

What do stakeholders understand by self-determination? Consensus for its evaluation

Abstract

Advances in international studies on self-determination point out the need for continuous efforts to deepen its understanding and implications. The aim of this study is to obtain a comprehensive pool of items to operationalize the self-determination construct that serves as a starting point towards a valid instrument based on the reports of others. We conducted a Delphi study of three rounds involving three panels of experts: ten professionals, five people with intellectual disability and six relatives of people with intellectual disability. Data analysis required both qualitative and quantitative methods. The initial pool of 131 items was refined through the different rounds to a final set composed of 115—some were removed and new ones were added. Content-based evidence is provided. In this study, we generated a potential valid pool of items to develop a new measurement tool based on the latest advances on the self-determination theoretical framework. The implications for future research focus on strengthening the knowledge of self-determination.

Keywords: content validity, experts, Delphi study, assessment, consensus, self-determination

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Introduction

The last few years have been marked by many changes and shifts towards improving the functioning, self-determination and quality of life of people with intellectual disability. These changes have clearly been influenced by the new paradigm of supports (Schalock et al., 2010; Thompson et al., 2009) and quality of life (Schalock & Verdugo, 2013), which are considered key elements for people with disabilities. Similarly, the increased emphasis on self-determination, and the self-advocacy movements, are fundamental pillars in the demands of people with disabilities, who want to be the decision-makers and the primary causal agents of their own lives (Wehmeyer, 2004, 2011; Wehmeyer & Abery, 2013).

There has been considerable progress in international studies on self-determination, ranging from proposals of theoretical models (Shogren, Wehmeyer, Palmer et al., 2015; Wehmeyer, Abery, Mithaugm, & Stancliffe, 2003; Wehmeyer, 1999) or the analysis of relevant predictive variables (Nota, Ferrari, Soresi, & Wehmeyer, 2007; Shogren, Wehmeyer, Palmer, & Paek, 2013; Vicente et al., 2017; Wehmeyer & Garner, 2003), to the development of assessment and intervention tools designed to enhance and promote the development and expression of self-determination (Abery, Elkin, Smith, Springborg, & Stancliffe, 2000; Mithaug, Wehmeyer, Agran, Martin, & Palmer, 1998; Shogren, Wehmeyer, Little, et al., 2015; Verdugo, Vicente, Fernández, Gómez-Vela, & Guillén, 2015; Wehmeyer & Kelchner, 1995). Many advances have been made in improving the understanding of this complex construct since almost two decades ago, when Wehmeyer (1999) first proposed the functional model of self-determination, and it continues to be refined and reshaped (Shogren, Wehmeyer, Palmer et al., 2015).

All definitions emanating from this original model agree that the most important factor is that a person acts as the causal agent in their own life. One of the first definitions

understood self-determination as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (Wehmeyer, 1996, p. 24). The essence remains the same in the reconceptualization of the traditional model: self-determination is a “dispositional characteristic manifested as acting as the causal agent in one’s life” (Shogren, Wehmeyer, Palmer et al., 2015, p. 258).

According to the functional model (Wehmeyer, 1999, 2005), self-determination is identified through four essential characteristics: autonomy, self-regulation, psychological empowerment, and self-realization. These characteristics are reflected in behavior through the development and acquisition of a broader set of essential components (e.g. planning, self-assessment, locus of control).

Advances in the theoretical framework have been accompanied in different countries by instruments based on the proposed models (Soresi & Nota, 2007; Verdugo, Vicente, Fernández et al., 2015; Wehmeyer & Kelchner, 1995). One of these questionnaires, aligned with the functional model of self-determination, is The Arc’s Self-Determination Scale (Wehmeyer & Kelchner, 1995). In Spain, researchers have used this instrument as a point of reference to develop: (a) the scale of Personal Self-Determination (Wehmeyer, Peralta, Zulueta, González-Torres, & Sobrino, 2006), whose Spanish translation is an accurate expression of the original version; and (b) the ARC-INICO Scale (Verdugo, Vicente, Fernández et al., 2015; Verdugo, Vicente, Gómez-Vela et al., 2015), which aligns in structure with the functional model, but differs in format and content. Similar tools have also been developed in Italy, such as a self-determination assessment questionnaire contained within a larger battery of items encompassing other constructs: ASTRID (Soresi & Nota, 2007).

There is currently debate around how to delimit and validate the dimensions that operationalize self-determination. Shogren, Wehmeyer, Palmer et al. (2015) have recently

adjusted the initial dimensions, and have proposed the Causal Agency Theory as a reconceptualization of the functional model. They suggest three new essential characteristics of self-determined actions: (a) volitional (i.e. autonomous and self-initiated actions); (b) agentic (i.e. self-regulation, self-direction and pathways thinking); and (c) action-control beliefs (i.e. psychological empowerment, self-realization, control expectancy, agency beliefs, and causality beliefs). These characteristics do not replace the earlier four-dimension concept, but include new dimensions and clarify others (Table 1).

< < Insert Table 1 about here > >

In recent years there have also been initiatives to develop new instruments. The first instrument to assess the three new essential characteristics was the *Self-Determination Inventory: Student Report* (SDI:SR) (Shogren, Wehmeyer, Little et al., 2015), which is being adapted and validated for application in Spain by Mumbardó-Adam, Guàrdia-Olmos, Giné, Shogren and Vicente (in press). As with most of the instruments developed previously, this tool is a self-report measure for young people (from 13 to 22 years old) with or without intellectual disability.

While past research has started to study the new self-determination model and associated questionnaires, it is still necessary to increase our knowledge. For example, most scales which assess self-determination (Hoffman, Field, & Sawilowski, 2004; Shogren, Wehmeyer, Little et al., 2015; Verdugo, Vicente, Fernández et al., 2015; Wehmeyer & Kelchner, 1995) focus on adolescence (from 11 to 20) and school-age (student assessment) populations. These measures also focus on self-reporting, and do not take into account important information that might be gathered from third-parties (e.g. caregivers or teachers).

It is important to evaluate a questionnaire with an adult population given that self-determination may have a significant impact on post-school and adult outcomes (Shogren & Shaw, 2016; Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013), such as integrated employment or access to benefits (Martorell, Gutierrez-Recacha, Pereda, & Ayuso-Mateos, 2008; Shogren, Wehmeher, Palmer, Rifenbark, & Little, 2015). The transition from adolescence to young adulthood is a critical life stage for all individuals (Neece, Kraemer, & Blacher, 2009), including for people with intellectual disability and this transition is a time of opportunities but also of new risks and stress (Blacher, 200; Gallivan-Fenlon, 1994; Thorin & Irvin, 1992). Given the importance of this time of life and the role that self-determination may play in successful transition, it is important to develop assessment tools.

The aim of this study is to operationalize the reconceptualized construct of self-determination (Shogren, Wehmeyer, Palmer et al., 2015), with a view to reaching a consensus on a pool of items with which to assess self-determination in individuals with intellectual disability through the perspective of a third person (i.e. reports of others). This study focuses on the critical period from adolescence to early adulthood that involves the transition process (educational, employment or lifestyle), but before premature aging signs start to appear (Stax, Luciano, Dunn, & Quevedo, 2010). The consensus provided by stakeholders (academics; professionals; people with intellectual disability, and their relatives) will expand our knowledge of the construct of self-determination and its current frame of reference with a Delphi study that identifies observable indicators (i.e. items) for each dimension of the model.

Method

Participants

The study included 21 participants divided into three panels of experts: professionals ($n= 10$), people with intellectual disability ($n= 5$) and relatives of people with intellectual disability ($n= 6$). The experts were selected using an incidental sampling procedure. We contacted eight entities and organizations in Spain to request the participation of professionals, family members and people with intellectual disabilities. These organizations had very different characteristics (e.g. schools, occupational centers, special centers of employment, universities, fragile X and Down syndrome associations) to target a wide variety of perspectives. Once contact was established, we requested the voluntary participation of people who met the requirements for each panel. Participating in the family panel had the unique condition of being a parent of a child with ID. Parents were chosen as experts because self-determination emerges at an early age, when children and adolescents start to learn skills and develop attitudes and beliefs that enable them to be causal agents in their lives (Wehmeyer, 2014). Parents may have a more global vision from their wide range of experiences with their child, which may allow for a more complete perception of disability and self-determination across a lifespan.

Professionals had to meet the following requirements for the panel: (a) at least two years of experience with intellectual disability; (b) currently working in the field; and (c) a deep knowledge of the new support paradigm and concepts such as quality of life and self-determination. For the panel composed of people with intellectual disabilities, we asked the Huesca Down Syndrome Association to request volunteers who were young adults over 18 years old with intellectual disabilities.

The panel of professionals was mostly women (80%) with an age range from 26 to 56 years ($M= 38.8$; $SD= 11.9$). All had completed university studies with a bachelor's degree or higher (60% had a master's degree and 10% also had a PhD). The professionals studied psychology ($n= 3$), occupational therapy ($n= 1$), pedagogy or psychopedagogy ($n= 3$) and

special education ($n= 3$); and those who had a master's degree or doctorate had focused on disabilities and special needs. Fifty percent worked directly with people with disability, 20% were specialized in research, and 30% had a dual role of both research and direct care. The average number of years of professional experience was 13.4 (ranging from 3 to 30 years). Those working directly with people with disabilities (exclusively or combined with research) had varying work responsibilities. Some worked with specific syndromes associated with intellectual disabilities (Down syndrome, $n= 2$; or fragile X, $n= 1$); others worked in institutions caring for people with various types of intellectual disabilities, including significant disabilities ($n= 4$); and one individual worked in a school ($n= 1$). Five professionals worked with adults, and three with children and adolescents. We also asked the professionals about their knowledge in the disability field (paradigm of supports, self-determination and quality of life). Professionals rated their perceptions of their own competence on a scale of zero (no knowledge) to ten (full knowledge). The average result for the panel was medium-high ($M=8$) and perceptions were very similar to each other ($SD=0.6$; range 7 to 9).

The panel of people with intellectual disabilities was made up of one woman and four men (aged between 21 and 30; $M= 26.8$; $SD= 3.8$). All the participants were members of the Huesca Down Syndrome Association who had volunteered for the study. Three had Down syndrome and two had intellectual disability with no information about the etiology. According to the reports of the association, all had mild ($n= 3$) or moderate ($n= 2$) intellectual disability, were employed, and were living with other people with intellectual disabilities in supervised flats during the week and in the family home on weekends.

Finally, the panel of relatives included four fathers and two mothers of people with intellectual disability. Their ages ranged from 51 to 72 years ($M= 60$; $SD= 9.2$) and all had children over 18 ($M= 27.7$ years).

The study complied with the principles of the Declaration of Helsinki. Authorization to conduct this research was obtained from the Community of Aragon Research Ethics Committee.

Instrument: Pool of items

The research team implemented two initial steps to produce the initial pool of items. The first step was to conduct a review of the scientific literature on the construct of self-determination and existing assessment tools used internationally.

In order to explore the self-determination construct and the current theoretical models, we conducted a search in several databases (Web of Science, Scopus, PsycINFO, ERIC, and Medline), combining the descriptors ‘self-determination’ AND ‘disability’ OR ‘intellectual disability’ AND ‘model’ OR ‘theory’ OR ‘causal agent’. The inclusion criteria used to select the articles were: (a) peer-reviewed articles (b) written in English or Spanish. Articles that did not include any information about a model of self-determination in the title or the abstract were excluded. As result of this review, the theoretical model proposed by Shogren et al. (2015) was selected as our starting point to frame the next search. Once the theoretical framework was established, a new search was conducted for assessment tools with the goal of selecting items and indicators to develop a pool of observable items as a starting point for the Delphi study.

A search was made in the same databases, combining the descriptors (‘disability’ OR ‘intellectual disability’ AND ‘self-determination’ AND ‘assessment’ OR ‘evaluation’ OR ‘tool’; and their corresponding terms in Spanish). Six assessment tools were retrieved from this search: The ARC’s Self-Determination Scale (Wehmeyer & Kelchner, 1995); the AIR Self-Determination Scale (AIR Scale) (Wolman, Campeau, Dubois, Mithaug, & Stolarski, 1994); the Self-Determination Teacher Perception Scale (TPS) and the Self-Determination Student Scale (SDSS) (Hoffman et al., 2004); the Self-Determination Inventory (SDI):

Student Report (Shogren, Wehmeyer, Little et al., 2015); and the ARC-INICO Scale (Verdugo, Vicente, Gómez-Vela, et al., 2015).

Both reviews also focused on selecting items that represent the three essential dimensions of the self-determination construct (volitional characteristics, agentic characteristics, and action-control beliefs). In this way, the model was operationalized through 142 items that were drawn from the assessment tools as observable indicators that can be measured and that represented the breadth of content in each domain. All items were translated into Spanish and formulated in the third person. Most were selected from the most recent instruments (ARC-INICO Scale=61; SDI=43), others from the rest of the reviewed scales (TPS=16; SDSS=10; AIR Scale=13), but some required adaptation in order to be completed by an external observer and applied to young adult populations.

This initial pool of items was discussed by a group of three research team members, who had independently evaluated the 142 items prior to meeting, stating whether they would: (a) retain the item as was; (b) retain the item but reword the statement or move the item to one of the other dimensions; or (c) exclude the item. They could also suggest new items as appropriate. Following this first evaluation, changes and exclusions were applied to items where there had been unanimous agreement among the researchers: 16 items were maintained with no changes; 50 were retained but the statement was reworded or they were moved to another component; and 13 were rejected. Two further meetings were held in order to achieve consensus regarding items where opinions differed ($n=63$) and for the new items proposed ($n=24$). The result was a pool of 131 items, initially assigned to one of the three dimensions of self-determination (41 items assigned to the volitional actions dimension, 37 to the agentic actions dimension, and 53 to the action-control beliefs dimension). All were drafted in third-person to allow responses from the perspective of an external observer. Both full original lists of items are available from the first author if required.

Procedure

The Delphi technique seeks to reach a consensus in the opinions of experts who participate anonymously in a series of structured rounds (Hasson, Keeney, & McKenna, 2000). When accurately and rigorously applied, the technique can significantly expand knowledge in a particular subject area (Hasson et al., 2000). It has been widely used across various disciplines and for different purposes, including the development of assessment tools (Fernández, Verdugo, Gómez, Aguayo, & Arias, 2017; Gómez, Arias, Verdugo, Tassé, & Brown, 2015; Mengual-Andrés, Roig-Vila, & Mira, 2016).

The aim of our Delphi study was to use the consensus reached between stakeholders to establish a comprehensive set of observable items relating to self-determination. In brief, participants were tasked with assessing the initial pool of 131 items proposed by the research team. There was also an opportunity to propose new items. The experts on each panel were involved in successive rounds.

The rounds themselves were adapted to the characteristics of each panel, and therefore were not identical but complementary. The methods used to conduct the rounds were different depending on the group in order to accommodate the individual characteristics and specific needs of each panel, and thus facilitate their task. The rounds for professionals and relatives were conducted in an online environment (Moodle: Modular Object-Oriented Dynamic Learning Environment) with an open-source software platform that allows users to create courses or workspaces for sharing documents, creating discussion forums, and setting tasks and activities. Both panels had their own virtual space organized into different modules, which provided instructions and how-to tutorials, and hosted forums for informal contact and questions. Participants were given an unidentifiable pseudonym to ensure the required levels

of anonymity. For participants with intellectual disability, the procedure was completed in face-to-face rounds over several sessions (two sessions for the first round and one session for the second). The rounds used the same materials as the other panels, but with the added feature of a group interview format to ensure that members of this panel understood the proposed items and to provide them with immediate support as needed.

In this way, we achieved a high response rate and all participants who voluntarily joined each of the panels completed their respective rounds. Figure 1 shows the rounds and associated tasks for the three panels.

First round. The first round involved the evaluation of the initial pool of 131 items drafted by the research team. Using a four-point Likert scale (Table 2), all panels were asked to evaluate the importance of the proposed items (i.e. how relevant each item was in assessing the respective dimension of self-determination). The panel of people with intellectual disability needed two face-to-face sessions to finish the first round as the researcher needed to provide support (i.e. providing examples or reformulations) to guarantee that each item was understood. The panel of experts was also asked to review the initial pool of items for importance, but was also asked to evaluate the suitability (i.e. if the item belonged to the dimension to which it had originally been allocated) and observability (i.e. the degree to which the content of the item can be informed by an external observer) of each item.

<< Insert Table 2 about here >>

Second round. The aim of the second round was to analyze and discuss the results obtained in the first round, through discussion forums, and began with the panels of relatives and people with intellectual disability. Both panels separately discussed the results from the

previous round to identify important areas that were not well represented and areas where new items were needed. The discussion forum for relatives was anonymous and in an online environment, and the panel for people with intellectual disability was carried out in one face-to-face session similar to those of the previous round. The findings from the second round with relatives and individuals with intellectual disabilities were summarized and provided to the panel of professionals as an additional source of information for the professional panel's second round. The professionals were then asked to propose up to six new items per domain. They also discussed and reassessed any items regarded as non-valid in the previous round.

Third round. Only the panel of professionals was involved in the third round. Using the same criteria as the first round, they assessed the newly proposed and reinstated items to determine the final item list.

< < Insert Figure 1 about here > >

Data analysis

We used descriptive statistics (M , SD) to determine the minimum criteria for the retention or removal of an item based on the importance, sustainability, and observability ratings acquired in the first round. In the second round, the decisions about the items were taken by consensus based on the opinion of the participants. In the third round, the same descriptive analyses (M , SD) as used in the first round were carried out to determine the retention or removal of the items. Finally, the inter-rater agreement among judges was calculated using the weighted agreement statistic (B_N^W) (Bangdiwala, 1987). The statistic ranges were between 0 and 1: a score close to 1 indicates perfect agreement among judges (i.e. raters would have attributed the same score to the items), and a score close to 0 shows no agreement.

Results

Round 1

In the first round, the panel of professionals evaluated the pool of 131 items based on the criteria of importance, suitability and observability (the panel of relatives and of people with disability evaluated the first criterion only). Given that the scoring options ranged from 1 to 4, the criteria used to select the items with the best scores were similar to those used in similar studies (Fernández et al., 2017; Gómez et al., 2014, 2015): a mean greater than or equal to 2.9 and a standard deviation less than or equal to 1.1.

Table 3 shows the mean, median and standard deviation of the scores across the three criteria (i.e. importance, suitability and observability) of the 131 items, as well as the number and percentage of items considered non-valid in each panel. As can be seen, the panel of relatives identified the highest number of items as non-valid in the importance criterion. They considered over 20% of the items to be of little importance (and therefore, not valid). In contrast, the panels of professionals and people with intellectual disability accepted over 95% of the items proposed for the importance criterion as valid. The panel of professionals regarded most of the items as important and suitable (i.e. both the importance and suitability criteria returned high mean scores). The observability criterion, on the other hand, obtained the lowest scores, and therefore had the most non-valid items.

< < Insert Table 3 about here > >

We cross-referenced the results from the three panels and marked any items which had cross-panel agreement as valid items. In the first round, 76 items from the initial pool

were valid (Table 4). They were fairly evenly distributed across the dimensions, with approximately 33% of the items assigned to each dimension.

< < Insert Table 4 about here > >

Round 2

The second round focused on reviewing the results obtained in the first round. The panel of relatives and people with intellectual disability were tasked with discussing (separately) the results of their previous round, with the aim of reaching a consensus regarding the most and least important aspects required to assess self-determination. They also identified whether any elements needed to assess self-determination were missing. A report with a brief summary of the results of their previous rounds was provided (oral format for panel of people with intellectual disability and written format for relatives). Members of each panel answered questions such as ‘in your opinion, what elements are the most or least important in order to assess self-determination?’ or ‘what elements have you missed, and do you think they should be considered?’

The research team collected and analyzed the comments from both panels (Table 5), consolidating repetitions and grouping them by dimension. These findings were incorporated in the instructions provided for the panel of professionals, so they could take them into account in their second-round discussions.

< < Insert Table 5 about here > >

The panel of professionals was asked to complete two tasks. First, they were asked to review the items considered as non-valid in their first round ($n= 37$) in an anonymous discussion forum. They provided arguments to justify whether items should be removed or

adjusted to make them more relevant, trying to convince their colleagues to reach a consensus on each of the items under review. Following an analysis and review of the contributions from the experts, the research team reinstated eight items: (a) the wording of five items was changed to clarify content and enhance observability; (b) one item was split to create two separate items; and (c) two items were reinstated with no changes. The eight items remained in the dimensions to which they had originally been assigned. In summary, nine items were reinstated, and 29 items were definitively excluded (22.1% of the initial pool), either because there was no consensus among the experts about how to improve them or because the majority agreed on their limited importance or observability.

The experts were then encouraged to propose a maximum of six new items by dimension. As a result, 58 new items were put forward. Table 6 shows the number of new and reinstated items by dimension.

< < Insert Table 6 about here > >

Round 3

The aim of the third round, involving only the panel of professionals, was to evaluate the 67 items resulting from the previous round (i.e. the 58 newly proposed items and the 9 items reinstated as valid). The experts were asked to evaluate these items using the same three criteria as in Round 1 (i.e. importance, suitability and observability) and the same four-point Likert scale. To be considered valid, the items had to meet the same criteria as in the first round ($M \geq 2.9$ and $SD \leq 1.1$). Table 7 presents the mean, median and standard deviation, and the percentage of items considered non-valid across the three criteria (i.e. importance, suitability and observability). The results show that 39 items (58.2% of the total

set of items) were valid according to these criteria, compared to 28 non-valid items (41.8%) which were subsequently excluded.

< < Insert Table 7 about here > >

The results from the three rounds produced a final pool of 115 items: 76 items validated in the first round, and 39 items in the following two rounds. The volitional characteristic had a slightly higher number of items (almost 40% of the total), compared to 30% in agentic characteristics and action-control beliefs (Table 8). See Appendix A for the final pool of items (with denotations as to which items were original compared to reformulated or added later).

< < Insert Table 8 about here > >

Inter-rater agreement among the final pool of items

Lastly, we analyzed the degree of agreement among professionals for the three criteria representing the items: importance, suitability, and observability. We calculated Bangdiwala's weighted agreement statistic for ordinal data, ranging from 0 'no agreement' to 1 'perfect agreement'. Bangdiwala's agreement statistics were greater than .70 for the pool of items, indicating a high level of agreement. Agreement, as shown in Figure 2, was highest for the importance criterion ($B_N^W = .85$), followed by suitability ($B_N^W = .81$) and observability ($B_N^W = .73$). Agreement is mainly concentrated around the response option corresponding to a score of 4 (i.e. "very important", "reflects the dimension very well", and "fully observable"), as shown in the charts for all three criteria. This high level of agreement among experts on the importance, suitability and observability of the items attests the validity of their content,

suggesting that they could be used for the purposes of assessing the three dimensions of self-determination.

< < Insert Figure 2 about here > >

Discussion

The aim of this study was to operationalize the construct of self-determination by proposing a pool of items for assessment by external observers with adequate evidence of validity based on content. We therefore used the Delphi method to ensure validity based on consensus across stakeholders (academics, professionals, people with intellectual disability, and their relatives). The result was a comprehensive set of items considered important, suitable and observable for the assessment of self-determination, according to the reconceptualized framework of the functional model of self-determination proposed by Shogren, Wehmeyer, Palmer et al. (2015).

Although it is necessary to conduct other specific analyses in order to understand the internal structure of the scale, the 115 items obtained by the qualitative analyses in the three-round Delphi study (i.e. the consensus from stakeholders) seem to indicate that their content represents the three hypothesized categories or dimensions of self-determination proposed by Shogren, Wehmeyer, Palmer et al. (2015).

The validity of the findings is further strengthened by the procedural structure of the Delphi method used, incorporating qualitative and quantitative evaluation methods in different rounds to reach a consensus among raters (i.e. stakeholders). In this sense, our research is comparable to previous studies which have used the Delphi method to develop and validate indicators for the assessment of similar constructs (Gómez et al., 2014, 2015; Fernández et al., 2017). The aim of these prior Delphi studies was to generate consensus on a

set of items to assess the quality of life of people with disability, and they later resulted in assessment tools with excellent evidence of reliability and validity (Fernández et al., 2018; Gómez et al., 2016; Verdugo, Gómez, Arias, Navas, & Schalock, 2014).

Some of the strengths of the Delphi method used are worth mentioning here. The first relates to the number of expert panelists. Balasubramanian and Agarwal (2013) stressed that this selection is of vital importance, and that the experts need to be highly qualified in the subject area of the study. Many studies (Kingston et al., 2011; Pietersma, de Vries & van den Akker-van, 2014) also include different groups of experts with a view to capturing the full spectrum of stakeholder perspectives. Although there is no consensus about the ideal number of experts, some authors prefer to use between 10 and 20 experts (Delbecq, Van de Ven, & Gustafson, 1975; López-Gómez, 2018; Ludwig, 1997), and others emphasize that the maximum number should be below 50 (Witkin & Altschuld, 1995). With a total of 21 participants across three panels representing stakeholders in the life of a person with intellectual disability (professionals, people with disability and their relatives), the panel selection in our study complied with all the recommendations. Furthermore, all participants were suitably qualified and experienced. The panel of professionals in particular was accorded a key role by virtue of their high level of expertise, not only in the field but also as regards the theoretical concept.

Another strength of our study is the method used to plan the iterative process of rounds. We believe that the number of rounds and time frame (which never exceeded two months) was appropriate for each panel, given that two aspects when using the Delphi technique must be considered: the high costs in terms of time and the risk of respondent fatigue (Hasson et al., 2000). The time frame for our study was therefore kept short (four and a half months), and the high response rate and nil drop-out rate suggest that there was no evidence of fatigue. Finally, we guaranteed anonymity for panel of professionals and the

panel of relatives (who communicated via an online platform using an unidentifiable pseudonym), although not for the panel of people with intellectual disability who participated face-to-face in a focus group. Future research could use methods to retain anonymity, but still ensure the panelists understand (e.g. through individual face to face interviews).

Our study is not free of limitations, however. Given the diversity of the panels, we were obliged to modify the traditional Delphi procedure to accommodate the specific characteristics of the participants. First, the rounds for each of the panels were complementary, but not identical. Secondly, the method used to conduct the study was online for two of the panels (professionals and relatives), but not for the panel of people with intellectual disability. In the latter case, the rounds needed to be face-to-face in order to provide support as needed and to avoid any difficulties associated with using an online platform. That said, we believe that these two limitations do not call the validity of the results into question, and that the inclusion of people with intellectual disability and their relatives enriches the study, regardless of any potential methodological complications. In fact, not having a panel of people with intellectual disability would not only diminish the validity of the study, but would go against the very philosophy of the concept of self-determination that we are advocating. Similarly, a family perspective is necessary due to the great support families usually provide during adolescence, acting as facilitators of self-determination and social inclusion for their children and their transition to adulthood (Arellano & Peralta, 2015; Wehmeyer, 2014; Young et al., 2017). The recruitment process also entailed some limitations. The panels were all composed via convenience samples, and consequently, their representativeness cannot be guaranteed (e.g. the panel of people with intellectual disability included five members recruited from the same association and was not representative in terms of gender or intellectual disability etiology). Similarly, the use of a limited range of panels (with voluntary Spanish participants) has limitations from an international perspective.

These limitations confirm the need for further research exploring the self-determination concept, theoretical model and the development of assessment tools.

In summary, the contribution of this study is to improve the understanding and operationalization of the construct of self-determination in young people and adults with intellectual disability in our country. It also serves to broaden and improve our knowledge of the conceptual framework on which self-determination is based, which continues to be a relevant issue at the international level. Bearing in mind that social constructs cannot be measured directly, but are assessed indirectly through indicators (Brown, Hatton & Emerson, 2013; Gómez et al., 2015), we have produced an extensive bank of items from which to develop a scale for assessment. This study therefore constitutes the first necessary step for future research into the assessment of self-determination in this population. The subsequent analyses of this measure (e.g. internal consistency, factor structure, convergent validity, divergent validity, etc.) will generate evidence of reliability and validity, as well as strengthen our knowledge of self-determination and the associated predictive variables.

References

- Abery, B.H., Elkin, S.V., Smith, J.G., Springborg, H.L., & Stancliffe, R.J. (2000). *Minnesota Self-determination Scales*. Minnesota: University of Minnesota, Institute on Community Integration.
- Arellano, A., & Peralta, F. (2015). Autodeterminación personal y discapacidad intelectual: un análisis desde la perspectiva de las familias [Self-determination and intellectual disabilities: an analysis from the perspective of families]. *Siglo Cero*, 46(3), 255–275.
- Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation*, 106(2), 173-188.
- Brown I., Hatton C., & Emerson E. (2013). Quality of life indicators for individuals with

- intellectual disabilities: extending current practice. *Intellectual and Developmental Disabilities* 51, 316–332. doi:10.1352/1934-9556-51.5.316
- Delbecq, A. L., Van de Ven, A. H., & Gustafson, D. H. (1975). *Group techniques for program planning: A guide to nominal group and Delphi processes*. Glenview, IL: Scott Foresman.
- Fernández, M., Verdugo, M. Á., Gómez, L. E., Aguayo, V., & Arias, B. (2017). Core Indicators to Assess Quality of Life in Population with Brain Injury. *Social Indicators Research*. doi:10.1007/s11205-017-1612-6
- Fernández, M., Gómez, L. E., Arias, V. B., Aguayo, V., Amor, A. M., Andelic, N. y Verdugo, M. A. (2018). A new scale for measuring quality of life in acquired brain injury. *Manuscript in preparation*.
- Gallivan-Fenlon, A. (1994). “Their senior year:” Family and service provider perspectives on the transition from school to adult life for young adults with disabilities. *Journal of the Association for Persons with Severe Handicaps*, 19, 11–23.
- Gómez, L. E., Alcedo, M. A., Arias, B., Fontanil, Y., Arias, V. B., Monsalve, M. A., & Verdugo, M. A. (2016). A new scale for the measurement of quality of life in children with intellectual disability. *Research in Developmental Disabilities*, 53-54, 399–410. doi:10.1016/j.ridd.2016.03.005
- Gómez, L. E., Arias, B., Verdugo, M. Á., Tassé, M. J., & Brown, I. (2015). Operationalisation of quality of life for adults with severe disabilities. *Journal of Intellectual Disability Research*, 59(10), 925–941. doi: 10.1111/jir.12204
- Gómez, L. E., Peña, E., Alcedo, M. A., Monsalve, A., Fontanil, Y., Arias, B., & Verdugo, M. A. (2014). El constructo de calidad de vida en niños y adolescentes con discapacidades múltiples y profundas: propuesta para su evaluación [The construct of quality of life for

- childrens and adolescents with multiple and profound disabilities: a proposal for the assessment]. *Siglo Cero*, 45, 56–59.
- Hasson, F., Keeney, S., & McKenna, H. (2000). Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing*, 32(4), 1008–1015.
- Hoffman, A., Field, S. L., & Sawilowski, S. D. (2004). *Self-Determination Assessment Battery. User's guide*. Detroit, MI: Center for Self-Determination and Transition.
- Kingston, A. H., Morgan, A. J., Jorm, A. F., Hall, K., Hart, L. M., Kelly, C. M., & Lubman, D. I. (2011). Helping someone with problem drug use: A Delphi consensus study of consumers, carers, and clinicians. *BMC Psychiatry*, 11, 1–7. doi:10.1186/1471-244X-11-3
- López-Gómez, E. (2018). El método Delphi en la investigación actual en educación: Una revisión teórica y metodológica [Delphi method in the current education research: a theoretical and methodological review]. *Educación XXI*, 21(1), 17–40. doi:10.5944/educXX1.15536
- Martorell, A., Gutierrez-Recacha, P., Pereda, A., & Ayuso-Mateos, J. L. (2008). Identification of personal factors that determine work outcome for adults with intellectual disability. *Journal of Intellectual Disability Research*, 52, 1091–1101. doi:10.1111/j.1365-2788.2008.01098.x
- Mengual-Andrés, S., Roig-Vila, R., & Mira, J. B. (2016). Delphi study for the design and validation of a questionnaire about digital competences in higher education. *International Journal of Educational Technology in Higher Education*, 13(1), 1–11. doi:10.1186/s41239-016-0009-y
- Mithaug, D. E., Wehmeyer, M. L., Agran, M., Martin, J. E., & Palmer, S. (1998). The Self-Determined Learning Model of Instruction: Engaging students to solve their learning

- problems. In M. L. Wehmeyer & D. J. Sands (Eds.) *Making it happen: Student involvement in education planning, decision making and instruction* (pp. 299-328). Baltimore: Paul H. Brookes.
- Mumbardó-Adam, C., Guàrdia-Olmos, J., Giné, C., Shogren, K., & Vicente, E. (in press). Psychometric properties of the Spanish version of the Self-Determination Inventory Student Report: a Structural Equation Modeling Approach. *American Journal on Intellectual and Developmental Disabilities*.
- Mumbardó-Adam, C., Shogren, K. A., Guàrdia-Olmos, J., & Giné, C. (2016). Contextual predictors of self-determined actions in students with and without intellectual disability. *Psychology in the Schools*, 54, 183–195. doi:10.1002/pits.21987
- Neece, C. L., Kraemer, B. R., & Blacher, J. (2009). Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellectual and Developmental Disabilities*, 47(1), 31-43.
- Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. L. (2007). Self-determination, social abilities, and the quality of life of people with intellectual disabilities. *Journal of Intellectual Disability Research*, 51, 850–865. doi:10.1111/j.1365-2788.2006.00939.x
- Pietersma, S., de Vries, M., & van den Akker-van, M. E. (2014). Domains of quality of life: results of a three-stage Delphi consensus procedure among patients, family of patients, clinicians, scientists and the general public. *Quality of Life Research*, 23(5), 1543–1556. doi:10.1007/s11136-013-0578-3
- Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E, Coulter, D., Craig, E. M., ...Yeager, M. H. (2010). *Intellectual disability: Definition, classification, and systems of supports* (11th ed.). Washington, DC: American Association on Intellectual and Developmental Disabilities.

- Schalock R. L., & Verdugo M. A. (2013). The impact of the quality of life concept on the field of intellectual disability. *Intellectual and Developmental Disabilities, 51*(4), 273-286. doi: 10.1352/1934-9556-51.4.273
- Shogren, K. A., & Shaw, L. A. (2017). The impact of personal factors on self-determination and early adulthood outcome constructs in youth with disabilities. *Journal of Disability Policy Studies, 27*(4), 223-233.
- Shogren, K. A., Wehmeyer, M. L., Little, T. D., Forber-Pratt, A. J., Palmer, S. B., & Seo, H. (2015). Preliminary validity and reliability of scores on the *Self-Determination Inventory-Student Report* version. *Career for Development and Transition for Exceptional Individuals, 50*(3), 251–263. doi:10.1177/2165143415594335
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Forber-Pratt, A., Little, T., & López, S. (2015). Causal Agency Theory: Reconceptualizing a functional model of self-determination. *Education and Training in Autism and Developmental Disabilities, 50*(3), 251–263.
- Shogren, K.A., Wehmeyer, M.L., Palmer, S.B., & Paek, Y. (2013). Exploring personal and school environment characteristics that predict self-determination. *Exceptionality, 21*, 147-157.
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G., & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *The Journal of Special Education, 48*(4), 256-267.
- Soresi, S., & Nota, L. (2007). *Astrid portfolio per l'assessment, il trattamento e l'integrazione delle disabilità* – Orientamento [Astrid portfolio for assessment, treatment and integration of disability - orientation]. Firenze: Giunti-Organizzazioni Speciali.
- Stax, T. E., Luciano, L., Dunn, A. M., & Quevedo, J. P. (2010). Aging and developmental disability. *Physical Medicine & Rehabilitation Clinics of North America, 21*, 419–427.

<https://doi.org/10.1016/j.pmr.2009.12.009>

- Thompson, J. R., Bradley, V. J., Buntinx, W. H. W., Schalock, R. L., Shogren, K. A., Snell, M. E., ... Yeager, M. H. (2009). Conceptualizing supports and support needs of people with intellectual disability. *Intellectual and developmental disabilities*, 47(2), 135-146. doi: 10.1352/1934-9556-47.2.135
- Thorin, E. J., & Irvin, L. K. (1992). Family stress associated with transition to adulthood of young people with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 17(1), 31-39.
- Verdugo, M. A., Gómez, L. E., Arias, B., Navas, P., & Schalock, R. L. (2014). Measuring quality of life in persons with intellectual and multiple disabilities: validation of the San Martín Scale. *Research in Developmental Disabilities*, 35, 75–86.
doi:10.1016/j.ridd.2013.10.025
- Verdugo, M. A., Vicente, E., Fernández, R. Gómez-Vela, M., & Guillén, V. (2015). A psychometric evaluation of the ARC-INICO Self-Determination Scale for adolescents with intellectual disabilities. *International Journal of Clinical and Health Psychology*, 15(2), 149–159. doi:10.1016/j.ijchp.2015.03.001
- Verdugo, M. A., Vicente, E., Gómez-Vela, M., Fernández, R., Wehmeyer, M. L., Badía, M., ... Calvo, M. I. (2015). *Escala ARC-INICO de Evaluación de la Autodeterminación: Manual de aplicación y corrección [The ARC-INICO self-determination scale: administration and correction manual]*. Salamanca: INICO.
- Vicente, E., Verdugo, M. A., Gómez-Vela, M., Fernández-Pulido, R., Wehmeyer, M. L., & Guillén, V. M. (2017). Personal characteristics and school contextual variables associated with student self-determination in Spanish context. *Journal of Intellectual & Developmental Disability*. <https://doi.org/10.3109/13668250.2017.1310828>
- Wehmeyer, M. L. (1992). Self-determination and the education of students with mental

- retardation. *Education and Training in Mental Retardation*, 27, 302–314.
- Wehmeyer, M. L. (1996). Self-determination as an educational outcome: Why is it important to children, youth and adults with disabilities? In D. J. Sands & M. L. Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for people with disabilities* (pp. 17–36). Baltimore, MD: Brookes.
- Wehmeyer, M. L. (1999). A functional model of self-determination: Describing development and implementing instruction. *Focus on Autism and Other Developmental Disabilities*, 14, 53–62. doi:10.1177/108835769901400107
- Wehmeyer, M. L. (2004). Self-determination and the empowerment of people with disabilities. *American Rehabilitation*, 28, 22–29.
- Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities* 30(3), 113–120. doi:10.2511/rpsd.30.3.113
- Wehmeyer, M. L. (2011). Empowerment. In A. Michalos (Ed.), *Encyclopedia of quality of life research* (pp. 1891–1892). Heidelberg, Germany: Springer.
- Wehmeyer, M. L. (2014). Self-determination: A Family Affair. *Family Relations*, 63(1), 178–184. doi:10.1111/fare.12052
- Wehmeyer, M. L., & Abery, B. H. (2013). Self-determination and choice. *Intellectual and Developmental Disabilities*, 51, 399–411. doi:10.1352/1934-9556-51.5.399
- Wehmeyer, M.L., Abery, B.H., Mithaug, D.E., & Stancliffe, R.J. (2003). *Theory in self-determination. Foundations for educational practice*. Springfield, IL: Charles C. Thomas
- Wehmeyer, M.L., & Garner, N. W. (2003). The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous

functioning. *Journal of Applied Research in Intellectual Disabilities*, 16, 255-265.

doi:10.1046/j.1468-3148.2003.00161.x

Wehmeyer, M. L., & Kelchner, K. (1995). *The Arc's self-determination scale*. Silver Springs, MD: The Arc of the United States.

Wehmeyer, M. L., Palmer, S. B., Shogren, K. A., Williams- Diehm, K., & Soukup, J. (2013).

Establishing a causal relationship between intervention to promote self-determination and enhanced student self-determination. *Journal of Special Education*, 46, 195–210.

doi:10.1177/0022466910392377

Wehmeyer, M. L., Peralta, F., Zulueta, A., González Torres, M. C., & Sobrino, A. (2006).

Escala de autodeterminación personal ARC. Instrumento de valoración y guía de aplicación: Manual Técnico de la adaptación española [Personal self-determination ARC scale. Assessment tool and user's guide: technical manual for the Spanish adaptation]. Madrid: CEPE.

Wolman, J. M., Campeau, P. L., DuBois, P. A., Mithaug, D. E., & Stolarski, V. S. (1994).

AIR Self-Determination Scale and User Guide. Palo Alto, CA: American Institutes for Research.

Young, R. A., Marshall, S. K., Stainton, T., Wall, J. M., Curle, D., Zhu, M., ... & Zaidman-

Zait, A. (2017). The transition to adulthood of young adults with IDD: Parents' joint projects. *Journal of Applied Research in Intellectual Disabilities*. doi:

10.1111/jar.12395

Table 1. Comparison of Self-Determination models (Shogren, Wehmeyer, Palmer et al., 2015, p. 31)

Essential characteristics		
Causal Agency Theory	Functional Model	Additional elements
Volitional action	Autonomy	Self-Initiation
Agentic action	Self-Regulation	Self-Direction Pathways thinking
Action-control beliefs	Psychological Empowerment Self-realization	Control expectancy Agency beliefs Causality beliefs

Table 2. Likert-response system used to evaluate the pool of items

Score	Importance criterion	Suitability criterion	Observability criterion
1	Unimportant	Does not reflect the dimension at all	Not observable at all
2	Of little importance	Reflects the dimension to a limited extent	Observable to a limited extent
3	Moderately important	Reflects the dimension to a moderate extent	Observable to a moderate extent
4	Very important	Reflects the dimension very well	Fully observable

Table 3. First-round descriptive data for the three panels.

<i>Criteria</i>	Panel of professionals			Panel of relatives			Panel of PID		
	<i>Median</i>	<i>M (SD)</i>	<i>Non-valid items (%)</i>	<i>Median</i>	<i>M (SD)</i>	<i>Non-valid items (%)</i>	<i>Median</i>	<i>M (SD)</i>	<i>Non-valid items (%)</i>
Importance	3.8	3.59 (.59)	2 (1.53%)	4	3.79 (.36)	31 (23.66%)	3.3	3.2 (.75)	2 (1.53%)
Suitability	3.8	3.53 (.65)	4 (3.05%)						
Observability	3.4	3.22 (.78)	34 (25.95%)						
Imp+Sui+Obs			37 (28.24%)						

Note. Imp+Sui+Obs= importance, suitability and observability; PID= people with intellectual disability.

Table 4. Summary of cross-panel valid items from the first round.

<i>Dimensions</i>	<i>Initial pool of items in round 1</i>	<i>Valid – Panel of Professionals (%)</i>	<i>Valid – Panel of Relatives (%)</i>	<i>Valid – Panel of PID (%)</i>	<i>Valid – cross-panel (%)</i>
Volitional characteristic	41 (31.30%)	36 (38.30%)	31 (31%)	41 (31.78%)	26 (34.21%)
Agentic characteristic	37 (28.24%)	28 (29.79%)	30 (30%)	37 (28.68%)	27 (35.53%)
Action-control beliefs	53 (40.46%)	30 (31.91%)	39 (39%)	51 (39.53%)	23 (30.26%)
Total	131 (100%)	94 (100%)	100 (100%)	129 (100%)	76 (100%)

Note. PID= people with intellectual disability.

Table 5. Findings from round 2 discussion forums (panel of relatives and panel of people with intellectual disability).

Dimension	Most relevant aspects identified by the panel of relatives and of people with intellectual disability (main findings from the forums)
Cross-dimensional	<i>Happiness-oriented</i> approach, not only targeted at achieving clear goals, but also the pursuit of activities which tend to produce emotions and signs of joy
Volitional action	Importance of knowing how to <i>ask for help if needed</i> , in aspects related to self-determination and social participation.
Agentic actions	Importance of knowing how to <i>look for other options and alternatives</i> when something goes wrong or a plan does not work.
Action-control beliefs	Importance of recognizing and knowing how to identify own <i>needs</i> (physical, emotional, social...), personal <i>tastes and preferences</i> . Importance of <i>empowerment</i> , as well as the ability to assertively express themselves and be active participants within their environment.

Table 6. Descriptive analysis of round 2 by dimension (panel of professionals).

<i>Dimensions</i>	<i>New items proposed</i>	<i>Non-valid items reinstated</i>	<i>Non-valid items excluded</i>
Volitional characteristic	16	6	0
Agentic characteristic	19	0	9
Action-control beliefs	23	3	20
Total	58	9	29

Table 7. Descriptive analysis of third round by criterion.

<i>Criteria</i>	<i>Median</i>	<i>M (SD)</i>	<i>Valid items (% valid)</i>	<i>Non-valid items (%)</i>
Importance	3.6	3.41 (.67)	62 (92.54%)	5 (7.46%)
Suitability	3.4	3.29 (.73)	58 (86.57%)	9 (13.43%)
Observability	3.2	3.09 (.79)	44 (65.67%)	23 (34.33%)
Imp.+Sui.+Obs.			39 (58.21%)	28 (41.79%)

Note. Imp+Sui+Obs= importance, suitability and observability.

Table 8. Summary of cross-panel valid items from first to third round.

<i>Dimensions</i>	<i>Valid first round (%)</i>	<i>Valid third round (%)</i>	<i>Total valid items (%)</i>
Volitional characteristic	26 (34.21%)	19 (48.72%)	45 (39.13%)
Agentic characteristic	27 (35.53%)	8 (20.51%)	35 (30.43%)
Action-control beliefs	23 (30.26%)	12 (30.77%)	35 (30.43%)
Total	76 (100%)	39 (100%)	115 (100%)