new indicators when they assumed some were missing in the list of indicators presented. Sometimes participants used this open question to add other remarks or ideas about the indicators (e.g., a suggestion about placing the respective indicator under another article).

Results. In Round 1, we had a response rate of 100% (i.e., all the 153 respondents). After the first round, 67 indicators were retrieved with an agreement of at least 75%. For 18 indicators, it was not possible to find consensus.
### TABLE 4

Relationship between the UNCRPD articles, QOL-domains, and indicators

<table>
<thead>
<tr>
<th>Article</th>
<th>QOL domain</th>
<th>UN Convention Articles, QOL domains, and indicators</th>
</tr>
</thead>
</table>
| 24. Education                                                          | Personal development | • Personal skills  
                                                                                                                  |                                                               |
|                                                                        |                   | • Educational setting  
                                                                                                                  |                                                               |
|                                                                        |                   | • Lifelong learning  
                                                                                                                  |                                                               |
| 14. Liberty and security of the person                                 | Self-determination | • Freedom of movement  
                                                                                                                  |                                                               |
|                                                                        |                   | • Freedom of choice  
                                                                                                                  |                                                               |
|                                                                        |                   | • Personal autonomy  
                                                                                                                  |                                                               |
|                                                                        |                   | • Safe environment  
                                                                                                                  |                                                               |
|                                                                        |                   | • Personal control  
                                                                                                                  |                                                               |
|                                                                        |                   | • The realization of personal goals  
                                                                                                                  |                                                               |
|                                                                        |                   | • Secure environment  
                                                                                                                  |                                                               |
| 21. Freedom of expression and opinion and access to information        | Self-determination | • The level of understanding the information  
                                                                                                                  |                                                               |
|                                                                        |                   | • The use of information  
                                                                                                                  |                                                               |
|                                                                        |                   | • Opportunities to express opinion  
                                                                                                                  |                                                               |
|                                                                        |                   | • Access to information  
                                                                                                                  |                                                               |
| 23. Respect for home and family                                       | Interpersonal relations | • Person has the right to set up his own family  
                                                                                                                  |                                                               |
|                                                                        |                   | • Person has the right to be a parent  
                                                                                                                  |                                                               |
| 30. Participation in culture life, recreation and sport                | Interpersonal relations | • Person participates in cultural events (e.g., concerts, theater, and museums)  
                                                                                                                  |                                                               |
|                                                                        |                   | • Person participates in recreational or leisure events (e.g., hobbies and community activity clubs)  
                                                                                                                  |                                                               |
|                                                                        |                   | • Person has the opportunity to travel  
                                                                                                                  |                                                               |
| 8. Awareness – raising                                                 | Social inclusion  | • Acts of awareness (e.g., projects, campaigns, ...) to increase social inclusion  
                                                                                                                  |                                                               |
| 9. Accessibility                                                       | Social inclusion  | • Presence in cultural events  
                                                                                                                  |                                                               |
|                                                                        |                   | • Presence in recreational or Leisure events  
                                                                                                                  |                                                               |
| 18. Liberty of movement                                               | Social inclusion  | • Physical access on community streets  
                                                                                                                  |                                                               |
|                                                                        |                   | • Physical access to public transportation  
                                                                                                                  |                                                               |
|                                                                        |                   | • Physical access in community buildings  
                                                                                                                  |                                                               |
| 19. Living independently and being included in the community          | Social inclusion  | • Living in a home with minimum intrusion from others  
                                                                                                                  |                                                               |
|                                                                        |                   | • Home ownership  
                                                                                                                  |                                                               |
|                                                                        |                   | • Rental agreement  
                                                                                                                  |                                                               |
| 20. Personal mobility                                                  | Social inclusion  | • A way to be personally mobile (e.g., by walking, using a wheelchair, or using crutches)  
                                                                                                                  |                                                               |
|                                                                        |                   | • A way to transport across environments (e.g., a car, a bike, and public transportation)  
                                                                                                                  |                                                               |
| 29. Participation in political and public life                        | Social inclusion  | • Membership on boards  
                                                                                                                  |                                                               |
|                                                                        |                   | • Running for public office  
                                                                                                                  |                                                               |
| 30. Participation in cultural life                                     | Social inclusion  | • Presence at concerts  
                                                                                                                  |                                                               |
|                                                                        |                   | • Presence in movie theaters  
                                                                                                                  |                                                               |
|                                                                        |                   | • Presence in museum visits  
                                                                                                                  |                                                               |
|                                                                        |                   | • Person has the opportunity to travel  
                                                                                                                  |                                                               |
| 5. Equality and non-discrimination                                     | Rights           | • Presence in the community  
                                                                                                                  |                                                               |
|                                                                        |                   | • Engages in open employment  
                                                                                                                  |                                                               |
|                                                                        |                   | • Person participates in community activities  
                                                                                                                  |                                                               |
|                                                                        |                   | • Person dates with persons of choice  
                                                                                                                  |                                                               |
|                                                                        |                   | • Person is intimate with persons of choice  
                                                                                                                  |                                                               |
| 6. Women with disabilities                                            | Rights           | • Receives personalized Supports  
                                                                                                                  |                                                               |
|                                                                        |                   | • Person participates in community life  
                                                                                                                  |                                                               |
|                                                                        |                   | • Person receives personalized supports  
                                                                                                                  |                                                               |
|                                                                        |                   | • Person has adequate financial resources  
                                                                                                                  |                                                               |

(Continues)
### Table 4
Continued

<table>
<thead>
<tr>
<th>Article</th>
<th>QOL domain</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. Children with disabilities</td>
<td>Rights</td>
<td>• Receives post-natal care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Receives supports to enhance personal growth and development</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Involved in educational program</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Provided adequate medical care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Included in their family</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Included in the community</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Make choices about contraception</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Person makes choices about end of life decisions</td>
</tr>
<tr>
<td>10. Right to life</td>
<td>Rights</td>
<td>• Supplying immigrants with a disability with sufficient legal, financial, and social supports</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Access to healthcare</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Accesses legal services</td>
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<tr>
<td></td>
<td></td>
<td>• Receives due process</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Is considered to be legally competent</td>
</tr>
<tr>
<td>11. Situations of risk and humanitarian emergencies</td>
<td>Rights</td>
<td>• Has a defense attorney</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Participates in one’s defense</td>
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<tr>
<td></td>
<td></td>
<td>• Are adjudicated by a magistrate, a judge, or a jury</td>
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<td></td>
<td></td>
<td>• If guilty, receives a fair sentence</td>
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<tr>
<td></td>
<td></td>
<td>• Person understands the charge</td>
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<tr>
<td></td>
<td></td>
<td>• Personal injuries caused by others (e.g., torture and maiming)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• If guilty, the punishment received is commensurate to that received by others</td>
</tr>
<tr>
<td>13. Access to justice</td>
<td>Rights</td>
<td>• Control over personal areas (e.g., bedroom, bathroom, home, or dwelling)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Personal access to communication (e.g., letters, e-mails, and phone)</td>
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<tr>
<td>14. Freedom from cruel or unusual punishment</td>
<td>Rights</td>
<td>• Lives in a safe environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Is not exploited by others (e.g., sexually, financially, and socially)</td>
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<tr>
<td></td>
<td></td>
<td>• Is not abused by others (e.g., physical and emotional)</td>
</tr>
<tr>
<td>15. Freedom from exploitation, violence and abuse</td>
<td>Emotional well-being</td>
<td>• Experiences respect</td>
</tr>
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<td></td>
<td></td>
<td>• Experiences dignity</td>
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<td></td>
<td></td>
<td>• Experiences equality</td>
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<td></td>
<td></td>
<td>• Physical status</td>
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<td></td>
<td></td>
<td>• Nutritional status</td>
</tr>
<tr>
<td>22. Respect for privacy</td>
<td>Rights</td>
<td>• Chronic conditions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Medical intervention if needed</td>
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<tr>
<td></td>
<td></td>
<td>• Emotional intervention if needed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Receives therapy (e.g., physical, occupational, and speech) appropriate to the person’s condition</td>
</tr>
<tr>
<td>25. Health</td>
<td>Physical well-being</td>
<td>• Full-time paid employment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Part-time paid employment</td>
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<tr>
<td></td>
<td></td>
<td>• Job training programs</td>
</tr>
<tr>
<td>26. Habilitation and Rehabilitation</td>
<td>Physical well-being</td>
<td>• Annual income covers basic living expenses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Annual income allows for discretionary spending</td>
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<td></td>
<td></td>
<td>• Adequate housing</td>
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<td></td>
<td></td>
<td>• Unemployment insurance</td>
</tr>
<tr>
<td>27. Work and employment</td>
<td>Material well-being</td>
<td>• Public assistance if necessary</td>
</tr>
<tr>
<td>28. Adequate standard of living and social protection</td>
<td>Material well-being</td>
<td></td>
</tr>
</tbody>
</table>

7
Round 2 of the International Delphi Study

Determining consensus. After Round 1, the authors created 153 feedback reports (one per participant) in the original language (when requested) and asked the coordinators per country to distribute them among the previous respondents. In the feedback reports, we presented the 18 indicators we could not find consensus on in Round 1. To facilitate comprehension of the actual level of disagreement, the data regarding the item results were presented using a bar chart with the overall percentages of group choices. Respondents were requested to reconsider their first answer and had the opportunity to add qualitative information about their decision to keep their initial answer or to change.

Results. In Round 2, we received responses from 90 respondents. Dropout rates appear frequently in international Delphi studies and in Delphi with a large number of participants (Hung et al., 2008). Respondents reached 75% or better agreement on each of the 18 indicators reevaluated. After conducting two rounds, overall consensus was found and the Delphi process ended. The 18 indicators were added to the 67 from Round 1, making a total of 85 indicators, where 75% or better agreement was found. UN Convention Articles/QOL pairings are presented in Table 4.

Discussion

In summary, the Delphi procedures resulted in finding at least one indicator per UN Article/QOL domain pairing. As a result, an international set of indicators is emerging that can be used to assist organizations and systems to implement UNCRPD requirements. However, there are a number of challenges and issues that need to be discussed in reference to determining cross-cultural indicators.

Challenges in Determining Cross-Cultural Indicators

As Mittler (2015) states, there is a need of a major paradigm shift not only in thoughts, but also in actions directed to the translation of aspiration to achievement. Fundamental to this shift is the full and equal involvement of persons with disabilities as principal stakeholders and change agents at every stage of the process. The two round Delphi study described above resulted in 85 measurable indicators giving important guidance to implement the UNCRPD cross culturally. However, the procedures and results described above illustrate six challenges to both policymakers and researchers: (1) the indicators are not always measurable or objective; (2) indicators with ethical connotations are challenging when approached from different cultural perspectives; (3) an indicator does not always represent a full article; (4) the definition of an indicator impacts the score; (5) indicators identified are not exhaustive; and (6) indicators might fit more than one article.

Although the indicators include a valuable list of outcomes to move on to the further implementation of the UNCRPD, some of the presented indicators (Table 4) will need more refinement. More specifically, when we analyzed the qualitative information retrieved from the participants, the representation of the eight QOL domains used as an analytic framework, two domains were under-represented in the number of indicators identified: Personal Development and Interpersonal Relations. In reference to Personal Development, the difficulty relates to how to incorporate supports into standards of living and full community or societal participation. For Interpersonal Relations, challenges concern distinguishing between quantity and quality. For example, one of the indicators of the quality of interpersonal relations is the social network of the person. This finding is supported by social network's literature where two perspectives emerge to understand and measure the concept (Forrester-Jones et al., 2006; Lunsky, 2006): a structural one (e.g., in terms of size and frequency) and a functional one (e.g., in terms of perceived emotional and practical support).

When we analyzed the representativeness of the UN articles, we found some challenges with Articles 5, 6, 9, 14, and 30. Finding consensus turned out to be harder on these articles. Possible explanations were extracted from qualitative information provided by the respondents. For example:

- Article 5 (Equality and non-discrimination). Issues about the measurability of indicators were raised. The efforts to make concrete indicators led to concerns whether those indicators could still belong to the broad scope of the respective article.
- Article 6 (Women with disabilities). Numerous cultural differences should be considered here. In some countries, a number of participants claimed the focus on "women" was not clear enough. Other countries do not recognize the need for a special article for women with disabilities.
- Article 9 (Accessibility). Accessibility should focus on a broad scope of areas such as public spaces and public buildings, but also having a passport and being able to cross borders. Respondents emphasized the need for awareness that presence may be affected by several other factors than accessibility.
- Article 14 (Liberty and security of the person). Some participants expressed worries about the concepts "liberty" and "secure," which they meant to be too vague. Some also were concerned that the use of these terms could lead to a paternalistic effect, as such moving us away from the head objective of implementing the UNCRPD.
- Article 30 (Participation in cultural life). There was concern about the quantity and quality of certain concepts. For example, if we consider friendship, the number of friends is less important than the quality of friendship. But the latter is not easy to measure, whereas the former is. Another remark concerned individual choice; to participate in cultural events implies a certain fascination or interest.

In summary, all the presented indicators listed in Table 4 reached a good level of agreement, however some of the qualitative comments suggest to pay special attention when using an indicator as representing a full article.

A Transdisciplinary Approach Involving Several Kinds of Expertise

The movement from traditional discipline-based research strategies to a transdisciplinary approach to research that involves
policymakers, researchers, practitioners, and individuals with ID and their families working jointly to produce both scientific understanding and societal applications is mentioned as one important trend in the field of ID (Shogren et al., 2009). But also within the broader scope of disability studies, bringing in the voice of self-advocates and family members is considered of ultimate importance (Goodley, 2011).

Sabatello and Schulze (2014) argued that how policymakers and professionals think about "disability" has a powerful effect on policy and practice. Do they use a human development approach, risking a return to the "medical model" that has pathologized individuals with disabilities and denied equalization? Or does their human development approach acknowledge that the individuals have capacities, and that policies and practices must augment these capacities as a means for equalization (Shogren & Turnbull, 2014)? Sabatello and Schulze (2014) emphasize the importance to work from "below" and involve people with disabilities themselves. This is also one of the recommendations from the World Report on Disabilities (WHO, 2011). Karr (2011) claims that social policies, such as the UNCRPD, are based on tenets of respect and empowerment of persons with disabilities. From that point of view, it is critical to use the input of persons with disabilities themselves (Karr, 2011).

In this study, the empowering and emancipating view was a strong drive and the researchers requested to bring in the perspectives of self-advocates next to that of family members, practitioners, and academics. The voice of self-advocates is also considered to be of central importance to translate research and training into practice—these programs will require national and locally co-ordinated effort, which includes the central involvement of people with disabilities (Cohen et al., 2015).

In this study, a first exploratory step in finding indicators to measure the operationalization of the UNCRPD by using a QOL framework has been taken. Representatives from some of the countries suggested to add extra indicators that could not be investigated in the scope of this research, for example, obtaining necessary supports to have and keep children, the right to not being sterilized against one's will, equal wages, and so forth. It would be valuable to explore other important indicators nationally or internationally in further research.

Some respondents discussed the validity of the articles of the UNCRPD being critical instead of determining specific indicators matching the respective articles. As mentioned before, it was difficult to find consensus for the article about women with disabilities (Article 13, United Nations, 2006). Some representatives from particular cultures consider this article as unnecessary; other respondents want to stress the importance of the fact we are talking about women here (not "persons" as in the description of the indicators).

Challenges remain in relation to how policy can be developed, or in relation to how human rights may be implemented in terms of QOL. For this reason it is critical, as stated by Brown (2017), to recognize that this can only work effectively if there is appropriate communication between those with disabilities, their primary carers, managers of agencies, and policymakers. The subjective perspective of importance and value of a specific article or indicator has to be underpinned by the involvement of the person in the process. Therefore, the importance of the articles and related QOL domains is relative to the respective disability policy, the agency’s mission, and the individual’s goals.

Limitations

The study is not without limitations. During the Delphi process, 61 respondents dropped out in the second round. Sometimes a lack of time was given as a reason why the second round was no longer an option. Other reasons for dropout were that some respondents expressed that they found it unnecessary to answer the questions a second time, as their opinion was already given. They gave additional remarks during the first round and requested some answers before they could move on with the questionnaire. Sometimes no reasons were given for not participating to the second round. The problems related to recruitment, panel composition and size, and participant dropout are common in the Delphi technique. Locating participants in each country and the uneven representation of samples per country are specific to the study and in other international studies (Huang et al., 2008). For this reason, the data presented should be considered as representative of the cultures involved in the study. Further research should focus on providing a global perspective by involving every country that ratified the convention. Some participants reported the questionnaire to be difficult and technical to fill out, especially for people with ID. Supports were provided by the natural and professional supporters, but sometimes were still insufficient (e.g., use of pictures may have been useful).

Another limitation considers measurability of UNCRPD related issues. Although there was consensus on the indicators, further work is required in moving beyond indicators to measurable items because some of the indicators identified are not measurable or objective in their current form, and some have ethical connotations that complicate their measurement.

As is debated widely in the QOL literature, relevant and important perceptions of people with ID/DD and their allies are not measurable in a quantitative way. For this reason the study used modified techniques and qualitative and quantitative methods. Moreover, using these qualitative techniques and methods does not automatically lead to not-objective data and further research may be needed in future to have the voices of self-advocates more present and validly represented in research (Brown, 2017).

Conclusion

In this article, we investigated if QOL provides a framework to implement the UN Convention cross culturally. This study represents a first exploration to obtain measurable indicators of the UN Convention Articles within a QOL framework. By using a Delphi methodology, multiple indicators for each Article/QOL domain pairing were identified by a group of international respondents. One of the recommendations of the World Report on Disability is to "adopt a national disability strategy and plan of action" (WHO, 2011), taking into account the already available policies and strategies (e.g., Council of Australian...
Governments, 2012). The finding of indicators with cross-culturally defined consensus is necessary to support national policies to find strategies to meet this recommendation. The cross-culturally shared framework of indicators presented in this article provides a new ground for the implementation of the UNCPRD. Efforts should continue to determine not only the relations among UN Convention Articles and measurable indicators, but also associated strategies for realizing the UN Convention in local policies and practices. When this is done, as Mittler (2015) suggested, the human rights framework reflected in the UNCPRD and the principles embedded in the concept of QOL will be translated into both policy and practice.

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References


