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ORIGINAL ARTICLE

Validation of the IFBRA severity scale among Persons with Disabilities in Brazilian social welfare

Validação da escala de gravidade do IFBRA entre Pessoas com Deficiência no seguro social brasileiro

Heleno Rodrigues Corrêa Filho[1], Edgar Merchan-Hamann[2], Éverton Luís Pereira[2], Lívia Barbosa[2], Daniela da Silva Rodrigues[2], William Rosa Souza[2], Gladston Luiz da Silva[3], Maria da Graça Luderitz Höefel[2]

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ABSTRACT This article reports on Brazilian validation project of the Brazilian Functioning Index Adapted (IFBRA) for granting retirement benefits. It assesses the functionality of Persons with Disabilities (PwD), considering the Functional Independence Matrix (FIM), performance, barriers and severity classification. The study was developed in three phases: 1. Construct and content: Collective consensus and technical review groups on the relevance of the object, measures, scope, domains and questions; 2. Face validity: National purposive sampling on acceptability, social, cultural, and linguistic interpretation; and 3. Accuracy: National census survey for reference standards; sensitivity, specificity, and effectiveness. A central in-person national training session, twelve national video conferences and six regional training sessions did validate the combination of International Classification of Functioning, FIM, and ancillary measures. Qualitative interviews that involved physicians, social workers and PwD policyholders in five Brazilian regions found the IFBRA acceptable and interpreted it homogeneously. A national census survey analyzed the agreement between 17,350 PwD policyholders and IFBRA applicators on their perception as to severity. Maximum effectiveness was achieved when two evaluators did match. IFBRA was considered valid as to relevance, comprehensiveness, acceptability, interpretation and accuracy, turning to be a new reference standard. The provisional classification used prior to validating the IFBRA was considered restrictive and unfair.

KEYWORDS Disability evaluation. Validation studies. Reproducibility of results. Pension. Retirement.

RESUMO *Este artigo relata o projeto brasileiro de validação do Índice de Funcionalidade Brasileiro Adaptado (IFBRA) para conceder aposentadorias. Avaliou a funcionalidade de Pessoas com Deficiência (PcD) combinando Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF), Medida de Independência Funcional (MIF), desempenho e barreiras, e classificou gravidade. O estudo teve três fases: 1. Construto e conteúdo: Consensos coletivos e grupos de revisão técnica sobre pertinência entre objeto, medidas, abrangência, domínios e quesitos; 2. Validade de face: Amostra intencional nacional sobre Aceitabilidade, interpretação social, cultural e linguística; e 3. Acurácia: Inquérito censitário nacional para padrão de referência; sensibilidade; especificidade e efetividade. Uma capacitação nacional presencial central, doze videoconferências nacionais e seis capacitações regionais validaram a combinação de CIF, MIF e medidas acessórias. Entrevistas qualitativas em cinco regiões brasileiras com médicos, assistentes sociais e segurados PcD avaliaram o IFBRA como aceitável e o interpretaram homogeneamente. A Pesquisa Censitária Nacional analisou a concordância entre 17.350 segurados PcD e aplicadores do IFBRA sobre a percepção subjetiva de gravidade. A efetividade máxima foi obtida quando combinados dois avaliadores. O IFBRA foi considerado válido quanto à pertinência, abrangência, aceitabilidade, interpretação e acurácia, constituindo novo padrão de referência. A classificação provisória utilizada antes de validar o IFBRA foi considerada restritiva e injusta.*

PALAVRAS-CHAVE *Avaliação da deficiência. Estudos de validação. Reprodutibilidade dos testes. Pensões. Aposentadoria.*

[1] Universidade do Distrito Federal (UnDF), Escola Superior de Ciências da Saúde (ESCS) – Brasília (DF), Brasil.
helenocorrea@uol.com.br

[2] Universidade de Brasília (UnB), Departamento de Saúde Coletiva (DSC) – Brasília (DF), Brasil.

[3] Universidade de Brasília (UnB), Departamento de Estatística (DE) – Brasília (DF), Brasil.

Introduction

According to Brazilian Census of 2010 by the National Institute of Geography and Statistics (IBGE), from the nation's total population of two hundred million inhabitants, a fraction of forty-five million (45,606,048) were registered as insured tax payers at Brazilian National Social Security. They belonged to the formal job market with at least one registered employment position per year. A subset of 23.9% of those insured contributing workers was annotated as having one or more declared disability – either physical, hearing, motor, mental or intellectual[1].

Despite Article Five of Brazilian Constitution, which reinforces universal and equal rights beyond any distinction based on ability or disability, Person with Disabilities (PwD) (Pessoas com Deficiência – PcD) are still discriminated with regards to accessibility to education, health services, transportation, information, communication, social participation, and jobs[2].

Since the 1990's, federal public policies started to surpass these inequalities by promoting inclusive measures at national level, so as to allow PwD to enter the job market. The right to a preemptive proportion of the labor force was established by Federal Law Nr. 8,213 as of July 1991, in fixed ratios according to the company size by number of employees: 2% up to 200; 3% from 201 to 500; 4% from 501 to 1,000; and 5% of 1,001 and above[3].

In 2007, Brazilian government ratified the 2006 United Nations Convention on the Rights of Persons with Disabilities. In 2008, the National Congress voted a referendum to the UN Convention that built up the Brazilian Constitutional Amendment #45. All public policies at federal, state and municipal levels were then obliged to abide by the new Amendment, by means of an adequate review of their stated rules, regulations and laws[4].

By that time, the Brazilian Secretariat of Human Rights (Secretaria de Direitos Humanos – SDH) was a ministerial branch of the Presidency Office. The SDH contracted a Brazilian Research and Development NGO – Instituto de Estudos do Trabalho e Sociedade (IETS) – to develop a scale to measure and qualify the type and intensity of disabilities presented by PwD. The result was, in 2012, the Índice de Funcionalidade Brasileira (IFBR) – (Brazilian Functionality Index), aimed at recognizing rights to public policies benefits[5,6].

Brazilian National Congress passed the Complementary Law Nr. 142/2013 to promote both the UN Convention and the 45th Amendment, requiring in activity PwD to access the right to anticipate their retirement in a fraction of the regular contributive time valid for all other people. The National Institute of Social Security (INSS) was in charge of that task.

Those rights were graded according to the severity of disabilities assigned to workers, and rated as severe, moderate, light, or 'undefined' (with no right to benefits), by the newly adapted form of the IFBR, renamed Brazilian Functioning Index Adapted (IFBRA) in 2013, where 'A' would go to 'adapted for retirement concessions'[7,8].

The IFBRA included seven domains, totalizing 41 questions about personal activities based on a summary selection from the International Classification of Functioning, Disability and Health (ICF). The answers were marked with categorical scores to be summed up based on a categorical matrix with the Functional Independence Measures (FIM), that would consider other people's help, special goods and adaptive technologies, in comparison with others in the same social and cultural context.

A complementary evaluation adds a group of four questions with 'all or nothing' fuzzy criteria that would qualify and downgrade the IFBRA sum of scores for complete severe conditions of disabilities with aggravated dependence on motor or visual skills, communication and mental capacity since childhood. This matrix design combines concepts from public health and disabilities[9-11].

There was no stablished standard available to evaluate scores and determine the severity

of PwD's disability. There were neither historical precedents nor quantitative comparisons to categorize disabilities as severe, moderate, light or undefinable to accomplish what was stated by law[12].

This article describes how the project by the University of Brasília (Universidade de Brasília – UnB) Research Group was stablished to validate the IFBRA. We also present the general design and the results of constructing a reference scale as a standard categorical measure for further analysis.

Material and methods

We conducted a three-phase project: 1. Construct and contents: Evaluation by collective consensus and technical groups review of the pertinence among object, associate measures, comprehensiveness and adequacy of questions and domains; 2. Face validity: National convenience sampling to reach social, linguistic and cultural acceptability; and 3. Accuracy: National survey to determine: a reference standard; agreement; sensitivity; specificity and effectiveness.

Phase 1 comprised meetings and videoconferences with interested Brazilian researchers and publications on the issue of evaluating disabilities, together with INSS managers, physicians and social assistants involved in the national process of rating disability scores using the IFBRA.

At the first stage, a three day long national representative caucus started out the process in November 2013, with about two hundred participants. The attendees discussed the IFBRA structure, concepts of the judgment matrix involved, legitimacy of knowledge that gave ground to the 41 question content, and a field manual, besides their capacity to deploy the instrument and to disseminate its use among their companions in most Social Security agencies in Brazil. There were representatives of more than 150 agency facilities spread over five INSS regions of the Country.

The capacity building caucus was followed by national videoconferences with participants from all INSS regional offices, including those who attended the caucus, besides other physicians and social assistants designated to carry on PwD evaluation with the IFBRA.

A series of six regional and two central meetings provided the evaluation of IFBRA perspective of combining the matrix of ICF with FIM and the Fuzzy criteria. The groups of researchers, managers, physicians and social assistants discussed the contents adequacy and developed a number of changes to the new field manual.

Phase II assessed the IFBRA as to face validity through local visits, to interview PwD and their designated evaluators on the acceptability and interpretation of the forty-one questions of the scale. Researchers and research assistants visited sixteen different local INSS agencies in Brazil to conduct semi-structured interviews with voice recording and writing, meant to address a national convenience sampling aimed at accessing social, linguistic and cultural acceptability.

Phase III was performed analyzing the information from all 17,350 evaluations conducted in Brazil from November 2013 up to January 2016, comparing the automatic scores obtained by the nation's official governmental records of the IFBRA with the answers to three questions we added at the end. They enquired on the subjective perception of severity of PwD interviewed and their evaluators – a pair comprised by one physician and one social worker.

We asked them about their subjective perception of the severity of the disability, including the PwD's opinion. We did not assess work incapacity, as these were people who only attended to have the severity of their disability evaluated, considering they were working and contributing to social security. This generated a set of categories of severity that surpassed the automatic sum of scores of the IFBRA that allowed for internal comparison. This comparison could consider a national survey for the period from 2013 through 2016.

In the absence of any standard, our approach was to construct one reference scale, collecting, confronting and measuring opinions of those three persons involved in each interview. We intended to seek which of them, or which combination of their subjective opinions could lead to the best reference standard to set the three cut-off points in the sum of scores of the IFBRA to define the four categories of severity determined under Law Nr. 142/2013.

We built up three tables of pairs of interraters percent agreement and decided which one would be the best comparison standard to set the cut-off points. The specific contents of Phases I, II, and III comprised a panel of specialists and technicians, one qualitative evaluation with collective consensus, and a quantitative accuracy evaluation. Detailed methods and complete results attained are beyond the scope of this publication and will be presented elsewhere.

The project was submitted to the analysis according to the specific Brazilian legislation and approval by the Ethics Committee on Research with Human Beings of the University of Brasília, at the School of Health Sciences (UnB/FS). The full texts and the approval of the CAEE project 37058914.5.0000.0030 (Opinion: 1.024.284) are available at the website of the National Ethics Committee for Research with Human Beings, pursuant Federal Law Nr. 14,874, as of 05/28/2024[13].

Results and discussion

Results from phase one included consensus evaluation by INSS experts and four university researchers in 'one national capacity building central caucus, twelve national videoconferences, and six regional developing and training conferences'. Participant researchers in this phase belonged to the UnB, São Paulo State (USP), Juiz de Fora – MG (UFJF) and Federal University of Rio de Janeiro (UFRJ).

Each videoconference counted with the simultaneous participation of at least eight national regional offices, with physician and social assistants who were in charge of training and of conducting colleagues in new interviews so as to evaluate PwD with IFBRA. Participants in the discussions produced material about the scale and suggested changes to the field Manual, including several sentences and examples in detail.

Phase-One meetings produced written reports that brought up summary evidence that researchers and technicians did actually validate the construction of ICF, FIM – Functional Independence Scale – and accessory measures. Each section is dedicated to a three-hour videoconference to discuss one or two domains of the IFBRA. Questions raised were mostly about the comprehensiveness of queries, and on how homogeneous was the level of understanding to which interviewers should ask those questions.

All items of the IFBRA were maintained, and the preference of the groups pointed to explanatory additions to the field manual concerning linguistic adequacy, thus widening circumstances to apply the FIM criteria when deciding to register the score of social and environmental barriers specific to each working PwD.

Phase Two consisted of a nationwide qualitative sample of sixteen social assistants, seventeen physicians and forty-four PwD. Qualitative interviews in five Brazilian regions, with physicians, social assistants, and insured PwD, evaluated as acceptable, assigned IFBRA a homogeneous interpretation, and gave rise to demands for the exclusion and/or inclusion of new items to the scale in future remodeling.

Phase Three was a national survey that yielded more than seventeen thousand interviews (17,350) conducted by a pair of evaluators – one physician and one social assistant – with the PwD, prospective retirees from all twenty-six Brazilian states and the Federal District of Brasília.

We presented the age and sex profile and a summary of the types of disabilities of PwD interviewed in tables one and two. *Table 3* reports cut-off points derived from the percent agreement among raters and PwD. Missing records of subjective opinions of each one of the three people are responsible for the missing observations in the table totals under the total number of 17,350 respondents in Brazil during the period.

These seventeen thousand prospective retirees represented a small fraction of the three hundred thousand persons, 325,291 or 0.73% of the total of working PwD in the job market – people the managers of Brazilian National Social Security fears could show up at the INSS agency doorsteps.

That huge number of potential demands for anticipating retirement came from another census from the 'Yearly National Registry of Social Interests on Hired and Laid off Employees' (RAIS) from years 2010-2011 by the National Labor Department. This number excludes military and tenured public employees. If at one time all of those people would request the benefits under Law Nr. 142/2013, they could jeopardize the public budget, leading to a chaotic payment of retirement pensions[12]. Two years passed of spontaneous demands, results from our survey prove evident that this did not happen.

The INSS national survey of PwD demanding to qualify for the benefits of anticipating retirement yielded a two-year collection of spontaneous demands from workers that contributed to the National Social Security in this condition. Their ages and sex profiles are in *table 1*.

Table 1. Age and sex profile of prospective retirees among persons with disabilities who demanded evaluation with the IFBRA from October 2013 to January 2016 in Brazil

Age Group	Female	Male	Total	%
18-29	2	3	5	0.03
30-39	40	4	44	0.25
40-44	597	203	800	4.61
45-49	1856	981	2837	16.35
50-54	2660	1958	4618	26.61
55-59	2110	1299	3409	19.64
60-64	595	1530	2125	12.25
65-69	10	42	52	0.30
70-76	3	2	5	0.03
Ignored	3428	28	3456	19.93
Total	**11298**	**6047**	**17350**	**100.00**

Source: Author's own elaboration.

Note: Raw, unidentified individual data from DATAPREV – SUB System. (Five incomplete records were excluded).

Most working PwD were women (65%). The seven-number summary of age distribution was: minimum=19.0; mean=53.0; median=53.0; mode=55.0; Q1=49.0; Q3=57.0; and maximum = 76.0 years old. These numbers describe an almost normal age distribution of the PwD, where median, mode, and mean coincide, and the digits distribution across the table

resembles a 'stem and leaf display' centered at the median age group (Kurtosis -0.18).

It is somehow surprising to see PwD aged more than 54 working in the official job market and contributing to the National Social Security. The explanation for this may be the return of elderly workers to INSS offices claiming previous contributions in jobs they had when they were still young, due to the benefits brought by the new law.

Missing observations are due to the fact that the IFBRA computer forms contained supplementary records for personal identification data, including sex, age, and type of disability. Administrative clerks typed this data in. It was solely destined to grant connection with consistent central individual data registry of the National Social Security at DATAPREV, the public company in charge of keeping national data records.

We compared the distribution of the automatic sum of scores for severity from the IFBRA with the categories of disabilities used to classify PwD workers who attended exams by pairs of expert physicians and social assistants. *Table 2* exhibits the cross tables for the official results of individual exams and the IFBRA classification after automatic computing scores. That classification used a previous governmental, not validated scale that established the provisional boundaries for severity scores. [Severe =<5739; moderate =<6354; light =<7584; no benefits=>7585].

Table 2. Type of disability and official automatic classification of severity profile among potential retirees considered persons with disabilities who required evaluation with IFBRA to anticipate retirement according to Brazilian Federal Law LC142/2013 from October 2013 to January 2016 in Brazil

	Severity Classification % by the IFBRA–PRISMA system					
Impairment Type	**Severe**	**Moderate**	**Light**	**Undefined**	**Total**	**Groups**
Hearing	1.9	3.5	8.0	2.4	15.8	---------
Hearing+multiple	0.6	0.5	1.0	0.3	2.4	18.2
Cognitive+mental	0.6	0.4	1.2	0.7	2.9	2.9
Motor	6.3	11.4	30.2	10.8	58.8	---------
Motor+multiple	0.4	0.1	0.2	0.1	0.8	59.6
Visual	1.9	1.2	5.2	4.3	12.5	---------
Visual+multiple	0.5	0.4	0.5	0.2	1.6	14.1
Ignored	0.3	0.3	2.0	2.7	5.2	5.2
Total	**12.4**	**17.8**	**48.4**	**21.5**	**100.0**	**100.0**

Source: Author's own elaboration.

Note: Raw, unidentified individual data from DATAPREV – SUB System.

Brazilian 2010 Census raised information about the proportions of PwD in the general population, with special interest focus on the age span from 15 to 64. Visual deficiencies were the most frequent (60% of PwD in the age span), followed by motor (18%); hearing (13.4%), and mental & intellectual (4.5%)[1].

This age span – from 15 to 64 –, revealed in Brazilian Census, coincides in major parts with PwD workers age, but in different proportions. Most part of PwD working population had

motor deficiencies, not visual, thus reducing to less than 25% the importance of persons with visual impairment amidst their prevalence in the general population, and multiplying the prevalence of PwD with motor impairments three times over their prevalence.

Severity standard

We used the 'Item Response Theory' to exclude from the scale twelve items that did not contribute to the sum of scores. The construction of the sum of scores used the Item Response Theory model.

Consequently, the total of 41 ICF items was reduced to 29 to calculate the sum of scores of the matrix. We then conducted a sensitivity analysis, considering the perception of physicians and social workers' agreement outside the IFBRA scale as the 'platinum' standard. The rationale for this choice is described in a publication elsewhere.

The cutoff points were adjusted to maximize sensitivity and specificity above 85%, using the best agreement of physicians and social workers independently and outside the IFBRA matrix scale.

The adoption of a new validated scale should modify the provisional one used for official purposes, so as to reach a better level of justice in recognizing severity levels for early PwD retirements. One implication of the change in the scale would be the inclusion of more people in severe and moderate levels, besides the reduction of persons considered not entitled to receive benefits as they would be considered 'without deficiency' or 'undefined level of severity of the deficiency'. The values of the new cut-off points are in *table 3*.

Table 3. Validated cutoff points compared with the provisional PRISMA official scale after applying better sensitivity parameters to recognize the severity of deficiency in the phase III study, 17,350 interviews from October 2013 through January 2016

Expected Official Percentiles before validating	PRISMA Official Cutoff points before validating	Prisma Scores for two evaluators	IFBRA Validated Cutoff Points	IFBRA Phase III Severity Spans <=
5%	-	2200	2200	Severe
10%	-	3200	3200	Severe
25%	Severe <	5740	5740	Severe
50%	-	6060	6060	<= Severe
75%	Moderate <	6355	6355	Moderate
90%	-	6950	6750	<=Moderate
95%	Light <	7585	7750	<=Light
100%	No Benefit	8200	8200	No Benefit

Source: Author's own elaboration.

Note: Raw, unidentified individual data from DATAPREV – SUB System.

These three cutoff points (<=) came from what was called the 'Platinum Standard', derived from the intersection group of perception on severity from the agreement between physicians and social workers (MD ∩ SW). This name was an alternative to the first concept of 'gold standard', which would be based on the retirees' opinions, and was

abandoned due to very low agreement with the perceptions of the pairs of professional evaluators, with a clear and paradoxical trend from PwD to underestimate their severity. This trend even surprised some evaluators' bias on the matter.

Diverging from common sense, this perspective showed up in the previous validation research phases one and two. It was considered a natural consequence as it would come from the social positioning of both groups – evaluators and prospective retirees –, as they faced legal rights and socially built concepts on what deficiency is.

After validating with the 'platinum criteria', the ideal cutoff point on severity adopted rose from 5,740 to 6,060, possibly doubling the number of those PwD recognized as persons with severe disabilities at the very origin of validation cases, from 2013-2016.

In addition, moderate and light categories should be amplified to allow for lessening the unjust disregard of denying recognition to PwD rights to their legal early retirement. Moderate severity would start at 6,356, and light, at 7,750. The category named 'no benefits' would only start at 7,750 points assigned by two evaluators. This would include a total of 5,29% more people recognized as PwD, especially with 24,63% more people classified as 'light' from those who were excluded from benefits.

Research limitations

The criticism over our research may come from the impossibility of standardizing, beyond the simple text of questions on the computers' screen, the way of asking questions and typing the answers all over the country, and to the cross-sectional nature of the survey.

It was not possible to know how many PwD did not spontaneously request the INSS exams due to disinformation or ignorance about their rights under the law. We could not retrieve a sample of non-respondents from the three hundred thousand-reference population under these conditions, and they are possibly twenty times our spontaneous demand in the country.

There is an implicit survival bias in the 17.35 thousand attendees to the national exams survey. Severe cases would not show up in cross-sectional exams. A PwD worker would have to survive and stand job demands until registering to count his/her contributive time to INSS. He/she would reach the expectancy of retirement after completing the minimum working/contributing time of twenty years (women) or twenty-five years (men) or reaching the ages 55 (women) or 60 (men), having contributed for at least 15 years[8,12].

It seems inevitable that those who fail to complete these contributive and working times would be the ones with the most severe disabilities, suffering from harder social and environmental barriers, less educated, and even suffering from aggravating competitive diseases over others who could keep on working.

Another limit to our inference on this national survey is the possible inadequacy of the cut-off values for the IFBRA to other countries or regions, despite our intention to report the method of selecting the best agreement to establish the standard above specific results.

Two sources did reinforce the strength of our consideration about the convenience of selecting a standard composed by the simultaneous evaluation of two professionals. We sought the best and less questionable agreement, and we looked into a national sample of 17,35 thousand evaluations under the simultaneous subjective perspective of three viewers of the PwD, one expert physician, and one social assistant. This gave us a list of 52.05 thousand subjective observations to compare and make such a choice.

Final remarks

We concluded that the official and provisional methods did use restrictive cutoff points in the sum of scores of the IFBRA that excluded PwD workers from benefiting from their rights, due

to under-estimating severity.

We concluded as well that the classification of severity that was less stressful to reach and more consensual occurred when both professionals did agree on the severity by using their subjective limits to establish a cutoff point. We found this condition in the intersection of their classification tables. A severe case classified accordingly by both of them would forcefully be acceptable by most other means.

After the general description of proceedings for specialists' consensus, qualitative analysis of acceptability, and quantitative assessment of the agreement on subjective criteria for evaluating severity, we decided that the IFBRA could be validated for accuracy, adopting the intersection of classification between expert physicians and social assistants.

This would bring stable comparisons so as to establish future cut-off points. Other researchers could apply this method in other national and cultural settings without mechanical transposition of any classification based on the sum of IFBRA scores.

We finally considered that, according to a new reference standard, IFBRA did prove good validity with reference to pertaining domains, comprehensiveness, acceptability, interpretation and accuracy. Further analysis will address steps of each one of the three validation phases.

Authorship contributions

Corrêa Filho HR (0000-0001-8056-8824)* designed quantitative methods of validation, articulated with statistics and software engineering controls to design computer program outputs, discussed analysis and wrote the text to this report. Merchan-Hamann E (0000-0001-6775-9466)* coordinated the academic research team, responded to search funding and finance execution and control, discussed methods and participated in the analysis in all steps, specially on epidemiology techniques, including review and dividing topics of each report. Pereira EL (0000-0002-7771-1594)* designed qualitative methods of validation, coordinated graduate students to engage in the research field, described and applied the training for the field teams, organized training to obtain uniformity in conducting field evaluations, and reviewed and discussed the report. Barbosa L (0000-0003-2268-3212)* designed qualitative methods of validation, coordinated graduate students to engage in the research field, described and applied the training for the field teams, reviewed and discussed the report. Rodrigues DS (0000-0001-7391-1794)* designed qualitative methods with regards to rehabilitation and severity evaluation, described and applied the training for the field teams, organized training to obtain uniformity in conducting field evaluations, reviewed and discussed the report. Souza WR (0000-0002-8915-4895)* designed data collection techniques, database formatting, software and data collection ongoing security, designed computer outputs for data analysis according to the statistical planning. Silva GL (0000-0001-9650-2993)* coordinated quantitative distribution of sampling design, planned for the analytical approach to determine type of data collection and computer outputs, executed analytical procedures on the Item Response Theory, and coordinated quantitative analysis adequate to multiple responses and disability domains with regards to the ICF. Höefel MGL (0000-0003-2176-5013)* executed field capacitation actions throughout the country, combining quantitative and qualitative approach to train data collection teams, reviewed and dis cussed the report. ■

*Orcid (Open Researcher and Contributor ID).

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Editor in charge: Maria Lucia Frizon Rizzotto, Universidade Estadual do Oeste do Paraná (Unioeste), Cascavel (Paraná/PR), Brasil. Lattes: http://lattes.cnpq.br/7877904356698023 – Orcid: https://orcid.org/0000-0003-3152-1362 – e-mail: marialuciarizzotto@gmail.com