International Classification of Functioning, Disability and Health in a cohort of children with cognitive, motor, and complex disabilities

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The recently endorsed World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) is proposed as a new tool to describe human functioning and health in a multiprofessional approach for individuals of all ages. Its application to paediatric neurorehabilitation may be of great help, especially in children with complex disabilities. However, experience with its application in this field is still limited. We tested the application of ICF in 40 children (26 males, 14 females; age range 3 to 18 years; mean age 11 years 1 month, SD 5 years 3 months) with various types and degrees of disability. We tested the applicability and reliability of the classification, and studied its correlation with well-established measures of functioning (Verbal IQ; gross motor function measure; functional independence measure). The ICF proved to be applicable and reliable, and strongly correlated with established scales. However, several of the Activity and Participation components do not fully capture the developmental nature of many abilities of children. Our study, although acknowledging the universal application of the ICF, and the ICF's value as a clinical tool, calls for its specific adaptation to accommodate better the peculiarities of child functioning and disability.

See last page for list of abbreviations

In recent decades there has been a growing interest in complementing diagnostic classifications (e.g. International Classification of Diseases [ICD], World Health Organization [WHO] 1992; and the Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association 1994) with functional classifications for complete information on health-related conditions.

Especially in chronic disabling conditions, it is essential to document the impact of health status on the functioning of the person, and to change the focus from disease to the consequences of disease, as a result of interactions between personal and contextual factors. Such a shift can lead to more accurate planning, and a more effective allocation of resources (Simeonsson et al. 2000, Dahl 2002).

In 1980, the World Health Organization (WHO) issued the first International Classification of Impairments, Disabilities and Handicaps (ICIDH; World Health Organization 1980), which provided a conceptual framework for the description and functional classification of the three dimensions of disability (impairment, disability, and handicap), and which included an index of severity and prognosis.

ICIDH-2, the revised version of ICIDH, was published in 1997 after extensive research and review of models of disability. In its subsequent versions, β-1 and β-2 (WHO 1997, 1999; Bickenbach 1999), it introduced a bio-psychosocial perspective, and focused on components of health rather than on consequences of diseases, thus offering a more neutral view of functioning in health-related conditions. International experience supported such a conceptual model and a multidimensional approach to the complexity of disability (Bickenbach et al. 1999, Gray and Hendershot 2000, Halbertsma et al. 2000, Johnston and Pollard 2001, World Health Organization 2001).

The revised version of the original ICIDH was presented at the WHO Executive Board in January 2001 and then approved in May 2001 by the WHO General Assembly as the International Classification of Functioning, Disability and Health (ICF; WHO 2001).

Functioning is described as the dynamic interaction among three dimensions: body functions/structures, activity and participation, and environmental factors. Every component is subdivided into domains that encompass anatomical or physiological systems (Body Functions and Structures), life areas (Activity and Participation), and physical, social, and attitudinal environment (Environmental Factors), in which alphanumeric codes describe in detail specific aspects of human functioning (e.g. a person with myopia wearing glasses would be described by the codes: b156=perception functions; s220=structures of the eyeball; d110=watching; e115=products and technology for personal use in daily living). The letter before the numbers specifies which dimension is described (b, Body Function; s, Body Structure; d, Activity and Participation; e, Environmental Factors), the first digit describes which area is covered (e.g. b1, mental functions), and the two digits following the first specify the specific aspect described. More detail is provided by fourth and even fifth digits, which describe selected components of that aspect (e.g. s3: structures involved in voice and speech → s320: structure of mouth → s3204: structure of lips → s32040: structure of upper lip). Every code is followed by a set of qualifiers. A common qualifier used for all components specifies the severity of the problem presented by the person in that specific aspect: 0, no problem; 1–4, problem from mild to complete; 8 (not specified), is used

when there is insufficient information to specify the severity of the impairment; and 9 (not applicable), when it is inappropriate to apply a particular code (e.g. b650: menstruation functions for a child). Qualifiers for location and type of modification are used to describe appropriately changes in body structures. The Activity and Participation dimension is described by two qualifiers: one for capacity (what the person can do), and one for performance (what the person does). The first reflects activity, the second, participation. Finally, the environmental factors can be recognized as positive or negative interactors: in the first instance, they will act as facilitators, and the common qualifier will be preceded by the '+' sign, whereas in the second case they will act as barriers and will be graded according to the common qualifier without any additional notation. A schematic view of the ICF structure, and an explanation of its codes can be found at the WHO web site (www3.who.int/icf/training/icf.ppt).

The ICF checklist, published by the WHO, is a shortened version of the classification that uses only three digits. The codes in every component have been chosen to cover all major aspects of human functioning (169 codes out of 1494). ICF classifies the person's functioning over the lifespan on a continuum, from healthy to unhealthy individuals, taking into account the different components of health, and acknowledging the interplay of physical, personal, environmental, political, and social aspects. The information coming from ICD (aetiological diagnosis) and from ICF (functional profile) complement each other by providing a complete description of every aspect of a health-related condition.

There is still little practical experience in the use of these classifications in the paediatric population, because until recently (Ferngren and Lagergren 1990, Kennes et al. 2002) they have mostly been tested on adults. Although in the past 2 years several field trials specifically targeted the paediatric population by applying the ICIDH-2 β-2 version, and more recently the final version of ICF, there is widespread concern that ICF constructs may not fully describe functioning in childhood (Simeonsson et al. 2003).

The aim of our study was to assess the applicability and reliability of ICF in describing disability in children. It also aimed to verify for some Activity and Participation domains, the association with well-established evaluation instruments, so as to provide a test of ICF ability to reflect the functional profile of the child with efficiency.

Method

This study was done in a tertiary-care rehabilitation institute, the Conegliano Research Centre, in northeast Italy, from March to December 2001, and was organized in two phases.

PARTICIPANTS

Demographics and clinical summary of participants are provided in Table I. Participants were 26 males and 14 females (age range 3 to 18 years; mean 11 years 1 month, SD 5 years 3 months), attending neurorehabilitation and school in the Conegliano Research Centre. Selection of participants for this study was done first by stratifying the children attending the Centre by age and sex, then grouping them according to the prevalent medical diagnosis (learning disability*; paralysis; mixed cognitive, motor, and sensorial problem). Finally, the children were randomly selected from these groups. The experimental group was a fair representation of the case-mix composition of our entire patient population. The group was equally divided by age: 3–5 years, 6–12 years, 13–15 years, 16–18 years. The diagnoses, detailed by ICD codes for all the participants in the sample, are provided in Table I. All participants suffered chronic conditions not likely to be modified in a short time (months).

*US usage: mental retardation.

PROCEDURE

In the first phase of our study all participants were coded by using the ICF checklist. Coding was completed by a physician, a psychologist, a speech therapist, and a social worker, each one completing the ICF domains of their competence. Sources of information were: direct observation, written records, health-related professionals, and teachers.

For the type of disability (cognitive, motor or both) participants were assessed by the Wechsler Intelligence Scale for Children–Revised (WISC-R; Klinge et al. 1976) or the Wechsler Intelligence Scale for Adults–Revised (WAIS-R; Ryan 1983), Gross Motor Function Measure (GMFM; Russell et al. 1989) and Functional Independence Measure (FIM; Keith et al. 1987). Raters for these scales were psychologists and physiotherapists other than the ICF coders.

Statistical correlation between the averaged common qualifier value of codes attributed in the ICF Activity and Participation domains, which explore cognitive, motor, self-care, and interpersonal abilities, and scores obtained in the above-mentioned scales, was evaluated by using the determination coefficient test and Pearson's correlation coefficient.

A summary of the ICF domains and of the test contributing to that code is provided in Table II.

In the second phase of the study, 20 of the 40 participants were retested by the same raters by using the ICF checklist 3 months after the first testing. Test–retest reliability was evaluated for each category in different ICF components by Somer's D rank-order correlation coefficients for ordinal categorical values (Siegel and Castellan 1988).

Categories in which most participants were coded with qualifier 9 (not applicable) or qualifier 8 (not specified) were excluded. Test–retest results for Body Structures third qualifier (location) were also not evaluated statistically, given the 100% consistency between the first and the second test.

For each code assignment, test–retest reliability was defined on the basis of Somer's D confidence interval, considering 1.00–0.76 as very strong association, 0.75–0.51 as strong association, 0.50–0.26 as moderate association, and 0.25–0.00 as weak association.

Results

All children were successfully coded using the ICF checklist. A summary of ICD and ICF codes attributed to the participants is provided in Table I. The time taken to complete the checklist for each participant was 50 (SD 15) minutes. Some items of the ICF checklist are not appropriate for children, so they required the use of qualifier 9 (not applicable). Qualifier 9 was assigned 10.35 (SD 6.89) times for each record and was overrepresented in the Activity and Participation domains (6.6, SD 5.29). The areas in which qualifier 9 was used comprised d1: learning and applying knowledge (d140: learning to read; d145: learning to write; d150: learning to calculate); d6: domestic life (d620: acquisition of goods and services; d630:

Table I: Demographics and clinical summary of patients in study

Sex	*Age y*	*Prevalent disability*	*Diagnosis*	*ICD-10*	*d1*	*d3*	*d4*	*d5*	*d7*
	3–5y								
F	3	Motor	Spastic cerebral palsy/Dysarthria	G80.0/R47.1	0.00	1.00	0.60	1.83	2.00
F	3	Motor	Spastic cerebral palsy/Strabismus/Dysarthria	G80.0/H50.9/R47.1	1.00	0.20	3.50	3.28	0.00
M	4	Cognitive	Pachygyria/Severe learning disability/Specific developmental disorder of motor function	Q04.3/F72/F82.0	3.00	3.60	4.00	4.00	4.00
F	4	Multiple	Dyskinetic cerebral palsy/Amblyopia	G80.3/H53.8	2.50	1.00	4.00	4.00	3.00
F	4	Cognitive	Mild learning disability/Epilepsy	F70/G40.5	3.00	3.40	1.00	4.00	2.83
M	4	Motor	Dyskinetic cerebral palsy/Dysarthria	G80.3/R47.1	1.33	2.80	3.80	4.00	3.00
M	4	Multiple	Spastic diplegia/Amblyopia	G80.1/H53.8	2.33	0.25	2.25	1.80	2.00
M	4	Multiple	Dyskinetic cerebral palsy/Sensorineural hearing loss/Strabismus/Dysarthria	G80.3/H90.3/H50.9/R47.1	4.00	4.00	4.00	4.00	3.50
F	4	Cognitive	Down Syndrome/Severe learning disability/ Generalized epilepsy/Specific developmental disorder of motor function	Q90.8/F72/G40.4/F82	3.33	3.60	3.00	4.00	2.75
F	5	Cognitive	Trisomy 13/Severe learning disability/ Specific develop. disorder of motor function	Q91.5/F72/F82	2.00	3.00	1.75	4.00	2.83
	6–12y								
M	7	Cognitive	Mild learning disability/Specific speech articulation disorder	F71/F80.0	0.11	0.00	0.00	0.28	0.50
M	7	Multiple	Dyskinetic cerebral palsy/Microcephaly/ Severe learning disability/Epilepsy	G80.3/Q02.8/F72/G40.5	3.66	4.00	4.00	4.00	4.00
M	8	Multiple	Spastic diplegia/Mild learning disability	G80.1/F70	2.16	2.40	0.75	0.85	1.33
M	8	Multiple	Spastic cerebral palsy/Anarthria/ Moderate learning disability/Amblyopia	G80.0/R47.1/F71/H53.8	2.00	2.40	3.83	4.00	3.33
M	9	Cognitive	Moderate learning disability/Hyperkinetic conduct disorder	F71/F90.1	2.83	1.80	0.00	0.71	2.50
M	9	Cognitive	Mild learning disability/Specific developmental disorder of motor function	F70/F82.0	2.50	2.40	0.00	0.42	2.00
F	10	Cognitive	Neurofibromatosis/Moderate learning disability	Q85.0/F71	3.66	0.33	0.80	1.43	0.66
M	11	Multiple	Infantile hemiplegia/Mild learning disability/ Amblyopia	G80.2/F70/H53.8	3.33	0.66	1.00	1.00	1.16
M	11	Motor	Spastic diplegia/Strabismus	G80.1/H50.9	0.16	0.00	1.83	1.00	0.33
F	11	Cognitive	Moderate learning disability/Epilepsy/ Expressive language disorder	F71/G40.5/F80.1	2.16	1.80	0.40	0.14	1.83
	13–15y								
M	13	Multiple	Infantile hemiplegia/Mild learning disability	G80.2/F70	1.50	1.40	0.50	0.00	1.16
M	13	Cognitive	Prader-Willi syndrome/Mild learning disability	Q87.1/F70	1.67	0.00	1.75	0.57	1.00
M	14	Cognitive	Moderate learning disability/Acute disseminated encephalitis/Localization-related symptomatic epilepsy	F71/G04.0/G40.2	3.50	1.00	0.40	1.57	3.14
F	15	Multiple	Severe learning disability/Blindness/Atypical autism	F72/H54.0/F84.1	4.00	3.60	3.80	4.00	3.85
M	15	Cognitive	Mild learning disability	F70	0.83	0.00	0.80	0.28	1.71
M	15	Multiple	Spastic diplegia/Mild learning disability	G80.1/F70	1.33	0.00	1.60	0.66	1.66
M	15	Cognitive	Neurofibromatosis/Mild learning disability	Q85.0/F70	0.67	0.00	0.20	0.00	0.16
M	15	Cognitive	Mild learning disability	F70	1.00	0.00	0.00	0.14	1.83
F	15	Cognitive	Moderate learning disability/Ptosis	F71/H02.4	1.83	0.00	0.25	0.00	1.00
M	15	Cognitive	Silver Russel syndrome/Cystic fibrosis/ Moderate learning disability	Q87.1/E84/F71	2.00	0.00	2.20	1.43	2.71
	16–18y								
F	16	Multiple	Infantile hemiplegia/Mild learning disability/ Generalized epilepsia and epileptic syndromes	G80.2/F70/G40.4	1.16	0.60	0.60	0.00	1.00
M	16	Motor	Spastic cerebral palsy/Specific disorder of arithmetical skills	G80.0/F81.2	1.00	0.00	3.50	2.00	0.00
M	17	Cognitive	Severe learning disability/Pes cavus	F72/Q66.7	3.50	3.50	1.40	2.14	3.17
M	17	Multiple	Spastic cerebral palsy/Severe learning disability/ Amblyopia	G80.0/F72/H53.8	4.00	3.40	3.16	3.71	3.16
M	17	Multiple	Spastic diplegia/Mild learning disability	G80.1/F70	0.16	0.00	1.50	0.57	0.33
M	17	Cognitive	Severe learning disability	F72	2.00	0.40	2.00	0.86	3.00
F	17	Cognitive	Cornelia De Lange syndrome/Moderate learning disability/Specific developmental disorder of motor function	Q87.1/F71/F82.0	0.66	1.00	0.60	0.43	1.83
F	18	Multiple	Spastic cerebral palsy/Moderate learning disability	G80.0/F71	2.00	0.00	2.83	2.14	2.42
F	18	Cognitive	Down syndrome/Moderate learning disability	Q90.0/F71	2.00	1.00	1.80	0.71	3.28
M	18	Multiple	Spastic cerebral palsy/Moderate learning disability/Amblyopia	G80.0/F71/H53.8	3.67	3.00	3.83	4.00	3.71

ICD-10, International Classification of Diseases and Related Health Problems (WHO 1992). d1, Learning and applying knowledge; d3, Communication; d4, Mobility; d5, Self care; d7, Interpersonal interactions and relationships. Mean of severity qualifier assigned in each domain is shown for all patients.

preparation of meals; d640: doing housework; d660: assisting others); d7: interpersonal interactions and relationships (d770: intimate relationships); d8: major life areas (d830: higher education; d850: remunerative employment; d860: basic economic transactions; d870: economic self-sufficiency); d9: community, social, and civic life (d940: human rights; d950: political life and citizenship). There was an inverse relation between the number of times qualifier 9 was applied and age of the participant.

The correlation of ICF Activity and Participation domains with Verbal IQ, GMFM and FIM is shown in Table III. There was a strong and highly significant correlation among all considered variables ($p=0.0001$).

Description of environmental factors did not present significant problems in code assignment, but difficulties emerged in qualifier use, especially in the categories covered under e3 (support and relationships) and e4 (attitudes). For example, although it was easy to acknowledge the presence of the immediate family or caregivers as a relevant factor, we registered some difficulty in assigning the appropriate qualifier, both in terms of quantity (e.g. 2 versus 3 or 4 of the common qualifier) and quality (e.g. defining a factor as a barrier or a facilitator). This is reflected in the results of the test–retest experiment for this component. Results for test–retest reliability are shown in Tables IV–VII, which show the confidence-interval for association measure in each domain and category of the ICF components. In the Activity and Participation component, there was complete overlap of performance and capacity test–retest results; therefore Table VI shows only capacity (which is coded as Activity).

We found strong to very strong associations in each category of Body Functions, Body Structures, Activity and Participation components, except for one category in the 's6' domain (Urinary System Structure in Body Structures). This result was due to the inclusion of a newly diagnosed urinary malformation in one patient during the test–retest interval.

In the third part of the checklist, Environmental Factors, test–retest reliability was weak to moderate for 25% of items, and strong to very strong in the others. Items showing the weakest reliability were e3 (support and relationship), in particular e325 (acquaintances, peers, colleagues, neighbours and community members); and e4 (attitudes), particularly e440 (individual attitudes of personal care providers and personal assistants).

To better understand these results and further define instrument reliability in classifying disabling conditions, we calculated the proportion of patients having some impairment in each category in the different ICF components. Most of our patients had no impairment (qualifier 0) in 52% of Body Functions categories and in 75% of Body Structures categories. One hundred per cent of the patients had some limitation (qualifier 1–4) in 42% of Activity and Participation codes. Qualifier 0 in Activity and Participation was assigned to 55% of our group only for codes d550 (eating) and d560 (drinking).

Discussion

APPLICABILITY OF ICF IN ITS PRESENT FORM TO CHILDREN WITH NEURODISABILITIES

Our study addressed the applicability of the recently endorsed WHO classification of functioning (ICF) in a paediatric neurorehabilitation setting, and tested the ability of the ICF checklist to reflect well-established, child-adapted measures of function.

ICF revision in the past decade has implicated large international and multidisciplinary participation and has been guided by scientific principles. Nevertheless, ICF and the related checklist have been conceived for the adult population, and only a few field trials have been done so far on paediatric populations (Simeonsson et al. 2001, 2002; Beckung and Hagberg 2002). Childhood disability shows peculiar features because of developmentally related changes that interact, modulate, and are influenced by, chronic health conditions. Furthermore, children experience complex disability more often than adults, involving multiple functions and activities.

Another important aspect is the relevance of contextual factors for a child's participation and involvement in situations, including physical environmental factors and the partnership and attitudes of caregivers or family members (Simeonsson et al. 2000). This complex interplay causes modifications in requirement for service provision, with important medical, educational, and social implications. The functional multidimensional classification provided in ICF taxonomy and conceptual framework may then be instrumental in approaching childhood disability in different contexts.

The aim of this study was to field-test the applicability of the ICF checklist to developmental age, and to assess its reliability and validity in the clinical context of paediatric rehabilitation. All children in the experimental group, which offered a wide representation of disability in childhood despite its small size, were successfully coded by using the ICF checklist. However, in applying this classification to our paediatric

Table II: ICF domains and appropriate qualifiers are shown side by side with measures considered as contributing to that ICF code, and tested for statistically significant correlation

ICF domains	*Type of qualifier*	*Scales*
d1: Learning and applying knowledge	Capacity	WISC-R or WAIS-R: VIQ
d3: Communication	Performance	FIM: Communication
d4: Mobility	Capacity/Performance	GMFM/FIM: Locomotion
d5: Self care	Performance	FIM: Self care
d7: Interpersonal interactions and relationships	Performance	FIM: Interpersonal relationships

ICF, International Classification of Functioning, Disability and Health (WHO 2001); d1, Learning and applying knowledge; d3, Communication; d4, Mobility; d5, Self care; d7, Interpersonal interactions and relationships. WISC-R, Wechsler Intelligence Scale for Children–Revised; WAIS, Wechsler Intelligence Scale for Adults–Revised (VIQ, Verbal IQ); FIM, Functional Independence Measure; GMFM, Gross Motor Function Measure.

population, we found some difficulties that call for an adaptation of the instrument that is specific to children. Specific difficulties derived mainly from weak sensitivity for developmentally related functions and activities.

Points of criticism are especially related to psychomotor development: these changing aspects are not sufficiently and accurately described by this classification. The difficulty of classification is most apparent in preschool children. Even considering only children over three years old, as in our sample, most cognitive and social abilities are not appropriately classified. This is reflected by the discrepancy between the relative high use of code 0 in b (Body Functions), where relevant domains like mental function are covered by codes describing mostly basic areas (consciousness, orientation, sleep, memory, attention, etc.), and the very high use of qualifiers 1–4 or 9 in the corresponding section of d (Activity and Participation), where the basic mental functions are translated into life areas that are often not appropriate for small children (learning to read, write, or calculate).

Definitions in the Activity and Participation component need to be adapted or expanded for a proper description of many age-related acquisitions. This is reflected by our frequent use of qualifier 9 (not applicable) in this ICF component. In fact some items, especially those about community, social, and civic life, are applicable only to adolescents or young adults. Conversely, other areas critical to children's lives, like playing, are poorly represented. High use of qualifier 9 (not applicable), which was over 50% for codes d770 (intimate relationship), d830–d870 (higher education, remunerative

Table III: Correlation between selected ICF domains and scales

ICF domains	*r (p)*	*Scales*
ICF d1	–0.71 (0.0001)	Verbal IQ
ICF d4	–0.83 (0.0001)	GMFM
ICF d3	–0.82 (0.0001)	FIM Communication
ICF d4	–0.87 (0.0001)	FIM Locomotion
ICF d5	–0.89 (0.0001)	FIM Self care
ICF d7	–0.80 (0.0001)	FIM Interpersonal relationships

ICF, International Classification of Functioning, Disability and Health (WHO 2001); d1, Learning and applying knowledge; d3, Communication; d4, Mobility; d5, Self care; d7, Interpersonal interactions and relationships. GMFM, Gross Motor Function Measure; FIM, Functional Independence Measure. Pearson's correlation coefficient is shown for each considered sample.

Table IV: Test–retest reliability results for Body Functions

Categories in the Body Functions (b) component	*Estimate of association measure*	*Asymptotic standard error*	*Lower 95% confidence limit*	*Higher 95% confidence limit*	*Monte Carlo estimate of p-value*
b110 consciousness	1.0000	0.0000	1.0000	1.0000	0.0515
b114 orientation	0.9061	0.0565	0.7954	1.0000	0.0000
b117 intellectual	0.9485	0.0493	0.8519	1.0000	0.0000
b130 energy	0.8841	0.0387	0.8081	0.9600	0.0000
b134 sleep	0.9839	0.0154	0.9536	1.0000	0.0000
b140 attention	0.8502	0.0733	0.7065	0.9939	0.0000
b144 memory	0.8425	0.0853	0.6754	1.0000	0.0000
b152 emotional function	0.8832	0.0508	0.7836	0.9828	0.0000
b156 perceptual function	0.9871	0.0129	0.9617	1.0000	0.0000
b164 higher level cognitive functions	1.0000	0.0000	1.0000	1.0000	0.0000
b167 language	1.0000	0.0000	1.0000	1.0000	0.0000
b210 seeing	0.8803	0.0774	0.7285	1.0000	0.0000
b230 hearing	1.0000	0.0000	1.0000	1.0000	0.0000
b235 vestibular	1.0000	0.0000	1.0000	1.0000	0.0000
b280 pain	1.0000	0.0000	1.0000	1.0000	0.0000
b310 voice	0.8348	0.1424	0.5557	1.0000	0.0033
b410 heart	1.0000	0.0000	1.0000	1.0000	0.0000
b420 blood pressure	1.0000	0.0000	1.0000	1.0000	0.0000
b430 haematological	1.0000	0.0000	1.0000	1.0000	0.0000
b435 immunological	1.0000	0.0000	1.0000	1.0000	0.0000
b440 respiration	1.0000	0.0000	1.0000	1.0000	0.0000
b515 digestive	0.8837	0.0904	0.7065	1.0000	0.0000
b525 defecation	0.9948	0.0064	0.9823	1.0000	0.0000
b530 weight maintenance	0.8993	0.0684	0.7652	1.0000	0.0000
b555 endocrine glands	0.9907	0.0094	0.9722	1.0000	0.0000
b620 urination functions	0.9778	0.0114	0.9554	1.0000	0.0000
b640 sexual functions	NA	NA	NA	NA	NA
b710 mobility of joint	0.9822	0.0171	0.9486	1.0000	0.0000
b730 muscle power	0.9225	0.0487	0.8271	1.0000	0.0000
b735 muscle tone	1.0000	0.0000	1.0000	1.0000	0.0000
b765 involuntary movements	1.0000	0.0000	1.0000	1.0000	0.0004
b8 functions of the skin and related structures	1.0000	0.0000	1.0000	1.0000	0.0000

employment, basic economic transactions, and economic self-sufficiency), and 100% for codes d930–d950 (religion, human rights, political life) results in a ceiling effect, severely undermining the ability of ICF to detail fully child functioning in the domains describing interpersonal interactions, major life areas, and community and social life.

The measurement of health outcomes in chronic health conditions of children is a growing public health priority because of longer survival with recent medical advances, possible secondary conditions, highest prevalence and complexity of disability, and a need for the evaluation of treatment efficacy (Dijkers et al. 2000, Lollar et al. 2000, Majnemer and Limperopoulos 2002).

In the clinical context of paediatric neurorehabilitation, appropriate and accurate tools are essential to measure the most relevant outcomes for activity limitation and participation restriction (Majnemer et al. 2002). It is noteworthy that this component, while posing several problems linked to the high prevalence of qualifier 9, was the one that we found appropriate to assign the highest number of codes with qualifiers 1–4. In this perspective, Activity and Participation is a key ICF component for planning rehabilitation and environmental interventions, and for documenting functional benefits.

ICF domains correlate with well-established measurement tools

To confirm ICF as a valuable instrument to target rehabilitation projects on specific functional goals and to fully describe child functioning, we wanted to verify its concurrent validity correlating some ICF Activity and Participation domains with other well-validated measures of cognition (Verbal IQ by WISC-R or WAIS-R), motor function (GMFM) and autonomy (FIM).

We chose to map these instruments to ICF by selecting possible domain correspondence.

For the cognitive area, d1 domain (learning and applying knowledge) in the ICF full version provides detailed information for the classification of problems associated with cognitive disabilities of different aetiologies, and explores abilities that partly parallel those of Verbal IQ in WISC-R and WAIS-R. Consequently, we tested the correlation between ICF checklist d1 domain and Verbal IQ.

For motor function we mapped d4 domain (mobility) in the ICF checklist to GMFM, because they both score limitations in activities that are functionally connected, if not identical.

A strong association between a measure of motor function, such as the Gross Motor Function Classification System (Palisano et al. 1997) and ICIDH handicap code (Beckung and Hagberg 2000), or participation restriction in ICF d4 (Beckung and Hagberg 2002), has been described in children with cerebral palsy.

For communication, locomotion, self-care, and interpersonal abilities constructs, correlation between ICF d3, d4, d5, d7, and corresponding FIM domains has been considered (C Sykes, personal communication 2001).

We found a highly significant correlation between Verbal IQ by WISC-R, WAIS-R, GMFM, FIM, and all the selected ICF Activity and Participation domains.

Our results confirm ICF as a valid tool in describing the functional profile of children in a holistic representation, measuring multiple constructs crucial in documenting the impact of chronic health conditions. Moreover, the possibility to map measures derived from well-established assessment tools that are adapted for children over ICF domains, may function as a guide for a consistent use of the common qualifier (severity of the problem).

Test–retest reliability for ICF coding in the Activity and Participation domain, and the Environment Factor component

In the second part of our study, addressing test–retest reliability, we found strong to very strong associations in each category of Body Functions, Body Structures, and Activity and Participation components. The single exception, caused by an intervening new diagnosis, is in fact a further confirmation of the sensitivity of the system, but is also a warning for whose planning to use the classification in non-chronic conditions. The three-month interval was chosen because it

Table V: Test–retest reliability results for Body Structures

Categories in the Body Structures (s) component	*Estimate of association measure*	*Asymptotic standard error*	*Lower 95% confidence limit*	*Higher 95% confidence limit*	*Monte Carlo estimate of p-value*
s110 brain	0.94550	0.03937	0.86830	1.00000	0.00000
s120 spinal cord and peripheral nerves	1.00000	0.00000	1.00000	1.00000	0.00000
s2 eye, ear, and related structures	0.76430	0.15950	0.45170	1.00000	0.00000
s3 structures involved in voice and speech	0.97060	0.02577	0.92010	1.00000	0.00000
s410 cardiovascular system	1.00000	0.00000	1.00000	1.00000	0.00000
s430 respiratory system	1.00000	0.00000	1.00000	1.00000	0.00440
s5 structures related to the digestive, metabolism, and endocrine systems	1.00000	0.00000	1.00000	1.00000	0.00020
s610 urinary system	1.00000	0.00000	1.00000	1.00000	0.00000
s630 reproductive system	0.80000	0.16490	0.47680	1.00000	0.00710
s710 head and neck region	1.00000	0.00000	1.00000	1.00000	0.00000
s720 shoulder region	0.88740	0.10170	0.68800	1.00000	0.00000
s730 upper extremity	1.00000	0.00000	1.00000	1.00000	0.00000
s740 pelvis	0.94740	0.04174	0.86560	1.00000	0.00000
s750 lower extremity	0.97080	0.02749	0.91690	1.00000	0.00000
s760 trunk	0.96240	0.03522	0.89340	1.00000	0.00000
s8 skin and related structures	1.00000	0.00000	1.00000	1.00000	0.00250

would be too short to allow relevant clinical changes, given the chronic conditions affecting the children, but sufficient to allow the raters to become less accustomed to the process.

The higher incidence of impairments in ICF component 2 domains (Activity and Participation) than in ICF component 1 (Body Functions and Body Structures) is an expected finding considering the characteristics of the population studied. The strong to very strong association we found between test and retest indicates the good reliability of ICF in classifying disability in Activity and Participation domains.

One major concern in the translation of the ICF conceptual framework into clinical practice was that the differentiation between activity and participation might bring confusion. In our experience, we did not observe any specific problem

Table VI: Test–retest reliability results for Activity and Participation

Categories in the Activity and Participation (d) component	*Estimate of association measure*	*Asymptotic standard error*	*Lower 95% confidence limit*	*Higher 95% confidence limit*	*Monte Carlo estimate of p-value*
d110 watching	0.8913	0.0574	0.7789	1.0000	0.0005
d115 listening	0.9236	0.0390	0.8472	1.0000	0.0000
d140 learning to read	0.8758	0.0643	0.7498	1.0000	0.0000
d145 learning to write	0.9103	0.0490	0.8143	1.0000	0.0000
d150 learning to calculate	1.0000	0.0000	1.0000	1.0000	0.0000
d175 solving problems	0.7797	0.0913	0.6007	0.9586	0.0003
d210 undertaking single tasks	0.8490	0.1024	0.6483	1.0000	0.0000
d220 undertaking multiple tasks	0.7692	0.1148	0.5443	0.9941	0.0000
d310 communicating with, and receiving, spoken messages	0.9419	0.0463	0.8512	1.0000	0.0000
d315 communicating with, and receiving, non-verbal messages	0.8157	0.1398	0.5417	1.0000	0.0000
d330 speaking	1.0000	0.0000	1.0000	1.0000	0.0000
d335 producing non-verbal messages	0.8082	0.1448	0.5245	1.0000	0.0000
d350 conversation	1.0000	0.0000	1.0000	1.0000	0.0000
d430 lifting and carrying objects	0.9382	0.0368	0.8662	1.0000	0.0000
d440 fine hand use	0.9609	0.0265	0.9089	1.0000	0.0000
d450 walking	0.9506	0.0324	0.8871	1.0000	0.0000
d465 moving around using equipment	0.9767	0.0262	0.9255	1.0000	0.0000
d470 using transportation	0.9750	0.0221	0.9318	1.0000	0.0005
d475 driving	0.9480	0.0488	0.8524	1.0000	0.0000
d510 washing oneself	0.9644	0.0254	0.9147	1.0000	0.0000
d520 caring for body parts	0.9650	0.0250	0.9160	1.0000	0.0000
d530 toileting	0.9317	0.0365	0.8603	1.0000	0.0000
d540 dressing	1.0000	0.0000	1.0000	1.0000	0.0000
d550 eating	1.0000	0.0000	1.0000	1.0000	0.0000
d560 drinking	1.0000	0.0000	1.0000	1.0000	0.0000
d570 looking after one's health	1.0000	0.0000	1.0000	1.0000	0.0000
d620 acquisition of goods and service	1.0000	0.0000	1.0000	1.0000	0.0000
d630 preparation of meals	0.9310	0.0644	0.8048	1.0000	0.0000
d640 doing housework	0.9916	0.0101	0.9719	1.0000	0.0000
d660 assisting others	0.8800	0.0778	0.7275	1.0000	0.0002
d710 basic interpersonal interactions	0.8333	0.0475	0.7403	0.9264	0.0000
d720 complex interpersonal interactions	0.8727	0.0692	0.7372	1.0000	0.0000
d730 relating with strangers	0.7415	0.1139	0.5182	0.9647	0.0000
d740 formal relationship	1.0000	0.0000	1.0000	1.0000	0.0002
d750 informal social relationship	0.8688	0.0764	0.7190	1.0000	0.0000
d760 family relationship	0.9003	0.0376	0.8266	0.9740	0.0000
d770 intimate relationship	NA	NA	NA	NA	NA
d810 informal education	0.7603	0.1978	0.3726	1.0000	0.0001
d820 school education	0.8544	0.0957	0.6668	1.0000	0.0000
d830 higher education	1.0000	0.0000	1.0000	1.0000	0.0000
d850 remunerative employment	1.0000	0.0000	1.0000	1.0000	0.0299
d860 basic economic transactions	1.0000	0.0000	1.0000	1.0000	0.0011
d870 economic self-sufficiency	1.0000	0.0000	1.0000	1.0000	0.1106
d910 community life	0.9189	0.0639	0.7937	1.0000	0.0000
d920 recreation and leisure	0.9063	0.0473	0.8136	0.9990	0.0000
d930 religion and spirituality	NA	NA	NA	NA	NA
d940 human rights	NA	NA	NA	NA	NA
d950 political life and citizenship	NA	NA	NA	NA	NA

about the use of capacity (related to Activity) and performance (related to Participation) qualifiers. A sign of this consistency is the complete overlap of qualifier assignment in performance and capacity test–retest.

We cannot confirm the instrument reliability for Body Functions and Structures, because the few number of patients having some classifiable impairment in those components prevents a meaningful analysis.

We cannot exclude dependence on third-party subjectivity providing information in small or non-collaborating children as a cause for the weaker association (weak to moderate for 25% of considered items) found in the Environmental factors part. This aspect definitely weakens test–retest reliability for part 3 (Environmental Factors) code assignment in children. Environmental factors are especially meaningful for children, and particularly so for children with severe disabilities, in whom dependence upon others is maximized. Moreover, many of the environmental interactors (i.e. parents, persons in positions of authority, friends) may function at the same time as both facilitators and as barriers. For example, the continuous presence of family members may function as a relevant facilitator in several activities, but may at the same time limit considerably the development of the child's autonomy. This complicates coding, adding more subjectivity-driven error sources in the interpretation of environmental factors.

Conclusions

Our experience shows that ICF fulfils the requirement of a very useful, reliable, and valid multidimensional framework for defining domains and describing chronic disability, even in children aged 3–18 years.

At the same time, difficulties and inconsistencies call for specific adaptations to allow full application and comprehensive classification from infancy to adolescence. This may be achieved without changing the structural and conceptual framework of the present version. Areas where adaptation for children and youth is most needed are as follows: (1) Body function: intellectual functions, behavioural regulation,

Table VII: Test–retest reliability results for Environmental Factors

Categories in the Environmental Factors (e) component	*Estimate of association measure*	*Asymptotic standard error*	*Lower 95% confidence limit*	*Higher 95% confidence limit*	*Monte Carlo estimate of p-value*
e110 products and technology for personal consumption	1.0000	0.0000	1.0000	1.0000	0.0000
e115 products and technology for personal use in daily living	0.9154	0.0728	0.7727	1.0000	0.0000
e120 products and technology for personal indoor and outdoor mobility and transportation	1.0000	0.0000	1.0000	1.0000	0.0000
e125 products for communication	1.0000	0.0000	1.0000	1.0000	0.0513
e150 design, construction and building products, and technology of buildings for public use	0.9843	0.0145	0.9558	1.0000	0.0000
e155 design, construction and building products, and technology of buildings for private use	0.9818	0.0159	0.9506	1.0000	0.0000
e225 climate	1.0000	0.0000	1.0000	1.0000	0.0524
e240 light	0.6415	0.1787	0.2912	0.9920	0.0120
e250 sound	0.8283	0.1402	0.5536	1.0000	0.0000
e310 immediate family	0.8000	0.1005	0.6031	0.9970	0.0001
e320 friends	0.8273	0.1115	0.6088	1.0000	0.0000
e325 acquaintances, peers, colleagues, neighbours, and community members	0.5977	0.1345	0.3342	0.8610	0.0017
e330 people in position of authority	1.0000	0.0000	1.0000	1.0000	0.0000
e340 personal care providers and personal assistants	0.6744	0.1725	0.3364	1.0000	0.0014
e355 health professionals	0.9817	0.0176	0.9472	1.0000	0.0000
e360 health-related professionals	0.5105	0.2100	0.0988	0.9220	0.0053
e410 individual attitudes of immediate family members	0.8444	0.0731	0.7011	0.9880	0.0000
e420 individual attitudes of friends	0.7761	0.1691	0.4447	1.0000	0.0000
e440 individual attitudes of personal care providers and personal assistants	0.5702	0.1888	0.2001	0.9400	0.0028
e450 individual attitudes of health professionals	0.7681	0.1473	0.4794	1.0000	0.0000
e455 individual attitudes of health-related professionals	0.6877	0.1663	0.3619	1.0000	0.0002
e460 societal attitudes	1.0000	0.0000	1.0000	1.0000	0.0000
e465 social norms, practices, and ideologies	1.0000	0.0000	1.0000	1.0000	0.0000
e525 housing services, systems, and policies	1.0000	0.0000	1.0000	1.0000	0.0000
e535 communication services, systems, and policies	1.0000	0.0000	1.0000	1.0000	0.0000
e540 transportation services, systems, and policies	1.0000	0.0000	1.0000	1.0000	0.0000
e550 legal services, systems, and policies	1.0000	0.0000	1.0000	1.0000	0.0000
e570 social security, services, systems, and policies	1.0000	0.0000	1.0000	1.0000	0.0000
e575 general social support services, systems, and policies	1.0000	0.0000	1.0000	1.0000	0.0000
e580 health services, systems, and policies	1.0000	0.0000	1.0000	1.0000	0.0000
e585 education and training services, systems, and policies	1.0000	0.0000	1.0000	1.0000	0.0000
e590 labour and employment services, systems, and policies	1.0000	0.0000	1.0000	1.0000	0.0000

sensory modulation. (2) Body structures: growth (in weight, height, and head circumference) and the related problems (growth delay, anomalies of primary dentition). (3) Activity and Participation: learning, object and peer play, preverbal communication, caregiver child interaction, social life. (4) Environmental factors: support and relationships, attitudes, education and training services, labour and employment services.

Further experience is certainly needed to confirm ICF as a reliable tool for classifying functioning and disability and for teamwork in paediatric neurorehabilitation.

This represents a strong stimulus for extending our sample and verifying the results obtained in this preliminary experience.

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List of abbreviations

FIM	Functional Independence Measure
GMFM	Gross Motor Function Measure
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
WISC-R	Wechsler Intelligence Scale for Children–Revised
WAIS-R	Wechsler Intelligence Scale for Adults–Revised