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Creating a Disability Variable for Children with Disability Using the WHO ICF-CY Classification System

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Authors' contributions

This work was carried out in collaboration between both authors. Author NOI designed the study, undertook the majority of visits, collected data, and drafted the manuscript. Author KOG undertook repeated statistical analysis and accepted the manuscript. Authors NOI and KOG repeatedly discussed the statistical data results. Both authors read and approved the final manuscript.

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ABSTRACT

Aims: To create a single disability variable in 332 children with different disability severities, ICD-10 diagnoses, and ages by employing the WHO ICF-CY body functions coding system.
Study Design: Open field pilot research study.
Place and Duration of Study: H. C. Andersen Children's Hospital and Centre for Clinical Epidemiology, Odense University Hospital, Odense Denmark, between October 2010 and November 2011.
Methodology: We included 332 children (144 boys and 188 girls; age range 1.0–15.9 years) with spina bifida, spinal muscular atrophy, muscular disorders, cerebral palsy, visual impairment, hearing impairment, mental disability, and disabilities following treatment for a brain tumour. A set of 47 body function codes (b codes) representing a broad spectrum of functions in daily living and with five qualifiers each was scored during interviews with parents. Psychometric and Rasch data analyses were performed.

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Results: Mean code score for each child was 32.17 (range 0–159). The corrected code-total correlation was high (0.70). Inter-code correlation was mean 0.50 (range 0.01–0.97), and Cronbach´s alpha 0.98. Following Rasch analysis and due to disordering of Andrich thresholds (τs) and infit and outfit mean square values >1.5, the number of codes was reduced from 47 to 33. Retained codes all had ordered τs and mean square and corresponding Z-standardised values within the recommended range of 0.5–1.5. The *t*-statistic for differential item functioning across codes and diagnosis group, age, and gender was between 2.0 and 3.0. Graphical data for disability variable, the child-code map, paralleled clinical expectations across the total population of children.
Conclusion: WHO ICF-CY b codes can provide a coherent measure of the severity of disability in children across various diagnoses, age, and gender and add important information to WHO ICD-10 diagnosis codes when employed in daily clinical practice.

Keywords: Child; ICF-CY; b codes; psychometrics; Rasch analysis; disability variable; measure.

1. INTRODUCTION

Assessing disabilities in children in sufficient detail is essential in daily clinical practice, and for habilitation, rehabilitation, the development of new intervention strategies, and research [1]. In 2001 the World Health Organization (WHO) released the International Classification of Functioning, Disability and Health (ICF) to provide a common framework for the assessment of disability 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 encompassing the health condition of the individual with a disability, together with factors related to body function and structure, activities of daily living, and participation in social activities and other relationships. These factors should be evaluated in relation to environmental factors and personal factors that may have a positive or negative influence on the impact of the disability.

The ICF-CY consists of around 1,400 codes which can be applied to individuals and groups of individuals with various disorders or diseases.

The ICF and ICF-CY 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 [2,3].

Until now, research has been centred on how ICF-CY can be understood, used, and function [4-9]. Many studies have applied the functionality of ICF-CY to specific disorders, including cerebral palsy [10], muscular disorders [11,12], spina bifida [13], disability following brain tumours [14], chronic disorders [15], and disability following trauma [16]. Comparison of content with ICF-CY in other various instruments has been performed [17], and validation for core data sets for ICF-CY has begun [18,19] together with studies of ICF-CY functionality and code selection in specific clinical settings [20,21].

Psychometric and Rasch analysis has not yet been applied to data related to ICF-CY; however, an identical methodology has been employed in relation to the Nordic Five to Fifteen questionnaire [22].

All ICF-CY and ICF codes use five qualifiers on impairment. Accordingly, qualitative research on categorical qualifiers requires the extensive use of psychometric methods underpinned by Classical Test Theory. From its beginning in 2011, this was inspired by methods-related research on ordinal scales [23-25], and analysis has followed methods used in research on ICF data and other areas related to disability [26-32]. Parallel analysis of ICF-CY data has not yet been published.

We intended to explore the possibility of applying ICF-CY codes to children and young people with various disabilities of the broadest range possible that resulted from disorders of the spine, muscles, sensory organs, and central nervous system. We also aimed to illustrate the possibility of creating a common disability variable that can render a more exact measure of the degree of disability in each child and groups of children by forming quantitative measures from qualitative score registrations based on ICF-CY body functions codes.

2. SUBJECTS AND METHODS

2.1 Code Selection and Use

The ICF-CY classification has been declared open for clinical applications and research (3).

No core data set of ICF-CY 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 was used throughout the rest of the study irrespective of disorder, severity of disability, age, and gender. Second-, third-, and fourth-level codes were included. The set of codes included 47 codes for body functions. The codes were used to describe the performance of 332 children in activities of daily living.

2.2 Selection of Children and Interviews

The age criteria for participants were defined in advance: children of ages from 1–15 years at entry to the study were enrolled before 1 October 2011. Visits and interviews were conducted between 1 October 2010 and 30 November 2011. All children and their parents were known to us beforehand; most had been followed clinically for some years at the Department of Child Neurology, H. C. Andersen Children's Hospital, Odense University Hospital. 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, and disabilities following cerebral tumours. 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 that were visually impaired or hearing impaired or had moderate to severe mental disability were recruited by the same method.

2.3 Qualifier Level Wording

As in ICF, ICF-CY uses a universal scoring system consisting of a five-point Likert scale with qualifiers worded as follows for b codes:

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

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, the b qualifier levels were defined as follows:

- 0: Child's ability is as expected for his/her age
- 1: Child has difficulties but functioning is still in the expected range for his/her age
- 2: Child needs help with functions from another person
- 3: Child needs help and care due to limited ability of body functions
- 4: Child is totally dependent on others for body functions

2.4 Procedures

The ICF-CY data sheet and information on the study's aim and procedures were given to all families eligible for participation. After two to three weeks, the families were contacted by phone or in person at their home, if necessary; in this way it was possible to make contact with every family. Participation in the study was entirely voluntary and the decision about participation did not affect future clinical assignment.

All the families who agreed to participate were visited in their home by one of the participating medical doctors (NOI, LWL, KRB, NS, MNJ). Where the child lived in a residential facility, caregivers participated with the written consent of the child's parent or guardian. Functional abilities and the environmental and personal factors relevant to a complete assessment of functioning were discussed using the ICF-CY conceptual model. Factors related to the selected ICF-CY codes and qualifiers were then discussed with one or both parents. ICF-CY qualifiers were scored during conversation. Data about ICD-10 diagnoses were added to the scoring sheet on the basis of medical records and information obtained during the conversations. 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.

2.5 Psychometric Evaluation of ICF-CY Code Data

Within-scale analysis of responses from this single administration of b codes was undertaken.

It is recommended that correlations between contributing b and the total score computed from the remaining codes, the corrected item–total correlations, should exceed 0.40 [26].

Data targeting was estimated from the code scale midpoint and range and observed scores, together with 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 clinical meaning of the code scale and was further investigated in the Rasch analysis. Within-scale factor analysis including the above corrected item–total correlations and Cronbach's alpha (alpha = $N \times \bar{c} / \bar{v}$ + [N-1] x $\bar{c}$, 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 variable. The standard error of measurement (SEM) = SD x $\sqrt{(1\text{-alpha})}$ and 95% confidence intervals (95%CIs) = ± 1.96 x SEM were calculated.

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

2.6 Rasch Modelling 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 ICF-CY codes and their qualifiers. More specifically, the primary objective was to use the Rasch model to generate a continuous scale that would register changes in disability that might not be distinguished by the ordinal ICF-CY five-point qualifier scales or ICF-CY summations.

Item response theory (IRT) uses up to three parameters, but the Rasch model uses only one. IRT aims to fit a set of data, whereas data needs to be fitted to the Rasch model.

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 logP/(1-P) = B – D. Probability of success P can also 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 b code qualifiers.

Rasch analysis was applied to all five qualifiers for the ICF-CY b codes; this assumes equal distances between qualifier levels — an assumption which may not 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 at 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 b code qualifier level is generated. This scale constitutes the latent disability construct or variable for the children included in this study and the b 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 that originally represented the ICF-CY scores can be mapped to a scale that detects changes that lie between the individual steps of the ordinal scale; most importantly, the b code qualifier scores can be added to provide a true total score.

For individual children and specific b codes and their qualifiers to contribute to the formation of the disability variable, certain validity criteria must be met [27-30]. They are related to the adequacy of targeting children and b codes (criterion A), construction of the measurement ruler (criterion B), and successful measurement of children (criterion C):

Criterion A: The scale-to-sample targeting relates the disabilities of participating children to b codes and is illustrated by the child-code map.

Criterion B1: The b code response categories should be ordered so as to imply an impact continuum. In the polytomous ICF-CY scale, five qualifiers with four Rasch–Andrich thresholds ($\tau 1$, $\tau 2$, $\tau 3$, and $\tau 4$) are defined.

Criterion B2: The b codes of the disability variable (scale) are located on a difficulty continuum. By convention, the mean code location is set to 0 and values range from minus infinity to infinity — for all practical purposes a -6 to +6 continuum. A standard error (SE) is associated with each measure. To be reasonably certain (p<.05) that two adjacent measures are different, the corresponding error distributions are considered identical and √2 x 1.96 equals 3 x SE [11]. The smallest distance considered to represent a meaningful difference between measures is given by 3 x SE plus the logit measure.

The code separation index is the number of different levels of the b code score that can be distinguished statistically, and should be at least 3 (strata = 3: very high, middle, and very low measures).

Criterion B3: Range and ordering of b codes locations on the difficulty continuum should reflect clinical assessments.

Criterion B4.0: The b codes should in combination define a single disability variable. Conformity with the Rasch model is denoted by fit and difference between the observed and expected data as residual. Fit residual for the b codes is a summary of the differences between observed and expected values for all responses to that code and is denoted as the code-child (item-person) interaction. Fit residuals are standardised and should be normally distributed with M = 0 and SD = 1. Fit is expressed as infit and outfit. Infit weights information (1/variance) and is less sensitive to unexpected scores. Outfit statistics are sensitive to outlier results that are rare or have occurred in an unexpected way. Both are expressed in terms of mean-squared values (IN.MSQ and OUT.MSQ). Values should be close to 1 [27].

Criterion B4.1: Standardised fit statistics (ZSTD) are *t*-tests of whether IN.MSQ and OUT.MSQ data fits the Rasch model perfectly. They are reported as z-scores or unit normal deviates (*t*-statistics corrected for their degrees of freedom). For double-sided p<0.05, ZSTD is >1.96. ZSTDs in the range -1.9–1.9 indicate a reasonable fit to the Rasch model. ZSTDs in the range 2.0–2.9 are noticeably unpredictable, ZSTDs ≥3 are very unexpected if they fit the Rasch model perfectly, and values ≤ -2 are too predictable [33-35].

Criterion B4.2: Point-measure correlation (PT-MEASURE CORR.) refers to point-biserial correlation and is the correlation between the observations for each child on each b code and all b code measures for the same child. The correlation can be compared with the expected value (PT-MEASURE EXP.) [36].

Criterion B4.3: When the child's functioning corresponds to a particular b code qualifier difficulty, 50% of observations should match the expected values (EXACH MATCH OBS% and EXP%). If OBS% < EXP%, the code data is more random than the model predicts. Similarly, OBS% > EXP% indicates better predictability [36-38].

Criterion B4.4: Item characteristic curves (ICC) depict the relationship between observed and expected values across logit locations. They should always be monotonic ascending curves.

Criterion B5: The response to one item may bias the response to another item. This occurs if b codes conceptually close to each other relate to the same clinical factor. Highly locally dependent b codes will have a correlation of > +0.7 [36]. Negative correlations can also occur.

Criterion B6: The codes should be stable and perform similarly across diagnostic groupings, genders, and ages. If this is not the case, there will be differential item functioning (DIF) or item bias [36]. DIF is here expressed as an approximate *t*-test of the item DIF against overall item difficulty.

Criterion C1: Measurements for all children should be valid. Fit residuals were examined as with b codes and with identical reference values.

Criterion C2: A child's location on the disability continuum should be reliable and reproducible. This reliability index or child (person) separation index (PSI) should have a value of at least 2 (strata = 2) and a reliability coefficient of at least 0.80 [36].

Criterion C3: The location of individual children on the disability continuum based on their logit measures should be clinically sound.

Winsteps 3.74.0 was used for Rasch measurements.

3. RESULTS

3.1 Descriptive Characteristics

A total of 367 eligible children were identified. The parents of 35 children decided not to participate for various reasons, and thus 332 children (90.5%) were included and their parents or caregivers completed the interview. The children included were of age mean 9.4 years, SD 3.8 years, and age range 1.0–15.9 years. The parents and caregivers of 12 children were visited in their permanent residences and 7 children in foster families.

The children of the participating parents were grouped according to discharge diagnosis. Sixty-three 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 tumours.

3.2 Results of Psychometric Analyses

There was missing data for 47 b codes in 796 out of a total of 15,604 responses (5.1%). This was due to the fact that some children were not old enough to be evaluated with respect to certain b codes. It was decided not to set age thresholds for the applicability of specific b codes, and the decision about whether to assign a score for a particular code was made on an individual basis.

There were high corrected code-total correlations (0.70), high inter-code correlations (0.50), and high reliability of 0.98 in terms of Cronbach's alpha.

3.3 Results of Rasch Analysis

Criterion A. The b codes selected and with a disability level corresponding to children's disability (targeting) is illustrated in the child-code map for b codes (Fig. 1). The number of b codes was reduced from 47 to 33 (Tables 1a and 1b). Data on b codes were pooled in relation to children with more severe disabilities (Fig. 1). This is due to the fact that a relatively large proportion of the children had relatively minor difficulties such as minor motor disability.

Criterion B1. Each b code location equals the mean of $\tau 1$, $\tau 2$, $\tau 3$, and $\tau 4$. The mean τs of all 33 b codes are illustrated (Fig. 2); the figure shows that there was an equal probability of observing adjacent qualifiers. Seven b codes were excluded because they resulted in disordered τ values (Table 1b).

Disordering may have been due to the fact that these b codes did not have a straightforward relationship with disabilities or relevance, meaning or wording could be misunderstood. These codes dealt with issues such as sleep pattern, pain, and continence.

Structure calibration across all the qualifier levels showed that τ thresholds and category measures increased with increasing qualifier values (Table 2). They were thus not overlapping but ordered meaning that parents understood qualifier levels as related to progressive disability.

Criterion B2. The SEs for scores on the selected b codes increased only slightly at the upper extreme of the disability variable and demonstrated a good fit between the construct and the sample data (Table 3). Thus codes employed among children with most severe disability could still differentiate and thereby measure.

Criterion B3. The range and order of b codes on the disability variable seems to be clinically sound. For many of the children in the sample, lower extremity motor difficulties were the major disability, while cognitive ability was normal. This accounts for the frequency ordering of the codes: b770 (gait pattern functions) was most common among the least disabled children, followed by b760 (movements of hands), b144 (memory functions), and b1408 (attention functions) applied where the disability had a cognitive dimension, whereas codes dealing with perception, b1564 and b156, played a role in assessing disability only in children who were severely disabled (Fig. 1).

Criterion B4.0. The b codes with outfit MNSQ measures >1.5 were excluded; this group included b codes with disordered qualifiers. Code b770 had outfit MNSQ 3.06 and infit MNSQ 2.74, but it was retained because it was the only one of the ICF-CY b codes that captured gross motor functional level across the range of disabilities present in the sample. Experimental removal did not change the ordering or values of the remaining b codes (data not shown). All other b codes except b260 (outfit MNSQ 2.04) had infit and outfit MNSQ values <2.0 (Table 3). Infit and outfit data reflects variance and demonstrates that grading on b code qualifiers was not a result of guessing or misunderstanding but of sound reflection on each child's level of disability. The same applies for ZSTD data described in the following under criterion B4.1.

Criterion B4.1. 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 may indicate problems with the validity of the data. Seven b codes had high outfit ZSTDs and 10 codes had high infit ZSTDs. Code b770 had the highest outfit and infit ZSTDs. Where MNSQ values are acceptable, ZSTD values are less important, and therefore no additional b codes were removed as a result of this analysis. The mean MNSQs and ZSTDs approximated ideal values, as did MNSQs for the b code qualifiers (Table 3).

Criterion B4.2. Observed point-measure correlations were all close to expected values (*Table 3*): individual b code correlations were related to other b code correlations in the same child. None of the correlations was negative (data not shown), indicating that all the b codes properly contributed to the disability variable and that the data for the selected b codes was unidimensional and thus unambiguous.

Criterion B4.3. There is an exact match between the child's functioning and b code difficulty when b code difficulty is identical to the child´s disability. An observed % higher than the expected % on a measure indicates a higher probability of an exact match. This was observed for 19 out of 33 b codes (*Table 2*).

Criterion B4.4. The ICC for b codes shows the relationship between the observed and expected values (Fig. 3). Fig. 4 illustrates the ICC for b770, which had a high outfit MNSQ of 3.06. The ICC for b770 indicates that this code showed a tendency to overestimate disability in more disabled children and underestimate disability in higher functioning children. This tendency was not uniform across b codes (curve data not shown). The ICC for b1255 shows low infit and outfit values (Fig. 4).

Criterion B5. High within-code category correlations are not desirable as it could point to the fact that by grading one code could influence the meaning and grading of another code representing a similar disability. In the 9 most highly correlated b code pairs, correlation coefficients ranged from 0.33 to 0.47; for the 10 most highly correlated d code pairs, the correlation coefficient ranged from 0.47 to 0.61. For both code categories, the maximum correlation coefficient was <0.7, indicating a satisfactory level of correlation (data not shown in table format).

Criterion B6. The b codes behaved differently with respect to diagnosis, gender, and age (Fig. 5). An approximate *t*-test for the DIF of each b code against overall b code difficulty was conducted using critical values ±2.0. Around 24% of b codes had *t* in the range 2.0–3.0, but four codes had a higher *t*. The separation index was 6.75, indicating that more than three levels of b codes could be differentiated with a reliability of 0.98. Results thus suggest that diagnosis, gender, and age to some extend could influence on interpreting the disability variable. Larger future studies with more children included in each diagnosis groups might point to the opposite.

Criterion C1. Fit data for children was analysed. Mean infit was MNSQ 1.08 and mean outfit MNSQ 1.00. Six children had infit MNSQ 1.5–2.0 and 25 children had infit MNSQ >2.0, (range: 2.02–3.15). Four children had outfit MNSQ 1.5–2.0 and 17 children had outfit MNSQ >2.0 (range: 2.05–4.64), giving a total of 42 children with either infit or outfit MNSQ > 2.0 (*Table 3*). Data illustrates that children with disabilities are quite different as some do not suffer from a single disability entity or ICD-10 code diagnosis but might well have more composite problems affecting daily living. Fit data for children might thus not be fully perfect and no children should be kept from ICF-CY b code registration for that reason.

Criterion C2. The child separation index (PSI) for b codes was 2.78, with a reliability of 0.89; both values are well above the required thresholds (2.0 and 0.80, respectively), indicating that three different levels of disability can be distinguished statistically using the b codes that were selected and with the same true SD of 1.72.

Criterion C3. Mean location on the b code-based disability variable (measure) was -2.05, SD 1.83, the highest location (representing the child with the greatest disability) was 4.79, and the lowest score (least disabled child) was -4.68. This highest and lowest score data does not correspond exactly with the data on the child-code map (Fig. 1), reflecting the known fact that extreme data is less reliable in Rasch analysis.

3.4 Comparison of Qualitative Data and Rasch Measures

The b codes were scored using the five-point Likert scale used across the ICF-CY. This scale provides qualitative data, which in principle should not be added; the use of summarised scores to provide a unitary measure of disability for individual children or groups of children is therefore potentially problematic. This study demonstrated that relatively more children are less disabled than their summed b code scores suggest if Rasch measures are employed (Fig. 6).

```
DISABILITY     CHILD-B CODE-MAP
VARIABLE
(MEASURE)

          <more>|<rare>
  4              +
                 |
              .  |
                 |
              .  |
                 |
  3              +
                 |
                 |
              .  |
              .  |
                 |
  2           .  +
              #  |
              .  |
                 |  b2702
           .# T  | T
           .#    |  b156
  1         #    +  b260
           ##    |  b1470  b1564  b5102
         .###    | S b16702
            #    |  b1266  b1561
           ##    |  b1478
           ##    |  b16700
  0        .#    + M b1141  b1142  b1251  b1253  b1255  b1260  b1408  b144
         ### S  |  b1250  b1254  b16710  b1672
         ###    |  b1252
        .###    |  b1300  b163   b2708
        .###    |S b760
      .#####    |  b1140  b1641  b1646
 -1 .#######    +  b1720
      .#####    |
    .#######    |T
    ########    |
     .######    |  b770
     ####### M  |
 -2    #####    +
  ##########    |
     #######    |
       . ###    |
      .#####    |
        ####    |
 -3 ########    +
        .###    |
        .###    |
          .# S  |
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-4   ########  +
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             # |
            .# |
    .######### |
               |
     .######## T+
        <less>|<frequent>
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Fig. 1. Distribution of the 33 b codes that fitted the Rasch model among 332 children

Each "X" represents 2 children. M = mean, S = 1 standard deviation, T = 2 standard deviations. Each | represents an interval of 0.2

Table 1a. The set of ICF-CY b codes initially used in the sample of 332 children, which fitted the Rasch model (n=33)

b 1140: Orientation to time (knows and understands day and time)
b 1141: Orientation to place (has appropriate orientation and correct turning of objects)
b 1142: Orientation to person (has identity of self and others and reads body language)
b 1250: Adaptability (has appropriate response to and accepts new tasks or situations)
b 1251: Responsivity (has appropriate response to and understanding of demands)
b 1252: Activity level (has appropriate energy level reaction to demands)
b 1253: Predictability (reacts in a predictable and suitable way to demands)
b 1254: Persistence (performs tasks in an appropriately sustained manner)
b 1255: Approachability (initiates contacts with others in an appropriate way)
b 1260: Extraversion (has appropriate approach to others)
b 1266: Confidence (has appropriate self-assurance, boldness, and assertiveness)
b 1300: Energy level (has appropriate initiation and fulfilment of tasks)
b 1408: Attention functions, other specified (concentrates and tolerates noise in an appropriate way)
b 144: Memory functions (has appropriate memory for events)
b 1470: Psychomotor control (has appropriate speed of activity and response time)
b 1478: Psychomotor functions (has control of inappropriate activities, movements, sounds, words)
b 156: Perceptual functions (reacts appropriately to sounds and light)
b 1561: Visual perception (perceives shape, size, and colour appropriately)
b 1564: Tactile perception (perceives touch and accepts being touched in an appropriate way)
b 163: Basic cognitive functions (understands abstract ideas and instructions)
b 1641: Organising and planning (has appropriate planning and carrying out of tasks)
b 1646: Problem-solving (plans, organises, explains, and solves tasks appropriately)
b 16700: Reception of spoken language (understands what is said and explained appropriately)
b 16702: Reception of sign language (reads and understands signs and pictures appropriately)
b 16710: Expression of spoken language (produces meaningful spoken messages)
b 1672: Integrative language functions (has appropriate conversation and explains appropriately)
b 1720: Simple calculation (carries out simple calculations)
b 260: Proprioceptive function (tolerates changes in body position and height in an appropriate way)
b 2702: Sensitivity to pressure (corrects clothes, feels sand in shoes, touches vibrating objects appropriately)
b 2708: Sensory functions related to temperature, other specified (senses and grips objects appropriately)
b 5102 (b5103, b51050, b51051): Chewing (chews and swallows food appropriately)
b 760: Control of voluntary movement functions (has appropriate movements of hands)
b 770: Gait pattern functions (walks and runs with appropriate patterns)

Table 1b. ICF-CY b codes initially used in the sample of 332 children which did not fit the Rasch model (n=14). Codes marked * showed qualifier disordering. See Table 2a for classification of b code digits

b 1340*: Amount of sleep (sleeps sufficiently well)
b 1341: Onset of sleep (falls asleep in an appropriate way)
b 1342*: Maintenance of sleep (able to sleep without disturbing interruptions)
b 1440: Sustaining attention (has appropriate memory for present events)
b 16701: Reception of written language (reads and understands the written text appropriately)
b 16711: Expression of written language (writes and expresses appropriately)
b 2100: Visual acuity functions (has normal seeing)
b 2300: Hearing functions (has normal hearing)
b 250*: Taste function (tastes and tolerates food texture appropriately)
b 265*: Touch function (tolerates hair washing, hair cutting, nail cutting)
b 2800: Generalised pain (senses pain appropriately)
b 5253*: Faecal continence
b 6202*: Urinary continence
b 6400*: Functions of sexual arousal phase (has appropriate and age-related interest and excitement)

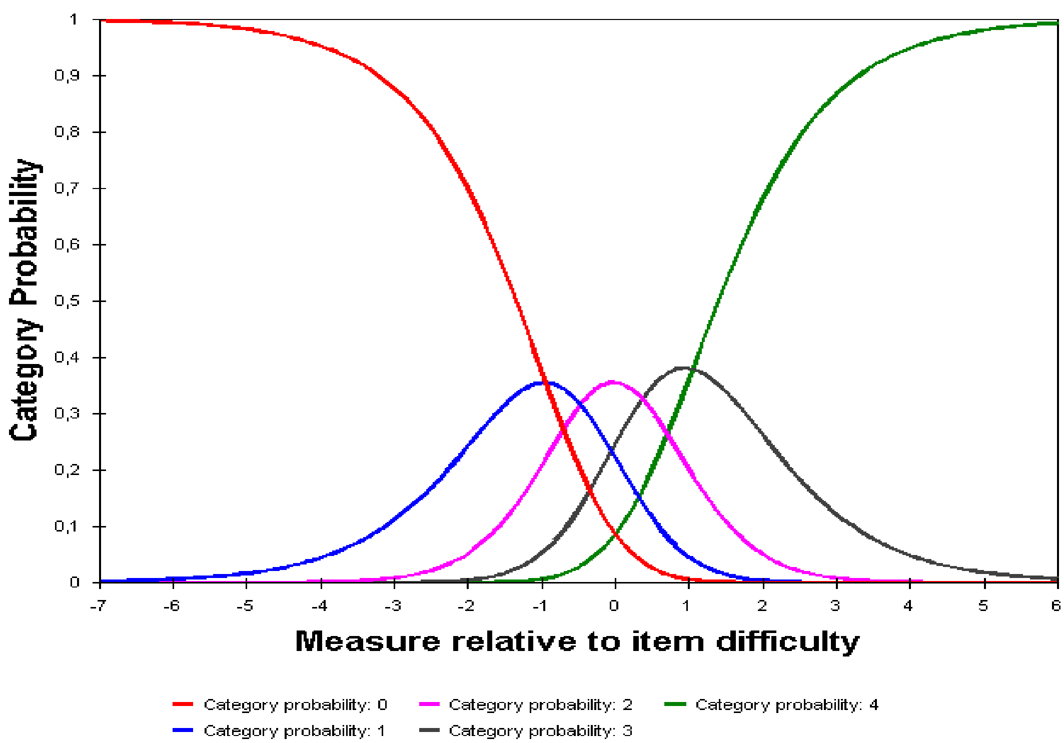


Fig. 2. Qualifier (category) information function for 33 b codes. Qualifier 0 = red, 1 = blue, 2 = purple, 3 = black, 4 = green

The τ values are where those curves meet, indicating 50% probability of each qualifier being selected. Note the almost equal distance between the four values measured on the disability variable (logits). If qualifiers were misunderstood and/or formulated in a problematic way, the probability curves would not follow qualifier ordering and/or there would be greater differences in the τ values.

Table 2. Structure calibration of the sample of 33 b codes

Qualifier	Observed count	Observed count %	Observed average	Sample expected	Infit MNSQ	Outfit MNSQ	T thres-hold	Category measure
0	6279	61	-2.86	-2.84	1.07	1.07	-	-2.36
1	1728	17	-1.32	-1.48	1.13	.85	-.93	-.95
2	1018	10	-.69	-.54	1.04	1.09	-.47	-.02
3	652	6	.26	.35	.96	1.19	.34	.94
4	549	5	1.55	1.47	0.99	1.12	1.05	2.43

Table 3. Measure locations in descending order of difficulty for the 33 b codes together with corresponding SE and fit data

			Infit		Outfit		PT-measure		Exact match	
B code	Measure	SE	MNSQ	ZSTD	MNSQ	ZSTD	CORR.	EXP.	OBS%	EXP%
2702	1.45	.12	1.84	4.65	1.27	.9	.48	.57	77.4	82.5
156	1.19	.11	1.40	2.7	1.13	.5	.55	.59	76.2	79.5
260	1.00	.11	1.94	5.7	2.04	3.2	.48	.61	73.0	77.4
1470	.83	.10	1.38	2.7	1.04	.3	.60	.64	74.6	75.3
1564	.83	.10	1.19	1.5	1.25	1.0	.62	.63	74.9	75.0
5102	.77	.10	1.42	3.1	1.66	2.4	.58	.64	72.1	73.9
16702	.59	.10	.83	-1.5	.44	-3.1	.70	.66	75.9	71.2
1561	.51	.09	1.14	1.2	.92	-.3	.66	.66	69.8	69.7
1266	.48	.09	1.56	4.2	1.46	2.0	.59	.66	63.6	69.9
1478	.26	.09	1.06	.6	.85	-.8	.69	.68	68.6	66.6
16700	.22	.09	.72	-2.8	.56	-2.8	.73	.69	69.2	65.1
1142	.07	.08	0.98	-.2	.97	-.1	.71	.70	66.3	62.9
1141	.07	.09	.84	-1.5	.81	-1.1	.72	.70	63.8	62.9
1260	.05	.09	1.10	.9	.88	-.7	.70	.70	62.0	63.4
1255	.01	.08	.79	-2.1	.67	-2.2	.75	.70	67.0	62.7
144	-.03	.08	.79	-2.2	.63	-2.5	.74	.70	64.9	62.2
1408	-.06	.08	1.71	5.8	1.92	4.5	.60	.71	55.3	61.7
1253	-.08	.08	1.12	1.1	.94	-.3	.71	.71	61.0	61.6
1251	-.08	.08	.65	-3.9	.50	-3.7	.77	.71	73.5	61.7
1672	-.10	.08	.58	-4.8	.51	-3.7	.78	.71	71.9	60.7
16710	-.19	.08	.79	-2.3	.70	-2.1	.75	.72	62.5	59.8
1254	-.19	.08	.67	-3.7	.61	-2.8	.77	.72	69.6	60.0
1250	-.20	.08	.81	-2.1	.62	-2.8	.76	.72	66.3	59.8
1252	-.29	.08	.61	-4.6	.52	-3.9	.78	.72	65.0	59.0
163	-.43	.08	.56	-5.3	.45	-4.7	.81	.74	67.0	57.6
1300	-.45	.08	.81	-2.1	.72	-2.2	.78	.74	60.5	56.7
2708	-.58	.07	1.31	3.1	1.39	2.6	.70	.75	47.9	54.5
760	-.60	.07	1.21	2.2	1.67	4.3	.68	.75	46.7	54.5
1140	-.77	.08	.79	-2.3	.81	-1.4	.79	.77	53.7	53.0
1641	-.84	.07	.46	-7.3	.44	-5.4	.85	.76	66.0	52.2
1646	-.88	.08	.54	-5.8	.48	-4.8	.85	.77	66.2	52.6
1720	-.94	.08	.89	-1.2	.77	-1.8	.80	.78	49.4	51.7
770	-1.61	.07	2.74	9.9	3.06	9.9	.52	.79	31.1	48.1
Mean	.00	.09	1.07	-.2	.99	-.7			64.6	63.2
SD	.66	.01	.48	3.8	.57	3.2			9.9	8.5

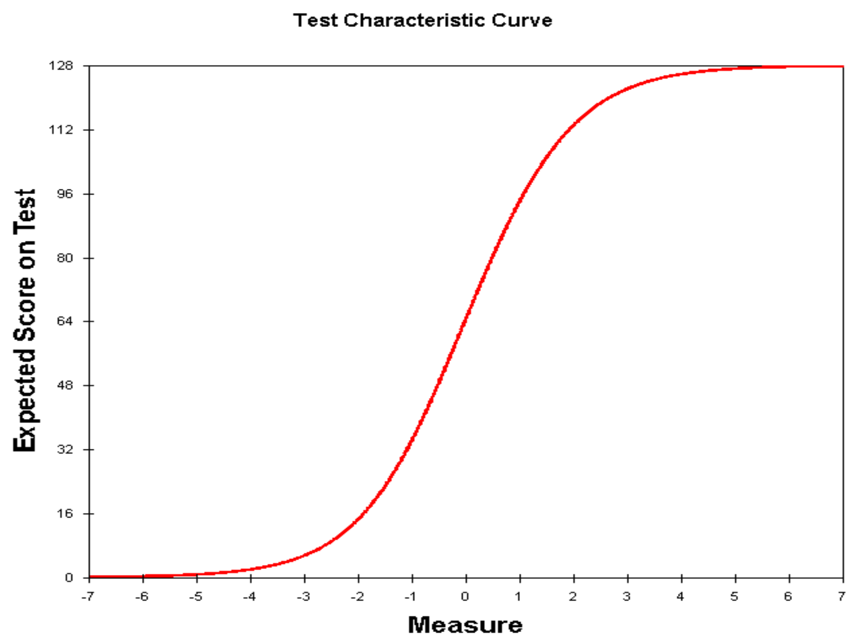
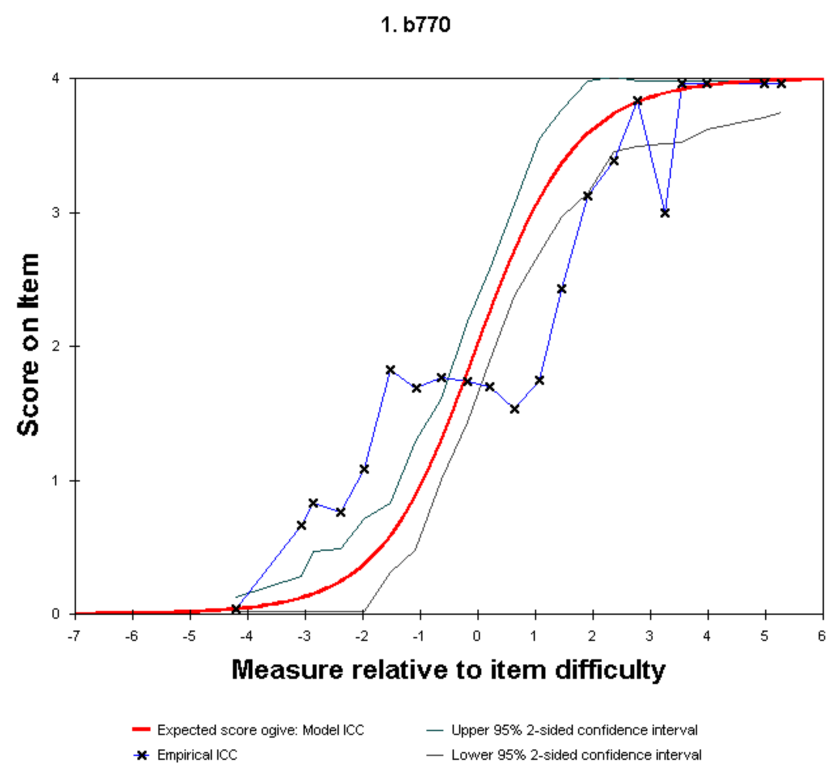


Fig. 3. Test characteristic curve (ogive) for the 33 b code scores relative to logit measures



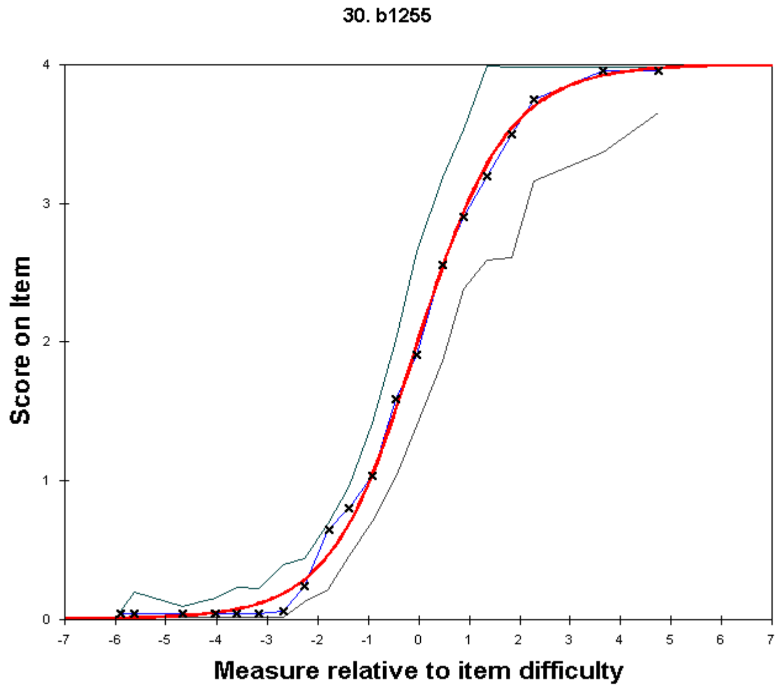
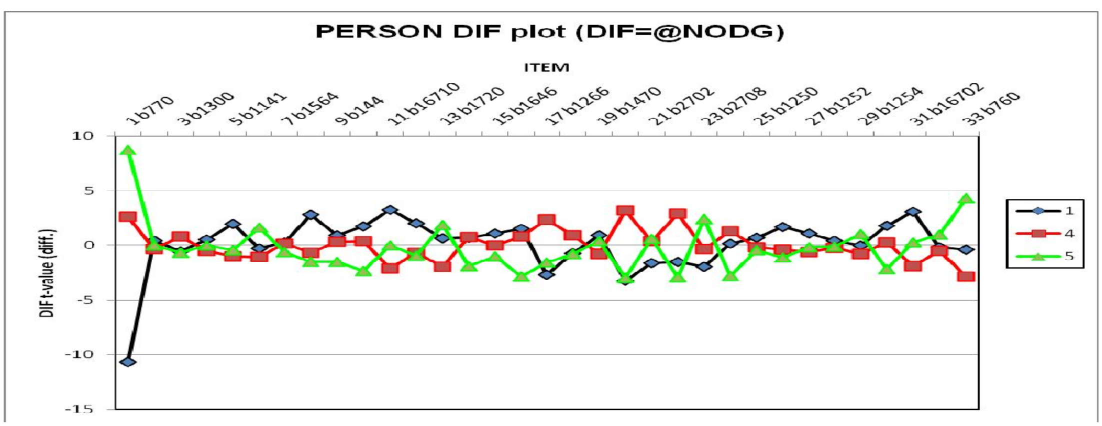
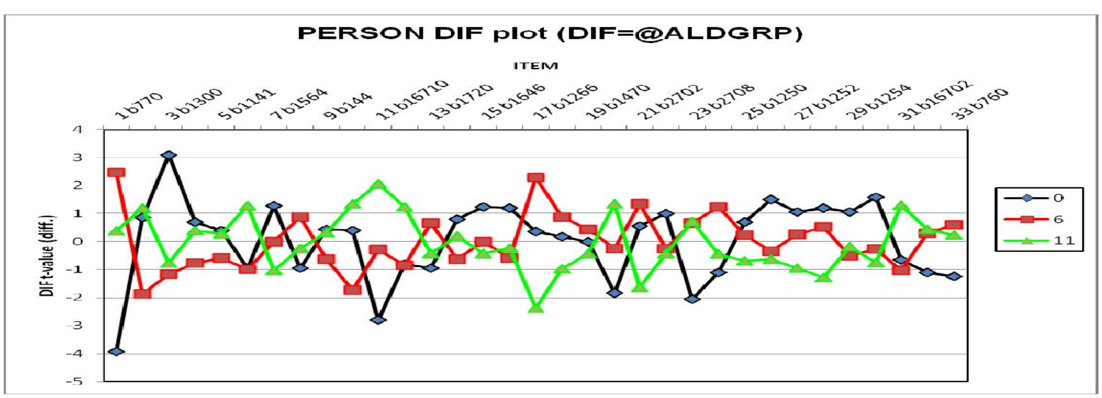


Fig. 4. The b code (item) characteristic curves (ICCs). b770 shows high outfit MNSQ values and b1255 shows low infit MNSQ values





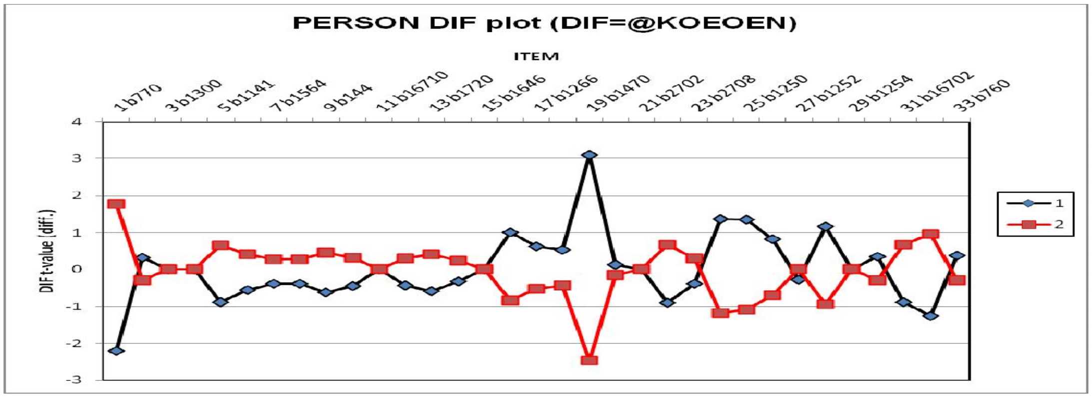
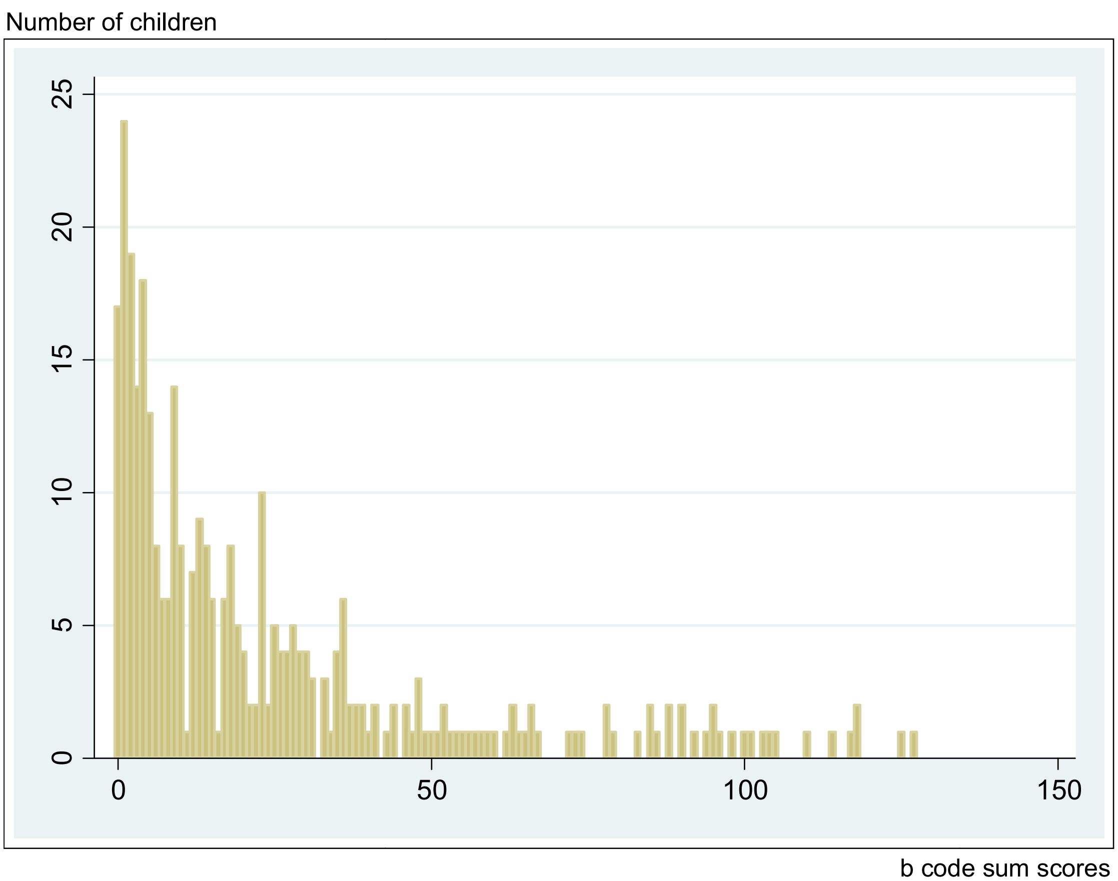


Fig. 5. Differential item functioning (DIF) across 33 b codes and diagnosis groups, age groups, and genders. Diagnosis groups (upper diagram): 1: spina bifida, spinal muscular dystrophies, and muscular disorders; 4: cerebral palsy; 5: blindness, deafness, mental disability, and brain damage following brain tumours. Age groups (middle diagram): 0: 1–5 years; 6: 6–11 years; 11: 12–15 years. Genders (lower diagram): 1: boys; 2: girls



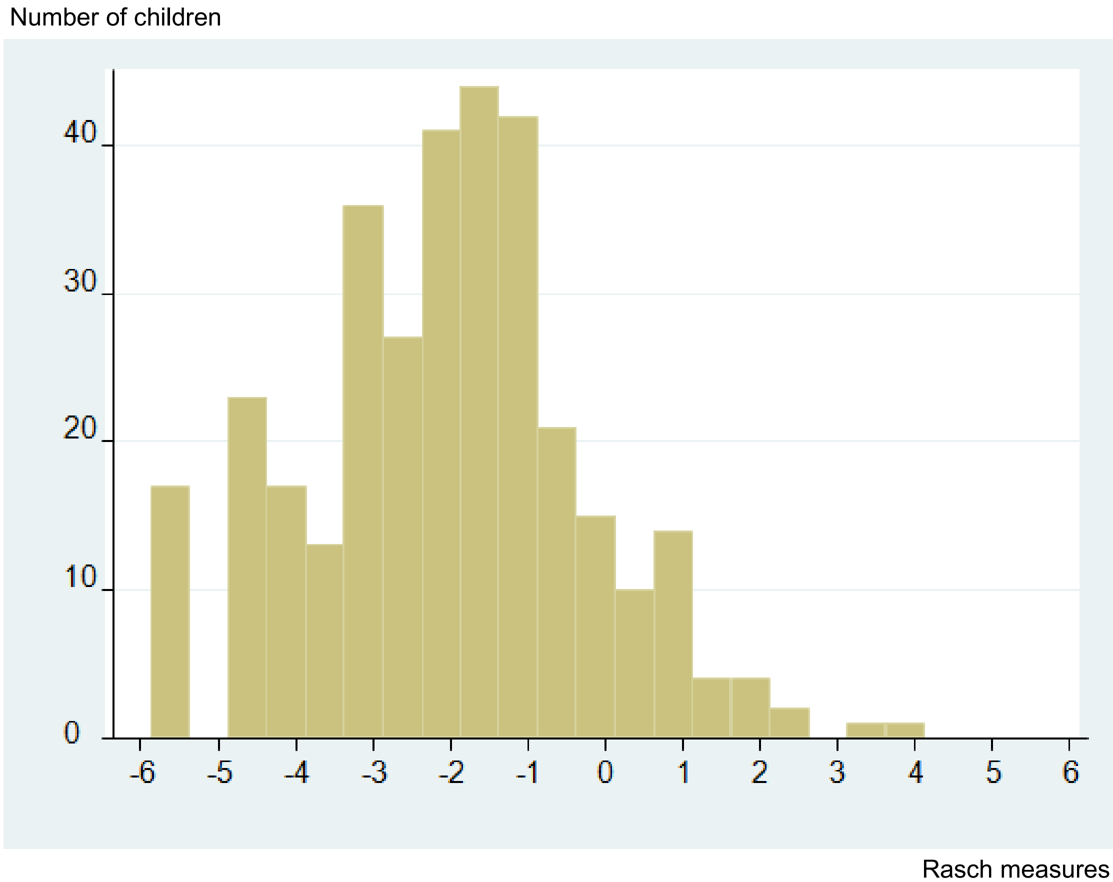


Fig. 6. Number of children (y-axis) and b code sum scores for the set of 47 b codes (x-axis) and number of children (y-axis) and summed measures according to Rasch analysis of 47 b codes (x-axis)

4. DISCUSSION

This study was undertaken to find out how ICF-CY codes might be used in clinical practice. 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, and children who were mentally disabled, vision impaired, and hearing impaired.

The ICF-CY body function b codes exhibited widely varying code means, variances, and SEM 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, 0.70, was high.

The Rasch model analyses children's disabilities in terms of b codes that are related to a disability variable, also termed the latent trait scale, a single latent dimension, or just measure.

However, a number of criteria must be met when Rasch analysis is used (27). This is important, since we aimed to determine whether a unitary and single disability variable might be used to characterise disability across conditions, types, and the 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 in 32 out of 47 b codes could be described in terms of a single disability variable.

The child-code map (person-item map) for b categories seemed sound; 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 only motor difficulties. This meant that an important group of the b codes was located in the upper half of the range of the disability variable as it was only relevant to the more disabled children, who had both motor and cognitive difficulties. Position on the continuum for the disability variable corresponded well with the complexity and severity of the factors assessed by particular b codes (Fig. 1).

Particular concern was shown to determine whether b codes behaved differently across diagnoses, ages, and genders. DIF 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 (Fig. 5).

From an ethical point of view WHO has stated that ICF and ICF-CY should always be used so as to respect the inherent value and autonomy of the individual, never be used to label individuals and children, always used with full consent of individuals and parents and that data should be used with confidentiality [2,3]. We have met those absolutely necessary demands first of all by considering disability in a positive way in terms of what the child is able to do and next to what extend it needs help from others. Also, we have been eager to find ways to describe more exactly and with least error possibly how disability is. Not from our perspective but from that of the parents and related to each child's daily living. By wording of codes we have opened the possibility of not only discarding individual codes in case of malfunctioning but instead rewording them in cooperation with parents and test them in future applications. Furthermore, the parents have been fully informed all way through the study and they all received written results material. It remains however to be analysed how ICF-CY functions b codes interplays with other ICF-CY codes to create a full picture of the health condition of each child.

In conclusion, ICD-10 codes do not necessarily indicate the severity of a disorder, and ICF-CY codes tells nothing of a child´s diagnosis *per se*. But combined in clinical practice, both can provide valid information on the assessment of functioning in all children with disabilities of varying types and magnitudes. Furthermore, ICF-CY codes can be added or withdrawn on a continuous basis while using electronic registration and repeated data analysis in order to refine the child-code map by adding codes to fill out possible gaps related to disability level and knowledge.

In perspective, WHO ICF-CY codes can constitute a basis for interactive evaluation of childhood disability with parents participating in evaluating their own child's disability and at the same time sharing their knowledge and experience in networks together with medical staff and health and social workers.

5. CONCLUSION

The WHO ICF-CY b codes seem to be the basis for forming a common disability variable across age, gender, and eight ICD-10 discharge diagnoses covering core elements in childhood disability related to body functions.

CONSENT

All eligible parents in a defined geographical area were contacted by mail, telephone, or in person. The parents were known to us. Participation was voluntary for parents and caregivers. All participating parents or authorised caregivers gave written acceptance with their signature for the use of collected and anonymised data.

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.

The protocol was accepted by, and registered at, the Danish Data Protection Agency (DOK121763) before start of the research. Approval for the protocol was sought from the National Board of Health (Project 7-202-05-207/8).

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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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