

Environmental needs in childhood disability analysed by the WHO ICF, Child and Youth Version

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ABSTRACT

INTRODUCTION: The WHO has launched a common classification for disabilities in children, the International Classification of Functioning, Disability and Health, Child and Youth Version (ICF-CY). We wanted to determine whether categories of the environmental (e) and the body functions (b) components of the classification could address environmental needs in children with different disorders and various disability severities.

METHODS: A set of 16 e categories and 47 b categories were selected and worded to best enable parents to describe children's everyday support needs and environmental influences through interviews in their own homes.

RESULTS: Of the 367 invited parents, 332 (90.5%) participated, providing data on children with spina bifida, spinal muscular atrophy, muscular disorders, cerebral palsy, visual impairments, hearing impairments, mental disability and disabilities following brain tumour treatment. The mean age of children across disabilities was 9.4 years (range: 1.0-15.9). The mean e code score was 35.7 (range: 4.0-64.0), and the mean b code score was 32.2 (range: 0.0-159.0). The most urgent needs as detected by qualifier 4 environmental categories scores were common among children with complex disorders and issues related to health professionals, legal services and health services.

CONCLUSIONS: Parents understand the environmental and body function components in a meaningful manner and the codes seem to be valid. Special emphasis should be given to environmental issues for children with more complex disabilities. There was no correlation between the severity of a disability and environmental issues, indicating that each child's needs were basically met, irrespective of disability severity.

FUNDING: partnership project § 16, 21, 31 administered by the Danish Health Authority.

TRIAL REGISTRATION: not relevant.

Assessing disabilities and related environmental factors in children is important for daily clinical practice, for rehabilitation and for the development of new intervention strategies and research [1]. In 2001, the World Health Organisation (WHO) released the International Classification of Functioning, Disability and Health (ICF) to provide a common framework facilitating the assessment of disabilities for clinical and research use; a Child

and Youth version (ICF-CY) was released in 2007 [2, 3]. The classification is based on a conceptual model that encompasses the individual's health conditions and factors related to body function and structure, daily living activities and participation in social activities and other relationships. These factors should be evaluated in relation to environmental factors and personal factors, which may have either a positive or a negative influence on the impact of the disability in question.

The ICF and ICF-CY use the same alphanumeric coding system. Each component is designated using a letter where "e" stands for the environmental component and "b" stands for the body functions component. Each component is subdivided into chapters and categories. Categories are further subdivided into the qualifiers 0, 1, 2, 3 or 4 each of which is designated a code [2, 3].

The present article focuses on how ICF-CY can be understood and used and how it functions [4-13]. We have previously described psychometric and Rasch data on b codes and d codes in detail [14-16].

In this open-field pilot research study, we analysed and compared psychometric data on environmental e code and body function b code scores. We further described relationships for the purpose of defining focus areas to improve healthcare by employing the ICF-CY. Data were obtained simultaneously in direct dialogue with parents.

METHODS

Study design and children with disabilities

No e or b category data set has as yet been published. Categories were therefore selected by one child neurologist on the basis of an a priori clinical judgement about which categories would best cover the range of disability under investigation. Both the categories and the wording were subject to several revisions during a preliminary round counting 25 out of the 332 interviews made with parents. The set of categories and wordings resulting from this process was used throughout the rest of the study irrespective of disorder, severity of disability, age and gender. The set included 16 e and 47 b categories. The categories were used to describe the performance of 332 children in activities of daily living and the environmental influences on those activities.

ORIGINAL ARTICLE

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Dan Med J
2016;63(6):A5238

All children and their parents were known to us beforehand; most had been followed clinically for some years at the Department of Child Neurology at the H. C. Andersen Children's Hospital, Odense University Hospital, Denmark.

Qualifier level wording

As the ICF, ICF-CY uses a universal scoring system consisting of a 5-point Likert scale with qualifiers worded as follows for e qualifiers (left) and b qualifiers (right):

0: No barrier	No impairment
1: Mild barrier	Mild impairment
2: Moderate barrier	Moderate impairment
3: Severe barrier	Severe impairment
4: Complete barrier	Complete impairment

To enable a more detailed discussion of the child's needs rather than simply focusing on the meaning of these basic definitions, the e code qualifier levels were used to describe satisfaction with support in terms of need for improvement and urgency for change.

The wording was as follows:

- 0: Satisfied; services, equipment and/or environment are functioning effectively.
- 1: Satisfied, but there is room for minor improvement.
- 2: Somewhat satisfied, but improvements should be made.
- 3: Not satisfied; improvements should be made within 3-6 months.
- 4: Not satisfied; there is an urgent need for improvement.

Similarly, b-code satisfaction levels were applied as follows:

- 0: Child's ability is as expected for his or her age.
- 1: Child has difficulties, but his or her functioning is still in the expected range for his or her age.
- 2: Child needs help with body functions, activities and participation.
- 3: Child needs help and care; he or she has only limited abilities with respect to body functions, activities and participation.
- 4: Child is totally dependent on others for body functions, activities and participation.

The selected e codes are listed in **Table 1**. The b codes were selected to cover a broad range of body functions [14].

Procedures

The ICF-CY data sheet and information on the study's aims and procedures focusing on the interviews were given by the child neurologist to all families who were eligible for participation. After 2-3 weeks, families were contacted by phone or in person at their home if they could not be reached by phone. The decision about participation was taken by parents alone and was entirely voluntary. Upon acceptance of participation, appointments were then made and home visits conducted. All children had assignments at the hospital and were known by us. Decisions about participation did not affect the child's future clinical assignment.

Definition of disabilities

Children have complex disabilities if more than one area of function is affected. For example, children with cerebral palsy have motor function difficulties, but may also suffer from cognitive difficulties and/or impaired vision.

Psychometric evaluation of International Classification of Functioning, Disability and Health, Child and Youth Version code data

Within-scale analysis of responses was undertaken. To summarise scores to form a single general assessment score, the codes needed to be internally consistent and to measure the same underlying disability construct.



TABLE 1

International Classification of Functioning, Disability and Health, Child and Youth Version e codes selected in order to effectively capture the needs of children across eight different discharge diagnoses and associated diagnoses.

e code	Description (examples)
e1151	Assistive products and technology for personal use in daily living (orthotic devices, bladder stoma, baclofen pumps and remote control systems)
e1201	Assistive products and technology for personal indoor and outdoor mobility and transportation (walking devices, wheelchairs and transfer devices)
e1251	Assistive products and technology for communication (writing devices, computer software, hearing aids, glasses and cochlear implants)
e1301	Assistive products and technology for education (specialised computer equipment, toys and books)
e150	Design and construction of products and technology for public buildings (entrance facilities, elevators, stairs, chairs, tables, toilets, screens and signs)
e155	Design and construction of products and technology for private buildings (entrance facilities, stairs, elevators, chairs, tables, toilets, kitchens, bathrooms and lifts)
e240	Light (intensity, quality, contrasts and computer screens)
e250	Sound (intensity, quality and screens against disturbing or background noise)
e340	Personal care providers and personal assistants (respite family care, respite institutions and personal assistants)
e355	Health professionals (doctors, nurses, physiotherapists, occupational therapists, speech therapists and social workers)
e360	Other professionals (teachers, nursery assistants and recreation centre teachers)
e460	Social attitudes (opinions or beliefs)
e540	Transportation services (cars, car lifts, parking, buses, trains and personal aids for transportation)
e550	Legal services, systems and policies (grants, laws, regulations, standards and grant administration)
e580	Health services, systems and policies (prevention, treatment, rehabilitation and promotion)
e585	Education and training services, systems and policies (knowledge of disability, education and apprenticeship)

It was recommended that the correlations between the contributing e and b qualifiers and the total score computed from the remaining codes – the corrected item-total correlations – should exceed 0.40 [17].

Data targeting was estimated from the code scale midpoint, range and observed scores as were floor and ceiling effects.

Reliability was operationalised as internal consistency and estimated with Cronbach's alpha coefficient for average inter-item correlation.

Validity was determined by non-statistical evaluation of the code scale's clinical meaning. Within-scale factor analysis, including the corrected item-total correlations, and Cronbach's alpha were used to calculate a score for a general assessment childhood disability construct. The standard error of measurement and 95% confidence intervals were calculated.

The relative distribution of qualifier-4 scores was calculated as average and percentage and further related to each individual child within the respective disability.

Stata 12 (StataCorp, TX, USA) was used for data analysis.

Approval: The protocol was accepted by and registered with the Danish Data Protecting Agency (DOK121763). Approval of the protocol was obtained from the Danish Health Authority (Project 7-202-05-207/8).

Trial registration: not relevant.

RESULTS

Descriptive characteristics

After 367 eligible children had been identified, the parents of 35 children decided not to participate for various reasons; thus, 332 children (90.5%) were included, and their parents or caregivers completed the interview. The mean age of the children included was 9.4 years (range: 1.0-15.9 years).

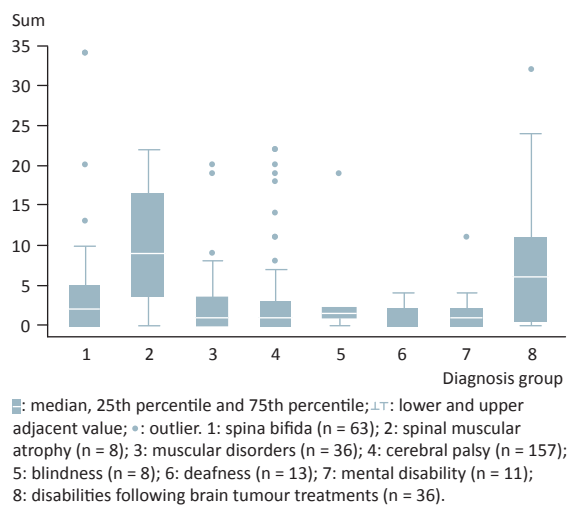
The children of the participating parents were grouped according to the child's discharge diagnosis. In total, 63 children had the discharge diagnosis spina bifida, eight had spinal muscular atrophy, 36 had muscular disorders, 157 had cerebral palsy, eight were visually impaired, 13 were hearing impaired, 11 had a mental disability and 36 had been treated for brain tumours.

Results of psychometric analyses of e and b codes

The mean score for e codes was 35.70 (range: 4-64), and the mean score for b codes was 32.17 (range: 0-159). The corrected code-total correlations were low for e codes (0.05) and high for b codes (0.70). The mean inter-code correlation was 0.26 (range: 0.01-0.85) for e codes and 0.50 (range: 0.01-0.97) for b codes. The correlation

FIGURE 1

Sum of 16 e code qualifiers across diagnosis groups.



between e codes and b codes was 0.13. Standard error of measurement was 2.15 and 5.12 for e codes and b codes, respectively, and corresponding 95% confidence intervals were ± 4.21 and ± 10.03 , respectively.

A score of 0 was recorded for 2,408 out of 5,644 e code responses (43%), indicating that a fairly high proportion of children were functioning well and did not need environmental adaptations.

A score of 0 was recorded for 796 out of 15,604 b code responses (5.1%). This was explained by the fact that some children were not old enough to be evaluated with respect to certain b codes.

The sum of e code qualifiers across diagnosis groups showed a greater spread among children with more complex disabilities, demonstrating a more diverse set of environmental demands in daily living (Figure 1).

The sum of e code scores related to b code scores showed a low relationship, with a correlation factor (R) of only 0.13. This demonstrates that children with higher b code scores had no greater environmental barriers; at least as documented by the selected e code qualifier scores.

Qualifier data on specific e categories demonstrated a relatively higher proportion of scores 1 and 2 when related to e355 (health professionals), e550 (legal services) and e580 (health services) (Table 2).

When dealing with qualifier score 4, in which the most urgent needs were not yet met, the relatively highest contribution of this score was noticed among children with severe disabilities (muscular atrophy) and complex disabilities (spina bifida, muscular disorders, cerebral palsy and disability following treatment for brain tumours) (Table 3).

DISCUSSION

The present study was undertaken to determine how ICF-CY environmental factors may be used in clinical practice to better address the needs of children with disabilities and to identify ways in which healthcare can be improved if ICF-CY is to be implemented. A sample of 332 children with various diseases was analysed, encompassing the broadest possible range of disability – ranging from children with almost no symptoms to children who were totally physically dependent, mentally disabled and vision- and hearing-impaired.

Selection of categories was done by one child neurologist on the basis of previous clinical experience with the children and their families. However, prior to larger-scale implementation of the ICF-CY in healthcare, decisions on category selections should be based on national or international consensus.

In order to facilitate the use of qualifiers by providing definitions that were as explicit as possible, the qualifiers were worded in terms of the level of help needed by the child for daily living activities, relative to unimpaired peers of the same age. Once explained in conversations during visits, parents and caregivers had no difficulty judging which qualifier level was most appropriate for their children. It is believed, but not proven, that such wording of e codes will help parents relate

more closely each single code to their issues of concern in daily living and dialogue with health authorities. In the same way, wording of b codes may help parents relate each single code better to disability as perceived in their own child.

Qualifier wording in terms of the need for help were applied universally regardless of disease diagnosis, although the means of getting help varied. For the very same reason, it is necessary to know the details of an individual's condition. ICD-10 codes and ICF-CY codes are therefore considered to be complementary and should be considered in conjunction in future data system implementations, clinical data handling, communications, evaluations and research.

Environmental factors (e codes) are contextual factors in the ICF-CY classification. The e codes relate to factors outside the child. The use of these codes is somewhat variable because of differences in need owing to age, disability type and disability severity. Herein, the environmental e codes were used to capture the need for changes in the environment in the broadest sense, from physical materials and assistive technology to health professionals and changes of the legal context (Table 1). Furthermore, we deliberately chose the home as the setting for interviews to build an impression of the environment and aids designed for each child. We

TABLE 2

Number (%) of selected e code sum scores for the sample of 332 children.

Gradient	e code							Average
	e1151	e1201	e1251	e1301	e355	e550	e580	
0	172 (52)	120 (36)	99 (30)	57 (17)	225 (68)	200 (60)	225 (68)	156 (47)
1	14 (4)	33 (10)	16 (5)	8 (3)	57 (17)	54 (16)	42 (12)	32 (10)
2	1 (0)	4 (1)	9 (3)	8 (2)	30 (9)	23 (7)	9 (3)	12 (4)
3	4 (1)	4 (1)	3 (1)	5 (2)	7 (2)	4 (1)	2 (1)	4 (1)
4	4 (1)	4 (1)	4 (1)	4 (1)	6 (2)	5 (2)	5 (1)	5 (1)
Not (yet) considered relevant ^a	137 (42)	167 (51)	201 (60)	250 (75)	7 (2)	46 (14)	49 (15)	122 (37)

a) Individual children in whom assistive products, technologies or services represented by corresponding e codes are not or not yet considered relevant by parents due to mild degrees of disability or young age.

TABLE 3

Number (%) of e code qualifier gradient 4 scores and diagnosis groups for the 332 children in the sample.

Gradient 4	e1151	e1201	e1251	e1301	e355	e550	e580	RDS (%)	RDS/EIC
Spina bifida (n = 63)	1 (25)	21 (18)	1 (25)	0 (0)	0 (0)	1 (20)	0 (0)	24 (16)	0.38
Muscular atrophy (n = 8)	0 (0)	3 (2)	0 (0)	1 (25)	0 (0)	1 (20)	0 (0)	5 (3)	0.63
Muscular disorders (n = 36)	0 (0)	22 (18)	0 (0)	1 (25)	0 (0)	0 (0)	0 (0)	23 (16)	0.63
Cerebral palsy (n = 157)	1 (25)	65 (54)	1 (25)	2 (50)	1 (17)	0 (0)	2 (40)	72 (48)	0.45
Visually impaired (n = 8)	0 (0)	2 (2)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	2 (1)	0.25
Hearing impaired (n = 13)	0 (0)	1 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)	0.07
Mental disability (n = 11)	1 (25)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)	0.09
Brain tumours (n = 36)	1 (25)	6 (5)	2 (50)	0 (0)	5 (83)	3 (60)	3 (60)	20 (14)	0.55

EIC = each individual child; RDS = relative distribution of scores.

believe that we would thus best understand the parent's assessments.

A comparison of diagnostic categories showed that children with spinal dystrophies and children who had been treated for brain tumours had the greatest needs for environmental changes (Figure 1). Children with both motor and mental difficulties, spina bifida, muscular disorders and cerebral palsy also had a relatively comprehensive need for environmental topics related to health services and legal issues (Table 2), and the greatest number of urgent needs with high (qualifier 4) scores also belonged to this group of children (Table 3). In daily clinical practice, especially among children with minor motor disabilities, concomitant mental difficulties are often not easily seen or experienced by health workers. Therefore, parents often need to explain this repeatedly and argue on behalf of their children; these parents therefore choose higher environmental qualifier scores.

It is important to note that issues related to equipment did not render high environmental qualifier scores. When we visited the homes, a striking finding was that each and every home was well-equipped with aids. Thus, environmental qualifier scores did not illustrate a lack of equipment per se, but may rather reflect some difficulties with issues related to personal help or the process of getting support to children whose difficulties are predominantly mental.

In general, however, we observed no favouring of children with greater or lesser disabilities, as we found no relationship between environmental (e code) qualifier scores and body function (b code) qualifier scores.

CONCLUSIONS

ICF-CY environmental e and body functions b categories and codes can be applied to detect needs in children with disabilities and especially so with regards to more complex issues. We believe that ICF-CY could become a valid tool in health services for children with disabilities, their parents and for society in general, especially as a tool for health services quality development. Very importantly, the ICF-CY could provide parents with a better and more quantified, valid and assessable way to advocate the needs of their children with disabilities.

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ACCEPTED: 18 March 2016

CONFLICTS OF INTEREST: Disclosure forms provided by the authors are available with the full text of this article at www.danmedj.dk

ACKNOWLEDGEMENTS: We are deeply grateful to all participating parents. The following paediatricians visited the families of children with disabilities following treatment for brain tumours: *Lone Walentin Laulund, Katrine Rytto Bergstein, Nina Szomlajski and Malene Nygaard Johansen*.

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