

PILOTING A TOOL FOR DEPENDENCE ASSESSMENT IN PERSONS WITH DISABILITIES

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Abstract: Introduction: 3.2% of the Romanian population is registered as having various forms of disability. There are different types and degrees of disability, but provision of needed social services to these persons has wide variation due to the difficulty to assess their degree of dependence. Aim: Our study aimed to pre-test a new tool for assessment of dependence in persons with disabilities, in order to ensure equity in their access to the necessary social services. Methods: We developed a new tool for the assessment of dependence in persons with disabilities, based on five domains of activity, each having four to six sub-domains. Each sub-domain was scored as a Likert scale. We pre-tested the new tool in 20 persons with disabilities and in 10 persons without disabilities, assessing its reliability, internal consistency and validity. Results and discussion: At least moderate agreement was found for all the sub-domains (Cohen's Kappa > 0.500) and at least substantial agreement ($k > 0.600$) for all the domains in Group with disabilities and almost perfect agreement ($k > 0.800$) was found for all domains and sub-domains in the group of people without disabilities. Mean scores of disability by domain and sub-domain were significantly lower in the group without disability, compared to the group with disabilities (T student test, $p < 0.05$). Strong or moderate inter-item correlations were found between most of the items. The Cronbach's Alpha reached to 0.798 (normal) and 0.915 (standardized), proving a good internal consistency. A strong, positive and significant Spearman correlation ($r = 0.808$, $p < 0.001$) was found between the degree of dependence and the degree of disability. Conclusion: Our tool could be a valid instrument in assessing the dependency of the people with disabilities, but further research is necessary on a wider population.

Cuvinte cheie: dizabilitate, grad de handicap, dependență, echitate în acces, servicii sociale

Rezumat: Introducere: 3.2% din populația României este înregistrată ca având diferite forme de handicap. Există diferite tipuri și grade de handicap, dar furnizarea serviciilor sociale necesare acestor persoane variază foarte mult, datorită dificultății de evaluare a gradului lor de dependență. Scop: scopul studiului nostru este de a pre-testa un instrument nou de evaluare a dependenței persoanelor cu handicap, care să asigure echitate în accesul lor la serviciile sociale care le sunt necesare la nivel individual. Metode: am elaborat un instrument nou de evaluare a dependenței persoanelor cu handicap, bazat pe cinci domenii de activitate, fiecare domeniu conținând între patru și șase subdomenii. Fiecare subdomeniu a fost marcat ca o scală Likert. Noul instrument a fost pre-testat pe 20 de persoane cu handicap și pe 10 persoane fără dizabilități, evaluându-i astfel reproductibilitatea, consistența internă și validitatea. Rezultate și discuții: S-a evidențiat o concordanță cel puțin moderată pentru toate subdomeniile (Kappa Cohen / $k > 0.500$), o concordanță cel puțin substanțială ($k > 0.600$) pentru toate domeniile în grupul persoanelor cu handicap, iar în grupul persoanelor fără dizabilități, o concordanță aproape perfectă ($k > 0.800$), pentru toate domeniile și subdomeniile. Scorurile medii de dependență pe domeniu și sub-domeniu au fost semnificativ mai mici în grupul persoanelor fără handicap, față de lotul celor cu handicap (T student test, $p < 0.05$). Au fost determinate corelații inter-itemi puternice sau moderate între cei mulți dintre itemi. Alpha Cronbach a avut valoarea de 0.798 (normal) și 0.915 (standardizat), ceea ce a demonstrat o consistență internă bună. A fost determinată o corelație Spearman puternică, pozitivă și semnificativă ($r = 0.808$, $p < 0.001$) între gradul de dependență și gradul de handicap. Concluzie: instrumentul nostru poate fi un instrument valid de evaluare a dependenței persoanelor cu handicap, dar este necesară o cercetare ulterioară pentru a-l putea aplica extins în populație.

INTRODUCTION

United Nations has proclaimed that all human beings are born free and equal in dignity and rights and that everyone has the right to an adequate standard of living for the health and well-being of himself and of his family, including the necessary

social services, and the right to security in the event of disability.(1) Disability was defined by the World Health Organization as an umbrella term for impairments, activity limitations and participation restrictions, consisting in the interaction between individuals with a certain health condition

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and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports).(2)

At global level, over a billion people (15% of the world's population) have some form of disability and 110 - 190 million (2 - 4% of the world's population) people have significant difficulties in functioning and these numbers are expected to rise in the next future due to the population ageing.(3) At EU level, there are around 80 million persons (one to six citizens) having disability of various severity and, on another hand, people with disabilities have a poverty rate 70% higher than the average.(4,5)

Usually, people with disabilities have poorer health outcomes, lower education, less economic participation and higher rates of poverty compared to people without disabilities, because they experience barriers in accessing the basic services like health, education, employment, transport or information and these difficulties are exacerbated in less advantaged communities.(3)

Thus, there is a strong commitment at EU level to protect the right of people with disability, starting with the Treaty on the Functioning of the EU, that requires the Union to combat discrimination based on disability when defining and implementing its policies and to adopt legislation against such discrimination.(6) Also the Charter of Fundamental Rights of the EU states that "Human dignity is inviolable. It must be respected and protected", that "EU recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community" and also prohibits any discrimination on the basis of disability.(7)

Three years ago, EU has assumed a strategy aiming to empower the persons with disabilities, so that they can enjoy their full rights, and benefit from participating in society and in the European economy.(8) Eight main areas for action were considered in this document: Accessibility, Participation, Equality, Employment, Education and training, Social protection, Health, and External Action.(8)

In Romania, a lot of progress has been achieved after the communism failure in assuring the fundamental rights for persons with disabilities, but there are still many challenges to focus on. The general rights for persons with disabilities are mentioned in the Constitution of the country, in the sense of assuring the needed protection for them and implementing national policies for social inclusion and equality.(9) These rights are detailed in specific legislation and in the full respect for the general principles stipulated by UN, WHO and EU.(10)

The persons with disabilities have additional or special rights in relation to access to health care, education and professional training, work place, social support, appropriate environment (home, public environment, public transport, information), leisure time and juridical assistance. The main responsible for guarantying these rights are, of course, the public institutions and especially the local administration from the communities where they live.

There is a formal system in place for supporting the persons with disabilities. Legally, ten types of deficiencies (physical, somatic, auditive, visual, mental, psychic, associated, HIV/AIDS, rare diseases associated and deafness-blindness) and four degrees of deficiencies (minor, medium, marked, severe) are defined. The social benefits are granted to the person according to the degree of disability. The classification upon degree of disability is established by regulation comprising medical and psycho-social criteria.(11) Beside the financial support, the person with disability needs also social services according to his/her degree of dependence, but dependence

assessment is a major challenge, due to the huge variability of conditions and degrees of gravity. On the other hand, there is a wide variety of social services that could be needed, in relation to degree of dependence of the disabled.

The Local Public Administration is responsible for providing social support services and this difficulty of dependence's assessment induces, practically, variability in evaluation of needs for social support and also differences in access to necessary services.

PURPOSE

Our study aimed to pre-test a new tool for assessment of dependence in persons with disabilities, in order to ensure equity in their access to the necessary social services.

METHODS

We developed a new tool for assessment of dependence in persons with disabilities, based on five main domains of activity, each having four to six sub-domains (table 1). Each sub-domain was scored as a Likert scale from 1 to 5, where one represented the normality and 5 the highest degree of dependence. The total score could range from 0 to 125. A relative importance was established by weight allocation, based on expert opinion. An advisory committee composed by seven persons with at least five years of experience in evaluation of people with disabilities allocated weights to each domain and sub-domains (table no. 1).

Table no. 1. Main domains and sub-domains of the scale

Domains	Weight	Sub-domains	Weight
Understanding and Communication	18%	Focusing the attention	16%
		Problems solving	15%
		Learning and abilities	17%
		Sight	19%
		Hearing	15%
		Communication	18%
Mobility	23%	Transfer	25%
		In-house mobility	21%
		Outside mobility	20%
		Using the medical devices	18%
		Using the stairs	16%
Self Care	26%	Feeding	23%
		Body hygiene	20%
		Getting dressed	18%
		Continence	23%
		Self health care	16%
Self Managing the House	19%	Housekeeping	24%
		Cooking	31%
		Washing clothes	22%
		Budget administration and shopping	23%
Social Involvement	14%	Interpersonal relationship	24%
		Using phone	17%
		Education, working	24%
		Using transport	22%
		Community living	13%

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The scale was pre-tested in 20 persons with disabilities, which came to the routine evaluation during the March 2012 and in 10 healthy persons.

Data analysis: The quantitative variables were assessed for normality using the Shapiro Wilk test. A score by domain and an overall score were calculated, by summing the products between the allocated score and the weighting factor.

The mean scores and correlations between domains and sub-domains were examined. For assessing reliability, two trained social workers applied the scale differently to each person in the same day. Internal consistency was evaluated by Cronbach's Alpha normal, standardized and calculated if item deleted. The validity was examined by Spearman correlation between disability score and the degree of disability.

The analysis was performed using the Statistical Package for the Social Sciences (SPSS) v 17.0.

RESULTS AND DISCUSSIONS

697169 persons were formally registered in Romania as having a disability at the end of 2012, meaning 3.2% of the general population (which is much below the EU or global proportion of persons with disabilities). Among these persons,

91% were adults and the rest children (under the 18 years of age) and 2.5% of them were institutionalised.(12)

From those persons, 34% and 54% have severe and marked disability. Most frequent types of disabilities are somatic, physical, mental and visual that account each more than 15% of the total number.

In our pilot study, we had 12 women and 8 men in the disability group (group A, or test group) and 1:1 gender ratio in the healthy group (group B or control group).

Age distribution ranged from 18 to 86 years in group A (mean: 60 years; median 59.5 years) and from 25 to 75 years in group B (mean: 42 years; median 42.5 years). In both groups age had a normal distribution ($p > 0.05$, Shapiro Wilk test).

The reliability was assessed by Cohen's Kappa and we obtained at least moderate agreement for all the sub-domains ($k > 0.500$) and at least substantial agreement ($k > 0.600$) for all the domains in Group A. In group B (people without disabilities we obtained almost perfect agreement ($k > 0.800$) for all domains and sub-domains.(13)

The scores characteristics by domain and sub-domain are shown in table 2.

Table no. 2. Centrality and variance of scores by domain and by group

Domain		Understanding and Communication		Mobility		Self care		Self Managing the House		Social Involvement		Overall score	
		A	B	A	B	A	B	A	B	A	B	A	B
Group													
Mean			4.84	16.47	5.75	19.41	6.50	20.16	4.75	10.93	3.50	77.49	25.34
95% Confidence Interval for Mean	Lower Bound	8.64	4.53	12.33	NA	15.48	NA	18.22	NA	9.13	NA	66.21	25.03
	Upper Bound	12.40	5.16	20.62	NA	23.34	NA	22.09	NA	12.73	NA	88.78	25.66
Median			4.50	14.98	NA	19.92	NA	21.57	NA	10.82	NA	89.59	25.00
Std. Deviation			.442	8.86	NA	8.40	NA	4.14	NA	3.84	NA	24.12	.442
Minimum			4.50	5.75	NA	6.50	NA	10.59	NA	3.50	NA	35.37	25.00
Maximum			5.36	28.75	NA	32.50	NA	23.75	NA	16.73	NA	111.37	25.86
Range			.86	23.00	NA	26.00	NA	13.16	NA	13.23	NA	76.00	.86

NA is due to obtaining the same score for all the sub-domain of the same domain.

Mean score was significantly lower in Group B compared to Group A (T student test, $p < 0.05$).

Internal consistency was assessed only for the group A, using Cronbach's Alpha direct, standardized and if item deleted. Due to the similarity of scores for all the sub-domain of the same domain in group B calculation of Cronbach alpha was not possible.

The inter-item correlation matrix showed positive, strong or moderate correlation between all the items, except correlations between understanding – mobility (weak and negative, $r = -0.077$, which is natural because the level of understanding is not necessary related to mobility) and correlation understanding – self care, which is also positive, but weak (table no. 3).

The Cronbach's Alpha value reached to 0.798 (values above 0.700 are considered acceptable), proving a good internal consistency.

The standardized Cronbach's Alpha reached to 0.915. Cronbach's Alpha decreased for most of the item deletion, except Understanding and Overall, but these values remained close to initial Cronbach's Alpha and below its standardized value, suggesting that corresponding items could be retained (table no. 4).

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Table no. 3. Inter-item correlation matrix, Group A

	Understanding and Communication	Mobility	Self care	Self Managing the House	Social Involvement	Overall score
Understanding and Communication	1.000	-.077	.230	.453	.730	.412
Mobility	-.077	1.000	.837	.709	.434	.837
Self care	.230	.837	1.000	.873	.703	.956
Self Managing the House	.453	.709	.873	1.000	.769	.934
Social Involvement	.730	.434	.703	.769	1.000	.817
Overall score	.412	.837	.956	.934	.817	1.000

Table no. 4. Cronbach's Alpha if item deleted

Domain	Cronbach's Alpha if item deleted
Understanding and Communication	.813
Mobility	.732
Self care	.704
Self Managing the House	.767
Social Involvement	.781
Overall score	.826

A strong, positive and significant Spearman correlation ($r=0.808$, $p<0.001$) was found between the degree of dependence and the degree of disability, proving that our tool could be a valid instrument in assessing the dependency of the people with disabilities.

CONCLUSIONS

A tool for assessing the degree of dependency is very necessary and useful for the local public authorities in order to provide equal access to social services for all the persons with disability. Our piloted tool has proven adequate reliability, internal consistency and validity to be used in the above mentioned purpose. Further research is necessary on a wider population, in order to extend its use in the field.

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