



# Parents' Assessment of Disability in Their Children With Down Syndrome

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## Abstract

**Aim:** To describe a population of children with Down syndrome and evaluate their parents' assessment of disability. **Methods:** Medical records of a population of 80 children with Down syndrome aged 5 to 17 years were analyzed for genetic background and associated diagnoses. And 27 parents to their children agreed to assess disability by employing a set of 26 International Classification of Functioning, Disability and Health body function (b) codes and activity and participation (d) codes. Clinical data were gathered and analysis of parents' assessment of disability using psychometric and Rasch analysis was performed. **Results:** Clinical data on 27 children assessed by their parents and 53 children not assessed had identical associated diagnoses. The 26 International Classification of Functioning, Disability and Health codes and qualifiers had a mean score of 2.67 (range 1.26-4.11) and corrected code-total correlations mean of 0.55 (range -1.17 to 0.82). Rasch analysis showed proper code MNSQ infit and outfit values with mean 1.03 and 1.06. **Conclusion:** Clinical data on 27 children assessed were similar to 53 children that were not evaluated. Parents' assessment of the 27 children showed good psychometric and Rasch analysis properties. Similar results might be expected in the total population of 80 children.

## Keywords

Down syndrome, childhood disability, parent assessments, International Classification of Functioning, Disability and Health, psychometric data analysis, Rasch analysis

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Children with disabilities are followed clinically throughout their childhood and youth. This also applies to children and youth with Down syndrome as we want to support families and communities and to detect on complications that might arise in childhood such as diabetes type 1, hypothyroidism, and celiac disease and treat when needed. We want to communicate with families on and between outpatient visits when needed to help them in their dedication to support their child's development and challenges in daily living. In order to communicate better between parents, medical professionals, social workers, and others, we in recent years have focused on valuing parent's opinions and impressions of disability in their children and to identify a common language that could be further developed and shared by health professionals and parents alike.

To that end and as a first approach, the World Health Organization International Classification of Functioning, Disability and Health has been employed.<sup>1</sup> We in first hand focused on body functions (b codes) and activity and participation (d codes)<sup>2,3</sup> and we joined them to cover better on issues in daily

living.<sup>4</sup> Especially, 26 joined b and d codes have been promising for good code properties and interpretation by parents. They have been repeatedly applied over time to originally 332 children and youth with muscular disorders, spina bifida, spinal muscular dystrophies, disabilities following treatment for brain tumors, visually impaired, hearing impaired, or had moderate to severe mental disability.<sup>5</sup>

We now apply that set of codes on the identical International Classification of Functioning, Disability and Health second level to parents to children with Down syndrome. Although preliminary in nature and relatively few in number of children

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**Table 1.** The 26 International Classification of Functioning, Disability and Health Codes Selected Were All Second Level Out of 4-Level Codes.<sup>a</sup>


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d410: Getting out of bed in the morning (might have reduced ability to move out of bed)
d530: Toileting (might have reduced ability to move and/or understand the need for toileting)
d510: Washing oneself (might have reduced ability to move and/or understand the need for hygiene)
d540: Dressing (might have reduced ability to move and/or understand the need for dressing)
b265: Touch function (might be sensitive to touch, noise, tooth brushing, hair brushing, and/or hygiene)
d550: Eating (might have decreased ability to move arms and hands and/or chew food)
b180: Experience of self and time functions (might have difficulties planning and/or performing tasks)
d450: Walking (might have difficulties walking)
d465: Moving around while using equipment (might have difficulties due to balance, muscle power, and/or coordination)
d110: Watching (might have difficulties focusing on, seeing, and/or interpreting traffic light signals)
d115: Listening (might have difficulties focusing on, hearing, and/or interpreting sound signals)
d130: Copying (might have difficulties understanding and/or responding to people mimicking and gesticulating)
d137: Acquiring concepts (might have difficulties learning from own experiences)
b144: Memory functions (might have difficulties with short- and/or long-term memory)
b152: Emotional function (might have difficulties expressing appropriate emotions related to a given situation)
b160: Thought functions (might have difficulties having and expressing appropriate thoughts)
b140: Learning to read (might have difficulties learning to read and understanding content)
d145: Learning to write (might have difficulties writing and expressing thoughts in writing)
d150: Learning to calculate (might have difficulties calculating and understanding the use of calculation)
d160: Focusing attention (might have difficulties concentrating for the necessary time span and/or in a noisy environment)
d310: Receiving spoken messages (might have difficulties understanding what is being said and/or meant)
d330: Speaking (might have difficulties speaking and/or explaining to others)
d710: Basic interpersonal interactions (might have difficulties interacting, showing consideration, and/or responding to others' feelings)
d880: Engagement in play (might have difficulties playing constructively with self and/or interacting in play with others)
b164: Higher-level cognitive functions (might have difficulties accepting new situations, tasks, and/or impressions)
b134: Sleep functions (might have difficulties falling asleep, continuing to sleep, and/or getting sufficient sleep)

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<sup>a</sup>The codes listed are in the order they were presented in the questionnaire. Supplementary wording was provided in parentheses to help the parents understand the meaning of the codes.

participating, data on this particular International Classification of Functioning, Disability and Health approach has undergone qualitative as well as Rasch data analysis similar to those employed beforehand.

In parallel, clinical data on a population of children with Down syndrome were thoroughly screened and analyzed.

The primary objective of this particular study was both to obtain and to validate 26 International Classification of Functioning, Disability and Health code scores given by dedicated parents to children with Down syndrome for the purpose of applying repeated scoring of similar codes so that parents could join an including and intercommunicating health network for better health services.

## Methods

### Children With Disability

We intended to include all children diagnosed with Down syndrome (DQ900-909) and who were in the range of 5 to 17 years of age. They lived in the Southern Danish Region. The children were identified by extracting personal numbers (CPR numbers) from the Danish Civil Registration System. The CPR numbers were organized and checked for duplicates, correct diagnosis, associated diagnoses, age, and gender. Parents were contacted by surface mail once. Of those responding, the International Classification of Functioning, Disability and Health code data set of 26 codes was forwarded and explained and parents assessed independently of us and returned data by surface mail. They also

consented to let us analyze their children's electronic medical records for the purpose of obtaining data on discharge diagnosis and associated diagnoses. Upon accept from the Danish Data Protection Agency, data were compiled in the Excess data system and analyzed.

We excluded children whose parents did not respond to surface mail once, families the authors could not reach because the address could not be found, parents who did not want to participate, and families that had in the meantime moved out of the Southern Danish Region.

### International Classification of Functioning, Disability and Health Codes

Each of the 26 selected and combined b and d codes were topics related to daily living from early morning until night (Table 1). The qualifiers were worded in Danish language and in the same way as they had been previously (5) and scored by the parents as follows:

1. The child's ability is as expected for his or her age.
2. The child has difficulties but is still functioning in the expected range for his or her age.
3. The child needs help from another person with functions, activities, and participation.
4. The child needs help and care; the child has only limited ability with respect to body functions, activities, and participation.
5. The child is totally dependent on others for body functions, activities, and participation.

## Psychometric Analysis of International Classification of Functioning, Disability and Health Code Data

Data were analyzed for coherence by employing psychometric and Rasch analysis.

Data targeting was estimated from the code scale's midpoint and the range and the observed scores with floor and ceiling effects. The reliability was estimated using Cronbach  $\alpha$  coefficient, intercode correlation, standard error, and standard error of measurement. The validity was estimated with corrected code-total correlations and Cronbach  $\alpha$ :  $\alpha = N \times \bar{c}/\bar{v} + (N - 1) \times \bar{c}$ , where  $N$  = number of codes,  $\bar{c}$  = average intercode covariance, and  $\bar{v}$  = average variance. The standard error was measured as standard deviation/ $\sqrt{\text{number of children participating}}$ , and 95% confidence intervals were calculated by the formula  $\pm 1.96 \times \text{standard error}$ . The standard error of measurement was calculated as standard deviation  $\times \sqrt{(1 - \alpha)}$ . Stata 16 (StataCorp) was used for data analysis.

## Rasch Modelling on International Classification of Functioning, Disability and Health Code Data

The Rasch model defines an individual's probability of success ( $P$ ) on a given item in terms of the difference between the individual's disability ( $B$ ) and the item difficulty ( $D$ ). The probability of success  $P$  can also be expressed as  $\log(\text{odds}) = B - D$  or  $\text{logit} = B - D$ .

Rasch analysis was applied to all 5 qualifiers for the International Classification of Functioning, Disability and Health b and d codes. In practice, when a child's level of disability is equal to a certain qualifier level,  $B$  and  $D$  are identical, and the derived  $\log(\text{odds})$  or logit value will be 0. For codes at which the level for the child's disability level is higher or lower, the relevant logit value will be positive or negative, respectively.<sup>4-8</sup> A logit scale constitutes the latent construct or variable (also called the measure in Rasch terminology) for the 26 joined International Classification of Functioning, Disability and Health b and d code qualifiers.

Fit is denoted if the data conform to the Rasch model. Fit is expressed in terms of mean-squared values as infit MNSQ and outfit MNSQ. An infit MNSQ close to 1 indicates that the data are reliable (not assessed randomly), while an outfit MNSQ close to 1 signifies that the results are not at odds with the overall set of data.<sup>6-9</sup> Winsteps 4.4.4 was used to perform the Rasch measurements.

## Results

### Children With Disabilities

From start of the study, 94 children with unique personal numbers were identified from the Danish Civil Registration System. Of those, 11 children were excluded as 10 children were aged 18 years at the start of the study and one family could not be reached as their address was hidden from access.

Following the initial selection as mentioned, 83 families were now contacted by surface mail and receiving the questionnaire with International Classification of Functioning, Disability and Health codes for their assessment. Three families had moved out of the region at the time of contact by letter. Of the remaining 80 families, 42 did not respond to our letter and were not contacted once again or by other means. Eleven families stated that they did not want to assess their child with Down syndrome.

**Table 2.** Participating Children With Down Syndrome and Their Diagnoses.<sup>a</sup>

	Record	Assess	Total
Trisomy 21	21	11	32 (40.0)
Trisomy 21 translocation	2	0	2 (2.5)
Trisomy 21 mosaicism	3	2	5 (6.3)
Clinical diagnosis only	27	14	41 (51.2)
Total	53	27	80

<sup>a</sup>Children participating with medical record data only were 53 (record) and children also assessed was 27 (assess). Total number of children was 80. Percentage is given in parentheses.

**Table 3.** Participating Children and Diagnoses.<sup>a</sup>

	Record	Assess	Total
Birth	36	12	48
Nervous system	30	8	38
Eye	34	28	62
Ear, nose, and throat	59	27	86
Cardiovascular system	80	40	120
Respiratory system	24	7	31
Gastrointestinal system	36	15	51
Endocrine system	9	4	13
Musculoskeletal system	24	12	36
Kidneys and urinary tract	8	0	8
Blood and immune system	5	3	8
Others	43	15	58
Total	388	171	559
Total relative to children	7.3	6.3	6.9

<sup>a</sup>Children participating with medical record data only were 53 (record) and children also assessed was 27 (assess). Total number of children was 80. Numbers of associated disorders registered during children whole life were counted for each group and in total.

We now had a group of 80 children who lived in the Southern Danish Region and had not reached 18 years of age:

- A. The "record" group of 53 children whose parents did not participate in interview but whose medical records were looked through.
- B. The "assess" group of 27 families whose medical records were also visited and parents did assess disability in their children with the 26 codes as mentioned (Table 1).

The 80 children were between 5.2 and 17.6 years of age (mean 12.0 years). Fifteen children were girls (57%). Thirty-two children had trisomy 21, 2 had a translocation, 5 had a mosaic pattern, and in 41 of the oldest children the chromosomal abnormality was not further specified in the electronic patient record system (Table 2). Of the most prevailing associated somatic disorders, 32 children had hypermetropia, 30 children had chronic otitis media but were not hearing impaired, and 63 had cardiac septal defects; of those 2 children had been operated for a Steno-Fallot tetralogia and without complications to the central nervous system (Tables 3 and 4).

**Table 4.** Participating Children and Diagnoses.

		Record	Assess	Total
Birth	DP073 Prematurity	9	2	11
	DP21.0 Severe asphyxia	2	0	2
Nervous system	DF43.2 Adjustment disorder	6	1	7
	DF84.0 Infantile autism	1	0	1
Eye	DH52.0 Hypermetropia	19	13	32
	DH26.0 Infantile cataract	0	2	2
	DH65.2 Chronic otitis media	19	11	30
Ear, nose, and throat	DH90.0 Hearing loss	5	8	13
	DQ21.1 Atrial septal defect	38	12	50
Cardiovascular system	DQ21.0 Ventricular septal defect	10	3	13
	DJ05.0 Pseudocroup	9	4	13
Respiratory system	DJ45.0 Asthma bronchialis	9	2	11
	DQ41.0 Duodenal atresia	2	1	3
Gastrointestinal system	DK90.0 Celiac disease	2	1	3
	DE03.9 Hypothyroidism	6	2	8
Endocrine system	DE10.9 Diabetes mellitus	1	0	1
	DM21.4 Pes planus	4	0	4
Musculoskeletal system	DQ65.9 Dysplasia of hip joint	5	5	10
	DQ53.2 Retentio testis	5	5	10
Kidneys and urinary tract	DQ620 Hydronephrosis	1	0	1
	DD46.9 Myelodysplasia	1	0	1
Blood and immune system	DD83.9 Immune deficiency	3	0	3
	DJ15.7 Pneumonia	2	3	5
Others	DL63.9 Alopecia	1	0	1

Children participating with medical record data only were 53 (record) and children also assessed was 27 (assess). Total number of children was 80. Important selected diseases and known to be associated to Down syndrome registered during their whole life were counted for each group and in total. The record and the assess groups had similar range of associated diagnoses and they were also comparable in number with average 7.3 and 6.3 for each child (Table 3).

### Psychometric Analysis of International Classification of Functioning, Disability and Health Code Data

The International Classification of Functioning, Disability and Health code data from all 26 International Classification of Functioning, Disability and Health code sets underwent psychometric analyses. The data seem coherent and reliable. Mean scores were 2.67 (range 1.26-4.11), with mean corrected code-total correlations of 0.55 (range -0.17-0.82). The intercode correlation was 0.32 (range -0.50 to 0.85) and Cronbach  $\alpha$  was 0.93.

**Table 5.** Rasch Measure Data on 27 Children Assessed by Their Parents and 26 Joined International Classification of Functioning, Disability and Health Codes Employed.<sup>a</sup>

Rasch measures	Measure average	Measure range	Infit mean	Outfit mean	Highest infit	Highest outfit
Children score	-.64	-2.64 to 1.91	1.01	1.06	2.55	4.90
Code score	.00	-2.11 to 2.43	1.03	1.06	2.40	3.23

<sup>a</sup>The measure expresses the most severe disability as positive and the least severe disability as negative. The average measure for code score as well as children score should be close to 0. Infit and outfit MNSQ represent conformity to the Rasch model and should be close to 1. This is likewise indicated by proper infit and outfit data.

### Rasch Modelling on International Classification of Functioning, Disability and Health Code Data

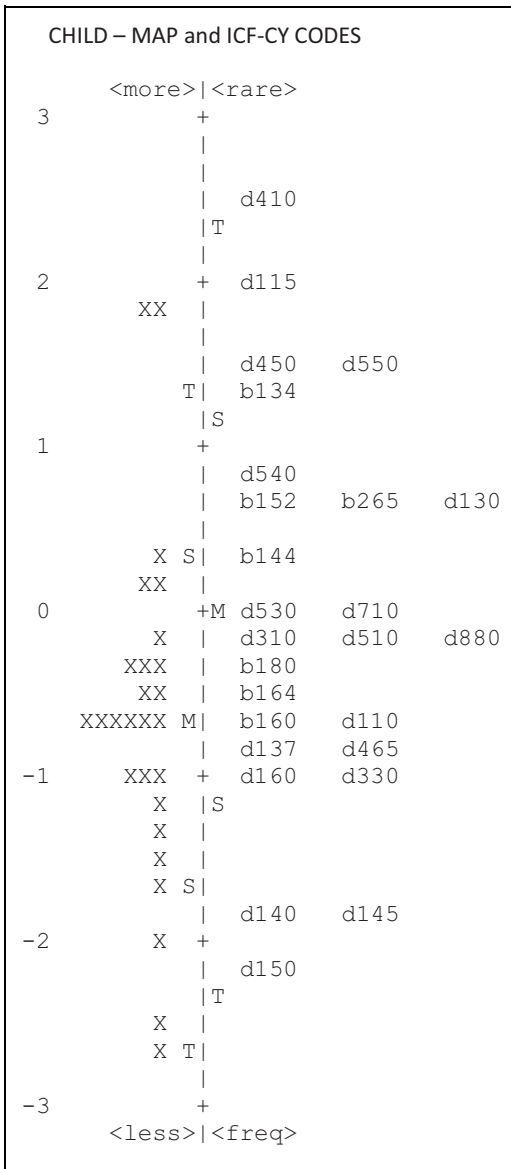
The International Classification of Functioning, Disability and Health code data from all 26 International Classification of Functioning, Disability and Health code sets underwent Rasch data analyses. The average measures on both child and code data were around 0, and the infit and outfit MNSQs were around 1 (Table 5). Data from one child did not show proper infit and outfit measures. And data on 2 codes did not give proper infit or outfit MNSQ values. Codes were d140 "learning to read" and b134 "sleep functions." Data illustrates that one out of 27 parents might have had difficulties assessing according to the set of codes employed. Furthermore, 2 codes seem difficult to use by the parents.

The child-International Classification of Functioning, Disability and Health code map demonstrated alignment between the population of children depicted on the left and International Classification of Functioning, Disability and Health codes on the right, as both children and codes were spread (Figure 1). But the map also illustrates that the mean score of the 5 qualifiers ( $M$ ) for the children and the mean ( $+M$ ) for the codes were somewhat displaced. Thus, in average more children did better or were more able relative to the codes employed. This is also illustrated by the fact that the most able children in fact had abilities to learn to calculate (d150), to learn to read (b140), and learn to write (d145). At the other, the upper end, of the spectrum a few children had difficulties with more basic abilities such as getting out of bed (d410), listening (d115), walking (d450), and eating (d550; Figure 1).

### Discussion

Care for children with disabilities and their families has become a focus of daily clinical practice. In particular, interventions and support to the whole family are important and can positively impact a family and a child's quality of life.<sup>10-17</sup>

Because support for children and families is crucial to their present daily living and their future, we wanted to find ways to improve relationships between families and services to connect



**Figure 1.** Child and disability map for 27 children: Each X in the left column represents one child. Mean equals mean, S represents 1 standard deviation and T represents 2 standard deviations. Each bar represents an interval on the measure scale of .12. International Classification of Functioning, Disability and Health codes are located in the right column. See Table 1 for further detail on the meaning of the codes.

them, the hospital setting, and health services in the community. This included providing ways for parents to identify disability in their own children and thus enter into a dialogue to build a mutual understanding of disability. To that end, we explored International Classification of Functioning, Disability and Health body function b codes and activity and participation d codes. We found that parents can contribute constructively in assessing disability in their children.<sup>2-5</sup>

We then wanted to explore how well the same approach with the identical set of 26 International Classification of Functioning, Disability and Health codes could apply to parents and their children with Down syndrome.

In order to know the population of children the best possible way, we searched information on age, gender, genetic diagnoses, and associated diagnoses. In total, 32 children had trisomy 21 and a minor group had translocation or mosaicism. Also, around half of the children had a clinical diagnosis only. Those were the relatively elder children in the group analyzed. We did not attempt to analyze the genetic background of this group of children who clinically without doubt had Down syndrome.

We also counted every associated diagnoses the children had obtained during their life and follow-up. The majority of them were associated with the cardiovascular system, the ear, nose, and throat and to the eyes, and the gastrointestinal system. This is in accordance with clinical experience (Table 3). Furthermore, there was no major difference between children whose medical records were researched only and the group of children whose parents assessed them also. The number of associated diagnoses was average 6.3 and 7.3, respectively (Table 3).

Chronic disorders often associated with Down syndrome, such as infantile autism, celiac disease, hypothyroidism, diabetes mellitus, and myelodysplasia, fortunately were minor in number as together they represented 14 (5.9%) of total 235 selected associated diagnoses (Table 4).

Parents might hesitate to assess disability in their children. This could especially apply when parents are inspired to assess for the first time and without really knowing on beforehand what their assessment might lead to. The parents were free to assess and we did not urge them to do so.

The children assessed were spread over the clinical spectrum of severity of disability (Figure 1) and number and composition of associated diagnoses were to a large extent equal in the group of children recorded and those assessed also (Table 3). As a result of this study, we might conclude that severity of disability or associated diagnoses did not seem to influence on which parents chose to assess their child. Also and accordingly the assessment performed by 27 parents might represent the 53 not assessed children with Down syndrome.

Considering the child-International Classification of Functioning, Disability and Health map, it demonstrates the alignment between children assessed and the assessment tool by which they have been approached. Data on alignment and placement of children and of codes will always be unique to the particular assessment setting and cannot be extrapolated to other groups of children or other International Classification of Functioning, Disability and Health codes.

Nevertheless, the map does inform on proper alignment and codes employed gives meaning in relation to the children assessed and to the parents who assessed them. In particular, we have found that many children with Down syndrome are able to learn to read, write, and calculate. Also, children with more disability do have difficulties with body transfer, walking, and eating.

The purpose of letting such a set of qualitative data undergo Rasch analysis is to get a better impression of the composition of a population of children with disability. Assessment can also

be repeated over time in order to detect possible changes and accordingly to adjust help and support to the particular group of children and to their families and caregivers.

One major drawback of this study is that a detailed testing of cognitive abilities in this group of children with Down syndrome has not been undertaken. And thus we cannot at present compare our data with other analysis tools and results.

In conclusion, parents assessed their children's disability well by using a group of 26 International Classification of Functioning, Disability and Health body function b codes and activity and participation d codes covering issues during 24 hours of daily living and assessed on a 5-step qualifier scale. Validity and reliability of that data set is of such a quality that it warrants further studies by us and hopefully by others as well. The ultimate goal is to improve health care.<sup>18</sup> This includes empowering parents to assess their own children with disability. And also to share that most valid information among health professionals, to inspire on a positive dialogue with parents participating and based on mutual trust. And, at the same time, to employ statistical tools that might monitor on quality of data on a perpetual basis.

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### Author Contributions

Both GJE and MB contributed equally to the study. GJE and MB contributed to conception; contributed to acquisition, analysis, and interpretation; drafted the manuscript; critically revised the manuscript; gave final approval; and agreed to be accountable for all aspects of work ensuring integrity and accuracy. NOI contributed to conception; contributed to analysis and interpretation; drafted the manuscript; critically revised the manuscript; gave final approval; and agreed to be accountable for all aspects of work ensuring integrity and accuracy.


### Declaration of Conflicting Interests

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### Ethical Approval

All of the eligible parents in a defined geographical area were contacted by mail to participate in this study. The parents were known to us and to our colleagues. Participation was voluntary for the parents and caregivers. The protocol was accepted by and registered at the

Danish Data Protection Agency (DOK 2017-41-4991) before start of the contact to the parents.

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