Assessing Children With Disabilities Using WHO International Classification of Functioning, Disability and Health Child and Youth Version Activities and Participation D Codes

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Abstract

Aim: Evaluation of the International Classification of Functioning, Disability and Health child and youth version (ICF-CY) activities and participation d code functions in clinical practice with children across diagnoses, disabilities, ages, and genders. **Methods:** A set of 57 codes were selected and worded to describe children's support needs in everyday life. Parents of children aged 1 to 15 years participated in interviews to discuss and rate their child's disability. **Results:** Of 367 invited parents, 332 (90.5%) participated. The mean age of their children with disability was 9.4 years. The mean code scores were 50.67, the corrected code–total correlations were .76, intercode correlations had the mean of 0.61, and Cronbach's α was .98. As a result of Rasch analysis, graphical data for disability measures paralleled clinical expectations across the total population of 332 children. **Conclusion:** The World Health Organization International Classification of Functioning, Disability and Health child and youth version d code data can provide a coherent measure of severity of disability in children across various diagnoses, ages, and genders.

Assessing disabilities in children with sufficient detail to detect even minor changes is essential in daily clinical practice as well as for habilitation, rehabilitation, and the development of new intervention strategies and research.[1] Many different tools and questionnaires are used in various clinical and research settings. In 2001, the World Health Organization (WHO) released the International Classification of Functioning, Disability and Health to provide a common framework for the assessment of disability in clinical and research contexts, and a child and youth version was released in 2007.[2,3] The classification is based on a conceptual model encompassing the health condition of the individual with a disability, together with factors related to body function (b codes) and structure (s codes), activities of daily living and participation in social activities (d codes), and other relationships. These factors should be evaluated in relation to environmental factors and personal factors that can have a positive or negative influence on the impact of the disability.

The International Classification of Functioning, Disability and Health and its child and youth version were developed with the involvement of professionals and persons with disabilities and are intended to be used as a common platform for the assessment of disabilities and for both children and their parents and caregivers.[2,3]

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Research centers on how International Classification of Functioning, Disability and Health child and youth version can be understood, be used, and function.[4-9] Many studies have applied the functionality of International Classification of Functioning, Disability and Health child and youth version to specific disorders, including cerebral palsy,[10] muscular disorders,[11,12] spina bifida,[13] disability following brain tumors,[14] chronic disorders,[15] and disability following trauma.[16] Comparison of content with International Classification of Functioning, Disability and Health child and youth version to other various instruments has been performed,[17] and validation of core data sets for International Classification of Functioning, Disability and Health child and youth version has been started,[18,19] together with studies of International Classification of Functioning, Disability and Health child and youth version functionality and code selection in specific clinical settings.[20,21]

All International Classification of Functioning, Disability and Health child and youth version and International Classification of Functioning, Disability and Health codes use 5 qualifiers for impairment and difficulty identically. Accordingly, qualitative research on categorical qualifiers requires the extensive use of psychometric methods underpinned by Classical Test Theory. From its beginning in 2011, the use of Classical Test Theory was inspired by methods-related research on ordinal scales,[22-24] and analysis has followed methods used in research on International Classification of Functioning, Disability and Health data and other areas related to disability.[25,26] Rasch analysis has not yet been applied to data related to International Classification of Functioning, Disability and Health child and youth version activities and participation d codes but has been analyzed by us in connection with b codes,[27] as identical methodology has been employed in relation to the Nordic Five to Fifteen questionnaire.[28]

The authors intended to explore the additional possibility of also applying International Classification of Functioning, Disability and Health child and youth version activities and participation d codes to children and young people with various, and the broadest range possible, disabilities resulting from disorders of the spine, muscles, sensory organs, and central nervous system and to illustrate the possibility of creating a common disability variable based on d codes which can provide a more exact measure of the degree of disability related to activities and participation and add to information obtained by b code data in possible future electronic clinical application of International Classification of Functioning, Disability and Health child and youth version.

Methods

Study Design and Children With Disabilities

This pilot study was an open-field research study that aimed to select and validate International Classification of Functioning, Disability and Health child and youth version codes commonly used for children with disabilities. No core data set of International Classification of Functioning, Disability and Health child and youth version codes has yet been published, so codes were selected on the basis of an a priori judgement about which codes would best cover the range of types and magnitudes of disability under investigation. Codes and wording were subject to several revisions during a preliminary round of 25 interviews. The set of codes and wordings resulting from this process were used throughout the rest of the study irrespective of disorder, severity of disability, age, or gender. Second-, third-, and fourth-level codes were included. The set of d codes for activities and participation totaled 57. The codes were used to describe the performance of 332 children in activities of daily living.

Children aged 1 to 15 years upon entry to the study were enrolled, and visits and interviews were conducted between October 1, 2010, and November 30, 2011. All children and their parents were known to us beforehand. The hospital's electronic patient record system was used to identify all children in the region of Southern Denmark with muscular disorders, spina bifida, spinal muscular dystrophies, or disabilities following cerebral tumors. Children from Funen Island (approximately 600 000 inhabitants), a minor geographical area within the Southern Danish region (approximately 1.2 million inhabitants), with cerebral palsy, who were visually impaired or hearing impaired or had moderate to severe mental disability were recruited via the same method.

Qualifier-Level Wording

As in International Classification of Functioning, Disability and Health, International Classification of Functioning, Disability and Health child and youth version uses a universal d code scoring system consisting of a 5-point Likert-type scale with the following qualifiers:

0: no difficulty,
1: mild difficulty,
2: moderate difficulty,
3: severe difficulty, and
4: complete difficulty

To enable a more detailed discussion of the child's needs, rather than simply focusing on the meaning of these basic definitions of level of impairment, d code qualifier levels were defined as follows:

0: Child's ability is as expected for his or her age.
1: Child has difficulties but activities and participation are still in the expected range for his or her age.
2: Child needs help with activities and participation from another person.
3: Child needs help and care due to only limited ability with respect to activities and participation.
4: Child is totally dependent on others for activities and participation.

Procedures

The International Classification of Functioning, Disability and Health child and youth version data sheet and information on the study's aim and procedures were given to all families eligible for participation. After 2 to 3 weeks, families were contacted by phone or in person at their homes, if necessary; in

this way, it was possible to make contact with every family. Participation in the study was entirely voluntary, and the decision to participate did not affect future clinical assignment.

All the families who agreed to participate were visited in their homes by one of the participating medical doctors (NOI, LWL, KRB, NS, and MNJ). When the child lived in a residential facility, caregivers participated with the written consent of the child's parent or guardian. Factors related to the selected International Classification of Functioning, Disability and Health child and youth version codes and qualifiers were discussed with one or both parents. International Classification of Functioning, Disability and Health child and youth version qualifiers were scored by one of us during conversation. Children were not interviewed or examined during these interviews. Data from the interview score sheets were then transferred to paper datasheets. These datasheets were subsequently used for the manual transfer of data for analysis and were consulted whenever errors were suspected or spotted during subsequent data processing. Data on International Classification of Functioning, Disability and Health child and youth version b codes and environmental e codes were obtained simultaneously.

Psychometric Evaluation of International Classification of Functioning, Disability and Health Child and Youth Version d Code Data

Within-scale analysis of responses from this single administration of d codes was undertaken. If scores are to be summarized to form a single general assessment score, the codes should be internally consistent and measure the same underlying disability construct. It is recommended that correlations between contributing d codes and the total score computed from the remaining codes, the corrected item–total correlations, should exceed .40 (26).

Data targeting was estimated from the code scale midpoint, range, and observed scores, together with floor and ceiling effects. Reliability was operationalized as internal consistency and estimated with Cronbach α coefficient for average interitem correlation. Validity was determined by nonstatistical evaluation of the clinical meaning of the code scale and was further investigated in the Rasch analysis. Within-scale factor analysis including the above-mentioned corrected item–total correlations and Cronbach's α ($\alpha = N x \bar{c}/\bar{v} + (N-1) \times \bar{c}$, where N = number of codes, $\bar{c}$ = average inter code covariance and $\bar{v}$ = average variance, was used to calculate a score for a general assessment childhood disability construct. The standard error of measurement = SD $\times \sqrt{(1 - alpha)}$, and 95% confidence intervals (95%CIs) = $\pm$ 1.96 $\times$ standard error of measurement, were calculated. Stata 12 (StataCorp, College Station, Texas) was used for data analysis.

Rasch Modeling Data

A crucial aim of this pilot study was to generate as much information as possible about children's abilities and disabilities from the selected International Classification of Functioning, Disability and Health child and youth version codes and their qualifiers. More specifically, the primary objective was to use the Rasch model to generate a continuous scale that would be sensitive enough to register changes in disability that might not be distinguished by the ordinal International Classification of Functioning, Disability and Health child and youth version 5-point qualifier scales or International Classification of Functioning, Disability and Health child and youth version summations.

The Rasch analysis model defines an individual's probability of success (P) on a given item in terms of the difference between the individual's ability (B) and item difficulty (D). $P = \exp(B - D)/1 + \exp(B - D)$ or $\log P/(1 - P) = B - D$. Probability of success (P) can also be expressed as log(odds) = B − D or logit = B − D. In all further data analyses in this study, probability of success (P) in Rasch terminology refers to probability of disability, person (B) refers to the child being assessed, and item difficulty (D) refers to the d code qualifiers.

Rasch analysis was applied to all 5 qualifiers for the International Classification of Functioning, Disability and Health child and youth version d codes, and this assumes equal distances between qualifier levels, an assumption that cannot be valid in clinical practice. Control for this was performed using a Rasch model for polytomous data, the Andrich Rating-Scale Model.

In practice, when a child's level of disability equals a certain qualifier level, B and D are identical, and the derived log(odds) or logit value will be 0. For codes in which the child's disability level is higher or lower, the relevant logit value will be correspondingly positive or negative. A logit scale that is independent of whether disability level is assessed by the d code qualifier level is generated. This scale constitutes the latent disability construct or variable for the children included in this study and the d codes and qualifiers used.

Graphically, values of the disability variable form a sigmoid curve where the x-axis is a logit scale. The ordinal scale originally representing the International Classification of Functioning, Disability and Health child and youth version scores can be mapped to a scale that detects changes that lie between the individual steps of the ordinal scale. Most importantly, the d code qualifier scores can be added to provide a true total score.

For individual children and specific d codes and their qualifiers to contribute to the formation of the disability variable, certain validity criteria must be met[26]: (A) adequacy of targeting children and d codes, (B) construction of measurement ruler, and (C) successful measurement of children. These areas have been described by the authors in detail[27] and will be dealt with in the results section. Winsteps 3.74.0 was used for Rasch measurements.

Results
Descriptive Characteristics

A total of 367 eligible children were identified. The parents of 35 children decided not to participate for various reasons; thus,

332 (90.5%) children were included whose parents or caregivers completed the interview. The children included had a mean age of 9.4 years, standard deviation 3.8 years, and age range 1.0 to 15.9 years. Before the first visit, each child's medical record was reviewed, and data on discharge diagnosis and associated diagnoses were recorded to ensure that the information used in the study was as up to date as possible. The parents and caregivers of 12 children were visited in their permanent residences and 7 children in their foster families.

The children of the participating parents were grouped according to discharge diagnosis, and 63 children had a discharge diagnosis of spina bifida, 8 had spinal muscular atrophy, 36 had muscular disorders, 157 had cerebral palsy, 8 were visually impaired, 13 were hearing impaired, 11 had a mental disability, and 36 had been diagnosed with and treated for brain tumors.

Results of Psychometric Analyses of d Codes

There was missing data for 57 d codes in 394 (3.7%) of 10 624 responses. This was due to the fact that some children were not old enough to be evaluated with respect to certain d codes. It was decided not to set age thresholds for applicability of specific d codes, and the decision about whether or not to assign a score for a particular code was made on an individual basis. There were high corrected code–total correlations for the d codes (.76), high intercode correlations (.61), and high reliability in terms of Cronbach α (.98). Means and standard deviations for observed scores for the codes were to the left of the ranges, indicating that a fairly high proportion of the sample had lower levels of disability.

Results of Rasch Analysis d Code Scores

(A) Adequacy of targeting children and d codes. The d codes selected (Table 1) along with disability level corresponding to children's disability (targeting) are illustrated in the child-code map for d codes (Figure 1). The number of d codes was reduced from 57 to 39. Data on d codes were pooled in relation to children with more severe disabilities (Figure 1). This was due to the fact that a relatively large proportion of the sample had relatively minor difficulties.

(B) Construction of measurement ruler. Each d code location equals the mean of $\tau 1$, $\tau 2$, $\tau 3$, and $\tau 4$; thus, d codes apply to children far below and above their mean locations. The mean τs of all 39 d codes are illustrated in Figure 2; and the figure shows that there was a fairly equal probability of observing adjacent qualifiers.

Structure calibration across all qualifier levels for the 39 d codes selected showed that τ thresholds and category measures increased with increasing qualifier values (Table 2), that is, they were ordered. The same pattern was observed when total qualifier score levels were considered.

The range and order of d codes on the disability variable seem to be clinically sound. For many of the children in the sample, lower extremity motor difficulties were the major

disability, and they had normal cognitive ability. This accounts for the frequency ordering of the codes: d4750 (riding a bicycle) was the d code which most commonly registered impairment in the least disabled children, with d5101 (washing whole body) and d710 (basic interpersonal interactions) registering impaired functioning when there was a cognitive dimension to the child's disability. Codes related to perception, for example, d3150 (communicating with receiving body gestures), made an important contribution to the assessment of disability only in children who were severely disabled (Figure 1).

All d codes with disordered qualifiers were excluded (Table 3). Experimental removal did not change the ordering or values of remaining d codes. Thereafter, no d codes showed infit or outfit mean squares (MNSQs) >2.0, and the data demonstrated a proper fit.

The standardized fit statistics (ZSTD) values reflect the probability that a given MNSQ value occurs by chance when the data fits the Rasch model. A positive ZSTD >1.96 can indicate problems with the validity of the data. Seven d codes had high outfit ZSTDs, and 3 d codes had high infit ZSTDs. No additional d codes were removed. The mean MNSQs and ZSTDs approximated ideal values.

Observed point–measure correlations were all close to expected values, as individual d code correlations were related to other d code correlations in the same child. None of the correlations were negative, indicating that all the d codes contributed to the disability variable and that the data for the selected d codes was unidimensional.

There is an exact match between the child's functioning and d code difficulty when d code difficulty is identical to the child's disability. An observed percentage higher than the expected percentage on a measure indicates a higher probability of an exact match. This was observed for 18 of 39 d codes.

High within-code category correlations are not desirable. In the 10 most highly correlated d code pairs, the correlation coefficient ranged from .47 to .61. For both code categories, the maximum correlation coefficient was <.7, indicating a satisfactory level of correlation.

The d codes behaved differently with respect to diagnosis, gender, and age. An approximate t test for the DIF for each d code against overall d codes difficulty was conducted using critical values ± 2.0. Around 50% of d codes had t in the range 2.0 to 3.0, but some codes had a higher t. The separation index was 7.8 for d codes, indicating that more than 3 levels of d codes could be differentiated with a reliability of 0.98.

(C) Successful measurement of children. Fit data for children were analyzed. Mean infit MNSQ was 1.03, and mean outfit MNSQ was 0.98. The number of children with infit MNSQ 1.5 to 2.0 was 36, and 9 children had infit MNSQ >2.0 (range: 2.04-2.64). Thirty-three children had outfit MNSQ 1.5 to 2.0, and 13 children had outfit MNSQ >2.0 (range: 2.01 3.37), giving 16 children with either infit or outfit MNSQ >2.0. Both infit and outfit MNSQ were >2.0 in 6 children.

The person separation index (PSI) for d codes was 3.49, with reliability of .92, indicating that 3 different levels of disability

Table 1. International Classification of Functioning, Disability and Health Child and Youth Version d Codes Initially Used in the Sample of 332 Children, Which fit the Rasch Model (n = 39).[a]

d130: Copying (imitating, mimicking sound, gesture, facial expression, signs)
d131: Learning through actions with objects (learning from playing with toys and objects)
d140: Learning to read (developing competence to read written material)
d150: Learning to calculate (developing competence to perform simple mathematical operations)
d155: Acquiring skills (learning to play games, keeping one's room tidy, manipulating toys)
d1550: Acquiring basic skills (learning to use eating utensils, play with toys, pointing board, wave in response)
d1551: Acquiring complex skills (learning to play games, understand and apply rules, appropriate sequences)
d177: Making decisions (making a choice among options, carrying out, learning consequences)
d2101: Undertaking a complex task (preparing, initiating and arranging for social play activities, own birthday)
d2302: Completing the daily routine (preparing, initiating and arranging for school, managing homework)
d3102: Comprehending complex spoken messages (understanding and responding appropriately to questions and instructions)
d3150: Communicating with—receiving body gestures (comprehending facial expressions, body language)
d3152: Communicating with—receiving drawings and photographs (comprehending meaning)
d4153: Maintaining a sitting position (remaining seated sufficiently long enough for eating, playing, drawing, writing)
d4451: Pushing (handling milk bottle on table, pushing a toy, pushing objects)
d4552: Running (moving appropriately with quick steps)
d4600: Moving around within the home (getting around, walking in home)
d465: Moving around using equipment (getting around in wheelchair, walking on crutches or walker)
d4701: Using private motorized transportation (parents as drivers)
d4750: Driving human-powered transportation (bicycle and tricycle)
d5101: Washing whole body (applying soap and water, hair washing, drying)
d5201: Caring for teeth (brush teeth, maintaining routine)
d530: Toilet (indicating needs, planning, carrying out, eliminating waste)
d540: Dressing (putting on and taking off clothes)
d550: Eating (indicating needs, carrying out, deciding on appropriate amount)
d560: Drinking (indicating needs, carrying out, deciding on appropriate amount)
d5702: Maintaining health (caring for self and being self-aware)
d6300: Preparing simple meals (organizing, proper preparing, serving)
d660: Assisting others (assisting and being concerned about needs)
d710: Basic interpersonal interactions (interacting appropriately and showing consideration)
d750: Informal social relationships (initiating, managing and maintaining play and causal relationship)
d770: Intimate relationships (creating and maintaining close or romantic relationship)
d845: Acquiring, keeping and terminating a job (leisure-time job)
d860: Basic economic transactions (purchasing, correct exchange, saving)
d8800: Solitary play (occupying oneself in purposeful play and game)
d8801: Onlooker play (purposefully observing others)
d8803: Shared corporative play (joining others in sustained engagement and understanding play rules)
d8808: Engagement in play, other specified (need for resting periods from shared play)
d920: Recreation and leisure (engaging in games, sport, hobbies and socializing)

[a]Subcategories of d codes are given by the first digit and are coded as follows: (1) mental functions; (2) sensory functions and pain; (3) voice and speech functions; (4) functions of the cardiovascular, hematological, immunological, and respiratory systems; (5) functions of the digestive, metabolic, and endocrine systems; (6) genitourinary and reproductive functions; (7) neuromusculoskeletal and movement-related functions; and (8) functions of the skin and related structures

could be distinguished statistically using this group of d codes with the same standard deviation of 1.51.

Mean location on the d code-based disability variable was −1.33, standard deviation 2.04, and the highest location was 4.73 and the lowest −4.47. This highest and lowest score data did not correspond exactly with the data on the child-code map (Figure 1), reflecting the fact that in Rasch analysis, extreme data are less reliable.

Discussion

This study was undertaken to find out how International Classification of Functioning, Disability and Health child and youth version activities and participation d codes and qualifiers might be used in clinical practice. A sample of 332 children with

various diseases was analyzed, encompassing the broadest possible range of disabilities, ranging from children with almost no symptoms to children who were totally physically dependent and including children who were mentally disabled, visually impaired, or hearing impaired.

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 in the child's activities of daily life, relative to unimpaired age peers. Once explained in conversations during visits, parents and caregivers had no difficulty judging which qualifier level was most appropriate for their child. In order to ensure that data obtained would be suitable for statistical analysis, codes were defined explicitly. The validity of this approach was subject of our statistical analysis approach. Furthermore, when applying Rasch data analysis
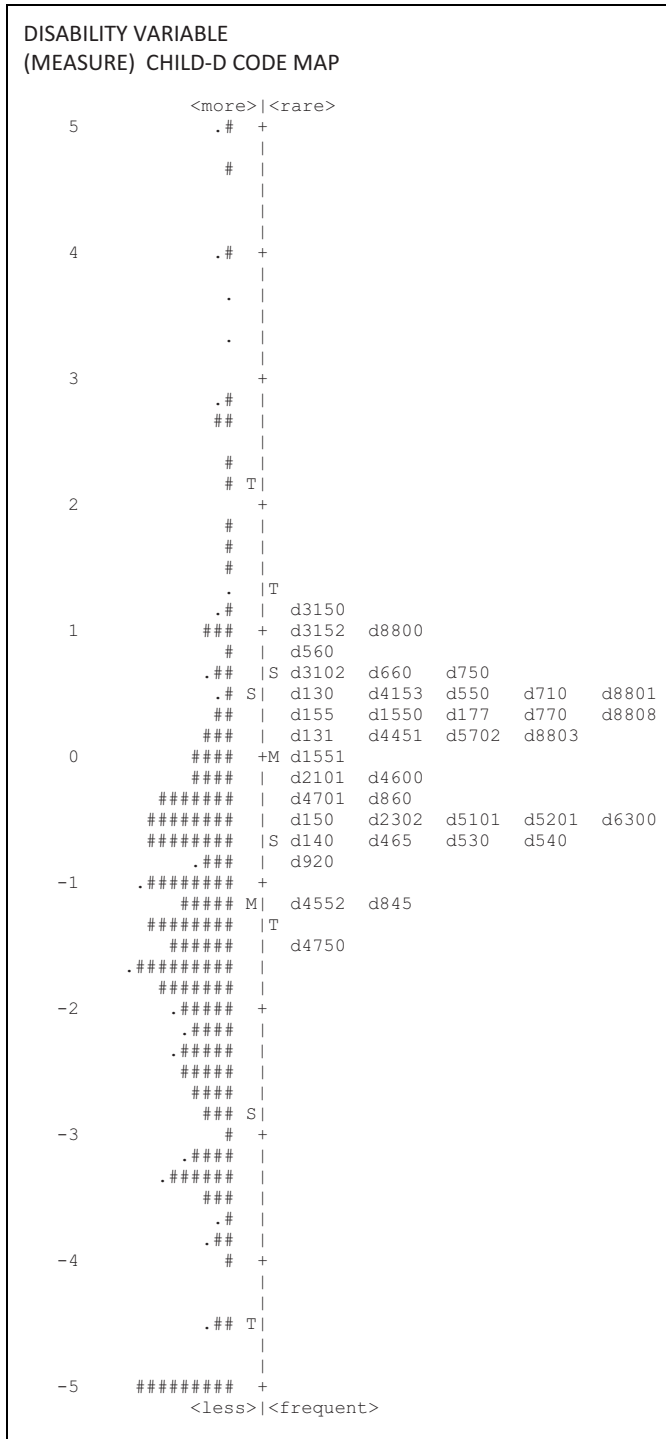
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DISABILITY VARIABLE
(MEASURE)  CHILD-D CODE MAP

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                 #  |
                    |
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    4        .#  +
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             .    |
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    3           +
            .#  |
            ## |
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            #  |
            #  T|
    2           +
            #  |
            #  |
            #  |
            .  |T
            .#  |  d3150
    1      ###  +  d3152  d8800
            #  |  d560
           .## |S d3102  d660    d750
           .# S|  d130   d4153  d550   d710   d8801
           ##  |  d155   d1550  d177   d770   d8808
          ###  |  d131   d4451  d5702  d8803
    0     #### +M d1551
          #### |  d2101  d4600
        ####### |  d4701  d860
        ####### |  d150   d2302  d5101  d5201  d6300
        ####### |S d140   d465   d530   d540
          .### |  d920
   -1 .######## +
          ##### M|  d4552  d845
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Figure 1. Distribution of the 39 d codes that fit the Rasch model among the 332 children in the sample. Each "#" represents 2 children and ."" represents 1 child. M indicates mean, S = 1 standard deviation and T = 2 standard deviations. Each | represents an interval of 0.2.

codes that do not fit might be rejected and thereby lost. If wording is no, mild, moderate, severe, or complete, problem there might be difficulty rescuing important codes. If codes are worded, however, the wording might be readdressed, possibly changed, reintroduced, and thereby be subject for future Rasch analysis.
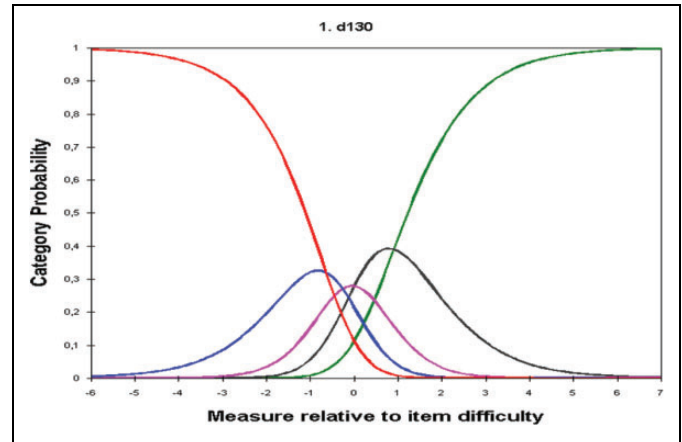

Figure 2. Qualifier (category) information function for 39 d codes. Qualifier 0 = red, 1 = blue, 3 = purple and 4 = black. The τ values are where those curves meet, indicating 50% probability of either qualifier being answered. If qualifier definitions were misunderstood and/or formulated in a problematic way, the probability curves would not follow qualifier ordering.

Also, qualifier wording in terms of need for help universally across the disease diagnosis was considered although with different means for help. For the same reason, it is necessary to know the details of an individual's condition. The *International Classification of Diseases*, *tenth revision* codes and International Classification of Functioning, Disability and Health child and youth version codes are therefore considered as complementary and should be considered together in future data system implementations, clinical data handling, communications, evaluations, and research.

The International Classification of Functioning, Disability and Health child and youth version activities and participation d codes exhibited widely varying code means, variances, and standard errors of measurement on a 95% confidence level, making it difficult to construct a unitary disability variable on the basis of psychometric data analysis alone, although the mean corrected code–total correlation, .70, was high.

A number of criteria must be met when a Rasch analysis is used. This is important, as this study sought to determine whether a unitary and single disability variable might be used to characterize disability across conditions, types, and severity of disability. This would avoid the need to have different sets of disability variables for different clinical diagnoses. It seemed possible to demonstrate that the data obtained could be described in terms of a single disability variable.

The child-code maps (person–item maps) for activities and participation d codes seemed sound, and children with only minor motor problems were located at the lower end of the range of the disability variable and those with severe and complex disabilities at the upper end of the range. A relatively large proportion of the children had motor difficulties only. This meant that an important group of the activities and participation d codes were located in the upper half of the range of the disability variable, as they were only relevant to the more disabled children who had both motor and cognitive difficulties.

Table 2. Structure Calibration of the Sample of 39 d Codes.

Qualifier	Observed Count	Observed Count%	Observed Average	Sample Expected	Infit MNSQ	Outfit MNSQ	T Threshold	Category Measure
0	6287	54	−2.32	−2.32	1.08	1.09	-	−2.11
1	1882	16	−1.18	−1.23	1.05	0.84	−0.64	−0.83
2	1074	9	−0.53	−.44	1.10	1.14	−0.26	−0.05
3	1020	9	−0.31	0.39	0.96	0.91	0.00	0.79
4	1319	11	2.02	1.96	0.95	0.96	0.90	2.25

Table 3. International Classification of Functioning, Disability and Health Child and Youth Version d Codes Initially Used Which did not Fit the Rasch Model (n = 18).[a]

d110*: Watching (intentional visual tracking of objects and watching others)
d115*: Listening (intentional listening to voice, teacher's voice, story, radio and other sources)
d145§: Learning to write (developing competence to write letters and symbols that represents words) (d140)
d1558*: Acquiring skills, other specified—catheterizing (handling procedures)
d1559**: Acquiring skills, other specified—performs enema (handling procedures)
d1600*: Focusing attention (focusing on voice and spoken word, avoiding distractions)
d2500*: Accepting novelty (responding appropriately to new tasks, events, demands)
d3503*: Conversing with one person (initiating, shaping and terminating dialogue)
d4103*: Sitting (getting into and out of seated position)
d4200**: Transferring oneself while sitting (moving from chair to another chair, bed, wheelchair, toilet)
d4402*: Manipulating (tying shoelace, manipulating toys, turning over pages)
d4502§: Walking on different surfaces (walking on sloping floor, walking on gravel, grass, snow) (d4600)
d4601§: Moving around within buildings other than home (getting around by oneself in kindergarten or school) (b4600)
d640§: Doing housework (clothes washing, using appliances and cleaning) (d6300)
d720§: Complex interpersonal interactions (initiating, managing and maintaining personal relationship) (d710)
d760*: Family relations (creating, maintaining relationships)
d820§: School education (learning, engaging, attending, working cooperatively, organizing, handling instructions) (d140)
d8802§: Parallel play (purposefully holding activities in same room and surroundings but not playing with others) (d8801)

[a]Codes marked *showed infit and/or outfit MNSQ values >1.5; codes marked **also showed qualifier disordering. Codes marked § correlated with codes in (). The codes marked § were retained due to better fit than those in ().

Position on the continuum for the disability variable corresponded well with the complexity and severity of the factors assessed by particular activities and participation d codes (Figure 1).

Particular concern was shown in determining whether activities and participation d codes behaved differently across diagnoses, ages, and genders. Differential item functioning seemed fair across most items for all these child characteristics, although consistency was least satisfactory across age, with t values close to 2 or −2 for some items.

Age of the child has not yet been specifically addressed in International Classification of Functioning, Disability and Health child and youth version terms, as this variable belongs to personal factors. Also, International Classification of Functioning, Disability and Health child and youth version codes are seen as universal across age[3]. During interviews with parents, each child's disabilities were always compared to what could be expected of a healthy child at corresponding age. The participation of parents was crucial to this study. They provided information based on their knowledge and experience of the children, and they participated in all International Classification of Functioning, Disability and Health child and youth version qualifier assessments, and the authors recognized the value of their active contribution. There can be a concern that parental assessments are likely to be biased. However, problems of this type were not encountered. All participating parents were very dedicated and honest, and it is believed that this will also be true more generally. If biased assessment was to occur, it could be uncovered by analyzing nonreflected assessments in terms of infit data and exaggerated assessments in terms of outfit data.

In conclusion, it is believed that a combination of *International Classification of Diseases*, *tenth revision* codes, a common set of International Classification of Functioning, Disability and Health child and youth version d codes for activities and participation and further International Classification of Functioning, Disability and Health child and youth version body functions codes, environmental codes, and personal codes could provide a good tool for the assessment of functioning in all children with disabilities of varying types and magnitudes. Rasch analysis should be part of this tool, as it adds very necessary power to International Classification of Functioning, Disability and Health child and youth version that provides the best possible assessment of an individual child or population of children over time. Rasch analysis should be implemented electronically. This could be achieved by equipping parents,

hospital- and community-based health workers, and social workers with access to a common and electronic network that is permanently available and updateable. Functions of codes could then be analyzed repeatedly, and codes could be added or subtracted to the code set employed. Thus, the methodology demonstrates a mode of selecting both comprehensive and core data sets. Most importantly, International Classification of Functioning, Disability and Health child and youth version code data could be obtained whenever needed, whether when dealing with health problems, sharing information among service providers, or for accreditation and research purposes. The authors hope this study will inspire the implementation of such a program, stimulate further research in this important field, and be of benefit to children with disabilities.

Authors' Contribution

NOI drafted protocol, interviewed families, sampled data, suggested data methodology, reviewed results of statistical analysis and drafted manuscript. KOG performed statistical analysis.

Authors' Note

Declaration of Conflicting Interests

Funding

Ethical Approval

Neither the Danish Ministry of Social Affairs nor the National Board of Health influenced the study protocol, data collection, data analyses or results. All eligible parents in a defined geographical area were contacted by mail, by telephone or in person. The parents were known to us. Participation was voluntary for parents and caregivers. The protocol was accepted by and registered at the Danish Data Protection Agency (DOK121763) before starting the research. Approval for the protocol was sought from the National Board of Health (Project 7-202-05-207/8).

References

1. World Health Organization. *World Report on Disability*. Geneva, Switzerland: World Health Organization; 2011.

2. World Health Organization. *International Classification of Functioning, Disability and Health: ICF*. Geneva, Switzerland: World Health Organization; 2001.

3. World Health Organization, International Classification of Functioning, Disability and Health: Child and Youth Version: ICF-CY. Geneva: World Health Organization, 2007.

4. Simeonsson RJ, Scarborough AA, Hebbeler KM. ICF and ICD codes provide a standard language of disability in young children. *J Clin Epidemiol*. 2006;59(4):365-373.

5. Leonardi M, Martinuzzi A. ICF and ICF-CY for an innovative holistic approach to persons with chronic conditions. *Disabil Rehabil*. 2009;31(suppl 1):S83-S87.

6. Ibragimova N, Granlund M, Bjorck-Akesson E. Field trial of ICF version for children and youth (ICF-CY) in Sweden: logical coherence, developmental issues and clinical use. *Dev Neurorehabil*. 2009;12(1):3-11.

7. Björck-Åkesson E, Wilder J, Granlund M, et al. The International Classification of Functioning, Disability and Health and the version for children and youth as a tool in child habilitation/early childhood intervention - feasibility and usefulness as a common language and frame of reference for practice. *Disabil Rehabil*. 2010;32(suppl 1):S125-S138.

8. Ståhl Y, Granlund M, Gäre-Andersson B, Enskär K. Review Article: Mapping of children's health and development data on population level using the classification system ICF-CY. *Scand J Public Health*. 2011;39(1):51-7.

9. Adolfsson M. Applying the ICF-CY to identify everyday life situations of children and youth with disabilities. Dissertation. Studies from Swedish Institute of Disability Research. No 39. Jönköping 2011

10. Andrade PM, Ferreira FO, Mendonça AP, Haase VG. Content identification of the interdisciplinary assessment of cerebral palsy using the International Classification of Functioning, Disability and Health as reference. *Disabil Rehabil*. 2012;34(21): 1790-801.

11. Raggi A, Leonardi M. Assessing activity limitations in patients with neuromuscular diseases: is the ACTIVLIM questionnaire linked to ICF and ICF-CY? *Int J Rehabil Res*. 2009;32(2): 148-153.

12. Bendixen RM, Senesac C, Lott DJ, Vandenborne K. Participation and quality of life in children with Duchenne muscular dystrophy using the International Classification of Functioning, Disability, and Health. *Health Qual Life Outcomes*. 2012;10:43. 1-9.

13. Liptak GS, Kennedy JA, Dosa NP. Youth with spina bifida and transitions: health and social participation in a nationally represented sample. *J Pediatr*. 2010;157(4):584-588, 588.e1.

14. Ajovalasit D, Vago C, Usilla A, et al. Use of ICF to describe functioning and disability in children with brain tumours. *Disabil Rehabil*. 2009;31(suppl 1):S100-S107.

15. McDougall J, Wright V, Schmidt J, Miller L, Lowry K. Applying the ICF framework to study changes in quality-of-life for youth with chronic conditions. *Dev Neurorehabil*. 2011;14(1):41-53.

16. Janssens L, Gorter JW, Ketelaar M, Kramer WL, Holtslag HR. Health-related quality-of-life measures for long-term follow-up in children after major trauma. *Qual Life Res*. 2008;17(5): 701-713.

17. Østensjø S, Bjorbaekmo W, Carlberg EB, Vøllestad NK. Assessment of everyday functioning in young children with disabilities: an ICF-based analysis of concepts and content of the Pediatric Evaluation of Disability Inventory (PEDI). *Disabil Rehabil*. 2006;28(8):489-504.

18. Leonardi M, Sattin D, Giovannetti AM, et al. Functioning and disability of children and adolescents in a vegetative state and a minimally conscious state: identification of ICF-CY-relevant categories. *Int J Rehabil Res*. 2012;35(4):352-349.

19. Pan YL, Hwang AW, Simeonsson RJ, Lu L, Liao HF. ICF-CY code set for infants with early delay and disabilities (EDD Code Set) for interdisciplinary assessment: a global experts survey. *Disabil Rehabil*. 2015;37(12):1044-1054.

20. Meucci P, Leonardi M, Sala M, et al. A survey on feasibility of ICF-CY use to describe persisting difficulties in executing tasks and activities of children and adolescent with disability in Italy. *Disabil Health J*. 2014;7(4):433-441.

21. Darcy L, Enskär K, Granlund M, Simeonsson RJ, Peterson C, Björk M. Health and functioning in the everyday lives of young children with cancer: documenting with the International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY). *Child Care Health Dev*. 2015;41(3):475-482.

22. Hobart J, Freeman J, Lamping D, Fitzpatrick R, Thompson A. The SF-36 in multiple sclerosis: why basic assumptions must be tested. *J Neurol Neurosurg Psychiatry*. 2001;71(3):363-370.

23. Hobart J, Lamping D, Fitzpatrick R, Riazi A, Thompson A. The Multiple Sclerosis Impact Scale (MSIS-29): a new patient-based outcome measure. *Brain*. 2001;124(5):962-973.

24. McGuigan C, Hutchinson M. Confirming the validity and responsiveness of the Multiple Sclerosis Walking Scale-12 (MSWS-12). *Neurology*. 2004;62(11):2103-2105.

25. Tennant A, Penta M, Tesio L, et al. Assessing and adjusting for cross-cultural validity of impairment and activity limitation scales through differential item functioning within the framework of the Rasch model: the PRO-ESOR project. *Med Care*. 2004;42(1 S):I37-I48.

26. Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: what is it and why use it? When should it be applied, and what should one look for in a Rasch paper? *Arthritis Rheum*. 2007;57(8):1358-1362.

27. Illum NO, Gradel KO. Creating a disability variable for children with disability using the WHO ICF-CY classification system. *Br J Appl Sci Tech*. 2015;11(1):1-19.

28. Illum NO, Gradel KO. The Nordic Five to Fifteen questionnaire could provide the basis for a common neurological disability variable. *Acta Pædiatrica*. 2014;103(8):879-885.