

Assessment of work ability decline in workers with intellectual and developmental disabilities

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Abstract.

BACKGROUND: People with intellectual and developmental disabilities (IDD) experience work ability decline through aging and disability (WADAD), conceptualized as the process of deterioration in work ability resulting from the interaction between disability and aging, which has a direct impact on their job.

OBJECTIVE: There is a need to focus on how this decline can be detected and to identify the main areas and indicators of WADAD in people with IDD, in order to build a targeted prototype assessment tool to determine a prevention protocol that extends people's positive working lives for as long as possible.

METHODS: We employed a literature review, Delphi panel, and working group through Modular Object-Oriented Dynamic Learning Environment (MOODLE).

RESULTS: We created a tool, composed of 76 items, 6 dimensions, and 17 indicators, to assess WADAD in people with IDD.

CONCLUSIONS: The indicators identified can be used to develop prevention and/or intervention protocols for WADAD and to produce guidance for the transition toward retirement, specifically for people with IDD. This tool helps extend the satisfying working lives—with support—of people with IDD, promoting social inclusion and participation as workers and not as pensioners.

Keywords: Aging, retirement, work ability decline, disability, job deterioration, assessment, intellectual and developmental disabilities

1. Introduction

The number of older people with intellectual and developmental disabilities (IDD) has been increasing as a result of lifestyle changes and improvements in health and medicine. In turn, this situation has led to better living conditions and quality of life (Schalock & Verdugo, 2002; Westerinen et al., 2016). In light

of the increase in life expectancy, research into aging and IDD is currently focusing on obtaining information about later adulthood as a life stage.

Work is considered essential in many aspects of life, playing a large part in the development and maintenance of self-image (Corcoran, 2004). Retirement, therefore, constitutes a major change. The issues of transition to retirement and active aging have been investigated for the general population, for example in the studies on productive aging by D'Amico (2012) and Macdonald and Cole (2016).

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For people with IDD, employment promotes self-esteem, confidence, independence, social inclusion, and physical and mental health, providing a sense of identity and enhancing quality of life (McGlinchey et al., 2013). The relationship between work and enhanced quality of life has been studied extensively (Verdugo et al., 2012; Santamaría et al., 2012; Verdugo et al., 2006, 2009; González, 2019). Recent articles have linked workforce participation to improvements in a number of the quality-of-life domains: for example, in material wellbeing, through financial independence; in social inclusion and interpersonal relationships, through socialization opportunities (Aguado & Martín, 2020); and in personal development (González et al., 2021).

Paid employment is seen as an indicator of empowerment and personal success for the person with IDD (Lysaght et al., 2009), promoting financial independence and social connections, as well as providing opportunities for community involvement (Llewellyn et al., 2004). Loss of employment, in contrast, is detrimental to social belonging and community participation, and contributes to a decline in active and productive living (Buys et al., 2008). In this context, people with disability in general, and with IDD particularly, need to be able to make self-directed choices about whether to continue in a satisfying work activity until they reach legal retirement age.

A literature review by the authors found studies on work ability in the general population, such as the Work Ability Index (Ilmarinen et al., 1991), which analyzes work impairment due to illness but does not address aging or disability. Other tools also applied to the general population, such as the WA Survey-Revised (WAS-R) (Noone et al., 2014) or the Work Ability – Personal Radar (WA-PR) (Ilmarinen et al., 2015), adopt similar approaches. Only one disability-adapted approach was identified (Lavasani et al., 2015), although no participants with IDD took part in the study. In summary, even though several studies have compiled procedures or approaches to analyze signs of deterioration in work ability as a consequence of aging, there appears to be no scholarly evidence on the subject in people with IDD. This highlights the scant research and lack of adequate tools in relation to work ability decline resulting from the interaction between disability and aging, specifically for the detection, prevention, and development of supports. That said, a few papers retrieved from the gray literature provide information on changes observed in older workers with IDD in the work setting.

Escolar (2002) identified various work-related changes in older staff with IDD in sheltered employment. Among these were a decrease in the pace of work, increased sick leave, clumsiness and fatigue, relationship difficulties, and reduced motivation. In relation to more personal aspects, the report pointed out mood swings, irritability, and neurotic features.

Another report (Vicente, 2005) highlighted such changes as non-compliance with schedules and absenteeism, lower quality of tasks, reduced ability to understand new instructions, difficulty in learning, and, finally, changes in autonomy reflected in reduced capacity to take care of oneself, as well as temporal and spatial disorientation.

Finally, Bejarano and García (2010) supported the findings of the two previous reports and added their own observations, namely decreased precision in tasks, resistance to change, memory and attention loss, and lower reflexes.

This reality, in the context of employment, can be interpreted as an emerging concept called work ability decline through aging and disability (WADAD), which may be conceptualized as the process of deterioration in work ability resulting from the interaction between disability and aging; and the ensuing risk of a mismatch between the position and the satisfactory completion of tasks, which may lead to forced or abrupt retirement for reasons of health or job instability (Stancliffe et al., 2017, 2018, 2019), entailing a drastic change in lifestyle.

The objective of this study is to detect and identify the main areas and indicators of WADAD in people with IDD, through an examination of the scientific literature and with the agreement of employment and disability experts. The overall aim is to build a targeted prototype assessment tool.

2. Method

First, we performed a literature review to identify the state of the art and establish a possible pool of items related to work ability decline associated with disability and aging.

Second, to develop the tool, we conducted a study using the Delphi method: through repeated consultations with a group of experts with extensive knowledge, a consensus of opinions was reached (Reguant & Torrado, 2016) to validate the content of the items collected through the review of instruments and literature.

Third, a working group composed of a different set of experts completed the process of creating the tool for the assessment of WADAD in workers with IDD and provided information to support the research team’s decisions in relation to the procedure and periodicity for application. In addition, it helped refine and modify the items selected in the Delphi, thus reinforcing consensus among all experts.

2.1. Participants

There were 25 participants (15 in the Delphi study and 10 in the working group). In the Delphi panel, 60% were women and 40% were men, aged between 38 and 60 years old. In the working group, 80% of participants were women and 20% were men, with ages ranging from 40 to 55 years old. All were selected for their expertise in the field of intellectual disability and employment or aging. The main characteristics of participants in the Delphi panel were as follows: 93.3% had at least 10 years’ experience in the field of disability; 53.4% had at least 6 years’ experience in the field of aging and IDD; 93.3% had at least 11 years’ experience in the field of employment or work-related issues; and 93.3% had experience in creating IDD intervention/assessment protocols. The main characteristics of participants in the working group were as follows: 80% had at least 10 years’ experience in the field of disability; 50% had at least 6 years’ experience in the field of aging and IDD; 70% had at least 11 years’ experience in the field of employment or work-related issues; and 60% had experience creating IDD intervention/assessment protocols. Further sociodemographic data can be found in Table 1.

2.2. Instrument

The instrument used was created by the research team. The literature review was the starting point for the instrument, which was modified in the Delphi process and the working group. It was a scale of 56 items grouped into 17 indicators, which in turn were categorized under six core dimensions (Table 2).

2.3. Procedure

2.3.1. Literature review

A bibliographic search was carried out across PsycInfo, Academic Search Complete, ERIC, Medline, Cinhal Complete, PsycArticles, PsycBooks, Psychology and Behavioral Sciences Collection, and

Table 1
Participant sociodemographic data

		Delphi panel (15)	Working group (10)
Gender	Women	60%	80%
	Men	40%	20%
Age	From	38	40
	To	60	55
Years of experience in the field of disability	0–5 years	0%	10%
	6–10 years	6.7%	10%
	11–15 years	13.3%	20%
	+15 years	80%	60%
Years of experience in the field of aging with IDD	0–5 years	46.7%	50%
	6–10 years	46.7%	30%
	11–15 years	0%	20%
Years of experience in the field of employment or work-related issues	+15 years	6.7%	0%
	0–5 years	0%	0%
	6–10 years	6.7%	30%
Perceived level of experience in the field of aging with IDD	11–15 years	20%	40%
	+15 years	73.3%	30%
	Limited	60%	60%
Perceived level of experience in the field of employment or work-related issues	Some	40%	40%
	A lot	0%	0%
	Limited	0%	0%
Validation and construction of assessment instruments	Some	40%	80%
	A lot	60%	20%
	Yes	53.3%	70%
Creation of IDD intervention/assessment protocols	No	46.7%	30%
	Yes	93.3%	60%
	No	6.7%	40%

PsicoDoc. The descriptors used were: work ability and intellectual disability or mental retardation or learning disability or developmental disability or learning disabilities and aging. Two of the results were discarded, one for being from the medical field and the other for not being a scientific article.

A second search was performed in the same databases with the same descriptors, changing intellectual disability for disability in general. In total, 69 articles were identified. Duplicates were eliminated, leaving 39. The criteria of access to the full text and the period 2000 to 2021 were applied; eight articles were obtained, of which three were discarded because they were medical in scope. Of the five remaining articles, one was particularly relevant (Brady et al., 2019) and provided access to several tools that focused on work capacity in the general population (Ilmarinen et al., 1991; Noone et al., 2014; Ilmarinen et al., 2015). Finally, a handsearching of the gray literature was performed, yielding a further four references (FEAPS Navarra, 2005; Lantegi Batuak, 2013; Signo, 2015; Gimeno, 2016).

Table 2
Dimensions, definition and indicators of WADAD

Dimension	Definition	Indicators
(PH) Physical health	General state of health that consists of the well-being of the body and the optimal functioning of the individual's organism, i.e., the individual's physical condition does not present alterations that could affect their ability to perform actions and tasks in the work environment or their presence and participation in it.	Fatigue; illness; sensory problems; dynamic coordination.
(MH) Mental health	General state of emotional, psychological, and social well-being of the individual, i.e., it is the absence of psychological disorders that enable normal functioning in different areas, influencing how we think, feel, and act when facing life. It can affect a person's capacity and productivity to perform actions and tasks in the work environment or their presence and participation in it.	Psychopathology; mood; adaptability.
(CF) Cognitive functioning	Mental processes that include the ability to learn and remember information; organize, plan, and solve problems; concentrate, maintain, and distribute attention; understand and use language, recognize (perceive) the environment correctly, and perform calculations, among other functions. Problems related to the impairment of cognitive functions may affect the person's ability to perform actions and tasks in the workplace or their presence and participation in it.	Processes; skills and/or attitudes.
(A) Autonomy	The ability to function independently in daily life. It includes the ability to make self-determined decisions. Problems related to self-care, loss or impairment of independent living skills, or self-management may affect the person's ability to perform actions and tasks in the workplace or their presence and participation in it.	Self-care and appearance; independence; self-determination.
(SBF) Social and behavioral functioning	The way in which we conduct interpersonal relationships and how we participate in society and the community. The occurrence of social or behavioral functioning problems can affect a person's ability to perform actions and tasks in the workplace or their presence and participation in it.	Behavior; interpersonal relationships; support and/or supervision.
(JF) Job fit	Existing fit between the jobs of an organization and the people who occupy them, i.e., the correct match between the worker's capabilities and the requirements and characteristics of the job. Adjustment problems, specifically related to the development of the job tasks, can affect a person's ability to perform.	Performance; environment.

2.3.2. Construction of the initial instrument

The researchers held five sessions to complete an initial item pool with dimensions and indicators. In the first session, after observing the initial list, the dimensions were created by looking at the most repeated general topics, thus yielding six dimensions: physical health, mental health, cognitive functioning, autonomy, social and behavioral functioning, and job fit. In the second session, the dimensions were defined by the research team. In the third session, with the definitions, the items could be assigned to dimensions and a screening of items that had the same or similar meanings could be carried out. The fourth session was devoted to creating the indicators; within each dimension, items were grouped by affinity in their content. To do this, an individual categorization was performed. The type of agreement was observed (total agreement if the views of all three researchers coincided, partial agreement if the views of two of the three researchers coincided, and no agreement if none of the views on categorization coincided). In addition, proposals for eliminations were made by each researcher individually. These results were discussed until a consensus was reached, both on the categories and on the elimination of items. In this way, the 17 indicators were created. Finally, in the last session,

the structure of the dimensions and indicators was reviewed, and some items were reformulated.

2.3.3. Delphi method

We used a MOODLE (Modular Object-Oriented Dynamic Learning Environment) virtual space.

In round 1, the panel analyzed the initial pool of 56 items; in round 2, it analyzed the 191 items put forward by the panel experts. The parameters to be analyzed were the suitability of the item to measure the dimension, the degree of importance for assessing WADAD, and the degree of observability by an external person. Participants used a Likert-type scale (1–4) and were asked to provide a justification for scores of 1 or 2. In both rounds, space was provided for comments or reformulations of the items. In round 3, we asked the Delphi participants to state their preference in relation to the wording of the items presented in rounds 1 and 2, providing them with both (original and reformulated) options based on the proposals received.

2.3.4. Working group

This took place virtually using Google Meet and was recorded with permission. The work of the group was divided into two parts. In the first part,

participants analyzed the tool. They appraised the distribution of items, indicators, and dimensions; they also considered potential overlap in the content of the items. In the second part, they provided information to support decisions on how the tool would be applied.

2.4. Data analysis

The Delphi phase evaluated the parameters of importance, suitability, and observability. Analysis was performed using descriptive statistics. The mean was used to indicate the degree of participation of each item in the criterion, and the standard deviation was used to observe the consensus among experts. While the consensus criterion ($SD < 1$) remained the same in rounds 1 and 2, the mean criterion changed (round 1, $M > 3$; round 2, $M > 3.5$) due to the increase in the number of items to be evaluated. In the third round, reformulations that had been approved by over 50% were retained. For the decision on cut-off points, other research on the development of assessment tools was taken as a reference (Fernández et al., 2018; Gómez et al., 2014, 2015; Heras et al., 2021). Following the example of Heras et al. (2021), the purpose of tightening the M criterion between rounds 1 and 2 was to limit the number of valid items and balance them with respect to the previous round, due to the fact that new contributions based on experience tripled the number of items obtained from the scientific literature. The working group performed a content analysis and drew up a list of proposals, including the suggestions and modifications made by the Delphi experts.

3. Results

3.1. Results from the literature review

From the references obtained in the procedure described above, and the experience of the research team, an initial group of 56 items on impairment of work capacity in both the general population and people with IDD was finally proposed. This initial pool of items was the starting point for the Delphi panel.

3.2. Results from the Delphi study

3.2.1. Delphi round 1: Appraisal of the initial pool of 56 items

Almost all items (96.43%) proposed showed good acceptance and passed the inclusion criterion ($M > 3$),

although two items (3.57%) did not and were removed. Regarding standard deviation, all items bar two (96.43%) showed a high degree of consensus and passed the inclusion criterion ($SD < 1$). However, after analyzing comments from the panel, we discovered that the lack of consensus was down to wording issues; the items were thus retained to be reworked in round 3. The experts proposed 191 new items.

3.2.2. Delphi round 2: 191 items proposed by the Delphi experts

Only 22 items (11.52%) passed the mean inclusion criterion ($M > 3.5$) in all parameters. The remaining items were excluded from the next round. As for standard deviation, 153 items (80.10%) passed the inclusion criterion ($SD < 1$). All 22 items that had passed the inclusion criteria for the mean also fulfilled the standard deviation criterion and thus were included in the tool.

3.2.3. Delphi round 3: Comments and reformulations

In all, 76 items from the two previous rounds passed the inclusion criteria. Of these, 37 items (48.68%) had a reformulated option to be evaluated in this round. Of this number, 21 items (56.76%) were included in the evaluation, while 16 items (43.24%) were rejected and not evaluated in this round because they were inconsistent with the rating system designed for the tool. To be selected, the reformulated option required a panel acceptance rate greater than 50%. The reformulated proposal was selected for 18 of the items (85.71%), while the original proposal was retained for three items (14.29%).

3.2.4. Final decisions from the Delphi phase

The research team asked for one item incorporated in round 3 to be appraised. It was added after verifying that it met all the inclusion criteria ($M > 3.5$; $SD < 1$). Another item was reformulated because it was too generic. To complete the process, the dimensions were reorganized: dimensions relating to the person (physical health, mental health, and cognitive functioning) were listed first, followed by those pertaining to how the person interacts with their environment (autonomy, social and behavioral functioning, and job fit). The final tool was configured with 76 items in six dimensions with good mean rates in the three parameters evaluated (Table 3).

Table 3
Mean of means and mean of standard deviation for each dimension for a total number of 76 items

	Suitability	Importance	Observability
Physical health (14 items)	3.5 (0.61)	3.43 (0.70)	3.47 (0.65)
Mental health (11 items)	3.52 (0.59)	3.26 (0.74)	3.43 (0.57)
Cognitive functioning (12 items)	3.67 (0.50)	3.62 (0.53)	3.52 (0.56)
Autonomy (13 items)	3.54 (0.57)	3.44 (0.70)	3.55 (0.52)
Social and behavioral functioning (10 items)	3.58 (0.61)	3.44 (0.65)	3.60 (0.56)
Job fit (16 items)	3.68 (0.58)	3.55 (0.62)	3.72 (0.46)
Total (76 items)	3.58 (0.58)	3.46 (0.66)	3.55 (0.55)

3.3. Results from the working group

Suggestions were made to modify the wording of three items, one item was eliminated, and another was rewritten. A new item was also added. After these modifications, it was concluded that the changes made did not modify the interpretation given by the experts for the different parameters evaluated in the Delphi. The newly added item was evaluated by the research team to check whether it met the inclusion criteria; it was included in the final tool.

Finally, some general additions and modifications were proposed for different parts of the tool to enable the collection of qualitative information.

4. Discussion

The need for research into WADAD in people with IDD has prompted us to create the PROLAB76 prototype tool, consisting of four sections: (1) data on the person being assessed; (2) WADAD questionnaire composed of quantitative and qualitative questions; (3) self-evaluation of the worker with disability; and (4) general information on the person and the environment (to support decision making). The objective of the tool is to identify signs of decline and how they interfere with work performance, with the aim of developing supports that enable a satisfying work situation to be maintained, based on the self-determined choice of the worker and with the mediation of professionals.

The 76 items use a Likert-type response system from 1 to 4 to assess (1) the FREQUENCY of occurrence of the signs of WADAD (never, rarely, sometimes, and frequently) and (2) the INTENSITY

of the decline vis-à-vis the previous assessment (no change, slightly worse, worse, and much worse). Taken together, these two parameters are an indicator of WADAD: they allow the presence of a sign or trait of decline to be determined, capturing its presence and intensity, but also, and perhaps more importantly, they demonstrate the extent to which this trait is accentuated over time.

Open-ended questions are used to record the strengths and/or support areas in each dimension, the perception of the workers with IDD about the decline and their work situation, their expectations, interests, and wishes about continuing work or transitioning to retirement, as well as other general information about the person and their environment.

The inclusion of the physical health dimension is based on the literature reviewed, which makes frequent reference to the signs associated with WADAD, such as ill health, sick leave, fatigue, and poor coordination (FEAPS Navarra, 2005; Brady et al., 2019; Gimeno, 2016; Ilmarinen et al., 1991, 2015; Lantegi Batuak, 2013; Marfeo et al., 2016; Noone et al., 2014; Signo, 2015). The dimensions of social and behavioral functioning, cognitive functioning, and job fit were also developed from the signs described in all the previously cited studies. For the mental health dimension, our experts were in favor of retaining many of the signs put forward by FEAPS Navarra (2005), which assessed the personal and social adjustment of workers (e.g., neuroticism, and behavioral or psychotic disorders). The autonomy dimension, with its corresponding indicators (self-care and appearance, independence, and self-determination), is based on different previous scales and the contributions of our experts.

The results of the Delphi study indicate that the selection of the initial item pool based on the scientific literature was appropriate, as many of the items were endorsed by the experts. Further, the items proposed by the Delphi experts incorporated signs of decline observed first-hand by specialists working in this field. This ensures that the tool we developed combines scientific evidence with professional praxis. The process guaranteed rigorous selection and consensus in the wording of the items, avoiding interpretation biases in the final tool.

Using an entirely new set of experts in the working group to evaluate the output of the Delphi phase ensured objectivity in the improvement process; it also made it easier to find flaws or ambiguities in the tool and make the necessary changes.

4.1. Limitations

The paucity of previous studies in this research area posed a challenge in being able to substantiate and understand WADAD in people with IDD. To address this issue, the review of the scientific literature, the research team's initial definition, and the Delphi study resulted in a suitable and structured proposal of items, indicators, and dimensions ultimately selected for the prototype tool.

Additionally, the COVID-19 pandemic made it difficult to access professionals and organizations, whose priority at the time was direct care. Nonetheless, the study was able to go ahead thanks to the commitment of the participants and the drive and perseverance of the research team.

4.2. Future research directions

Future research into WADAD and people with IDD should seek to analyze the functioning of the specific dimensions, indicators, and items, as well as other related factors (e.g., age, sex, type and degree of disability, participation in supported employment programs, participation in sheltered employment centers). The tool has been designed for longitudinal analysis to observe the evolution of the indicators and associated variables, and to analyze variations in the indicators of decline, which can then be taken into account in future prevention and intervention protocols. This will also allow the tool to be consolidated by analyzing its psychometric properties and endorsing its structure.

Future investigations should incorporate the views of staff working in assessment services, of support organizations, and of people with IDD and their families. This inclusive approach will help identify and determine people's needs as they approach the end of their working life and at the start of retirement, facilitating the development of prevention programs and intervention and support strategies.

5. Conclusion

This investigation sheds light on a hitherto under-researched area, given the limited information available on WADAD in people with disability, particularly those working in the regular employment sector. Until now, there has also been a lack of awareness as to the characteristics of WADAD, an absence of indicators that would signal the onset of decline,

and a dearth of reliable assessment methods. This situation has made it difficult for people with IDD to reach retirement age under the current legal frameworks available to them.

In this context, our study is of important scientific relevance. It compiled the key elements of WADAD and conducted an in-depth reflection on the subject, and from that proposed a model composed of six dimensions, 17 indicators, and 76 items. It is hoped that this model will be a basis for future progress, addressing the need to create protocols that prevent WADAD and to design guidelines that extend the satisfying working life of people with IDD. Our contribution therefore opens up a novel and necessary field for future research into work ability decline and the transition to retirement for people with IDD using active aging models.

Results from the application of PROLAB76 can be used to bring about change at different levels of the system. At microsystem level, the tool can provide information for the creation of individualized support plans to prevent or intervene in situations of WADAD, with the aim of extending the person's working life for as long as possible (if this is desired). These supports will undoubtedly promote work adjustment in workers with IDD. Data would also inform decision making on issues pertaining to the transition to retirement. This step does not mean that the work activity of the person with IDD stops, only that it changes perspective, with the individual having to adjust to a new reality. At the organizational level (mesosystem), the tool facilitates the collection of relevant information that can be used to create pathways for the transition to retirement, and to develop prevention protocols and/or interventions that serve as a basis for individualized support. Finally, at the community level (macrosystem), data collected using the tool support the development of public policies to address the growing needs of people as they age in the workplace and once they transition to retirement.

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Conflict of interest

There is no conflict of interest related to this study.

Ethical approval

Due to the nature of the study, ethical approval was not required.

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Informed consent

Since this was a Delphi method and a working group, the participating experts were not required to sign an informed consent form because they are considered advisors within the research team. However, an e-mail was sent explaining what the research consisted of, the institute that carried it out, the funders, the objective of the research and the work previously carried out. Subsequently, it was explained what the requested collaboration consisted of and the explanation of the research method used. In addition, in this e-mail they were offered the elaboration of a certificate of collaboration in the research. Finally, confirmation of participation was requested by e-mail.

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