

RESEARCH PAPER

## Implementation of ICF in goal setting in rehabilitation of children with chronic disabilities at Beitostolen Healthsports Centre

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**Purpose:** Develop an International Classification of Functioning, Disability and Health (ICF) Code Set, useful in goal oriented rehabilitation of a study population of children with chronic disabilities. **Method:** A triangulation of methods, using an interview to identify the main needs and goals of the study population, and a questionnaire to identify the main problems, with a registration of the frequency within each category. After qualitative and quantitative analyses this resulted in two sets of ICF categories. These two sets were then compared and merged into a proposed ICF Code Set for goal setting. **Results:** Thirty categories were identified from the interviews and the following linking process. Problems were reported in all suggested categories within the ICF questionnaire, resulting in 49 categories. The comparison of the two sets of categories resulted in a proposed ICF Code Set of 40 categories. **Conclusions:** Through a triangulation of methods, we developed a tailored code set for the goal setting process in rehabilitation for children with a disability, taking into account both individual preferences and the health professionals' perspective. Although the external validity is limited, our methodological procedures may have relevance for the implementation of ICF in other clinical settings and populations.

**Keywords:** Children, code set, goal setting, ICF

### Introduction

In the present study, we wanted to assess the problems and identify the main needs and goals of children with disabilities admitted to Beitostolen Healthsports Centre (BHC), within the framework of International Classification of Functioning, Disability and Health (ICF). Goal setting is a core component of the rehabilitation process, and ICF has been applied in order to facilitate this process. The ICF provides the most

### Implications for Rehabilitation

- ICF is increasingly used as the framework for goal setting in rehabilitation.
- Development of ICF Code Sets could provide a basis for individualized treatments through a structured goal planning process.
- A triangulation of methods in the development of such code sets, combining qualitative and quantitative methodology could be of value, seeing the health professionals' perspective being enriched and deepened by the patients' preferences.

adequate framework to describe the condition of the persons towards whom rehabilitative efforts are concentrated [1]. The bio-psycho-social perspective captures various components of functioning, and facilitates the collection of data on chronic health conditions [2].

In order to implement ICF in clinical practice, specific core sets have been developed in rehabilitation medicine [3–6]. The need for a reduction in ICF categories is also present for children. In rehabilitation this reduction would need to be based on functional characteristics in key domains, regardless of etiologies or diagnoses [7,8]. The original definition of core sets was applied to specific diagnoses. In the process of creating “Developmental core sets,” the concept “code set” is being applied, and has changed the term accordingly. The development of such code sets could represent an important contribution to clinical practice, deriving profiles of child functioning, including family involvement. It could provide a basis for individualized treatments through a structured goal planning process [9,10]. The patient should be an active participant in the rehabilitation process and the activity of the rehabilitation

team should be essentially goal oriented and take account of the preferences of the patient. Goal setting in rehabilitation is a complex intervention, based on a rich theoretical foundation. ICF has been found to be applicable in order to identify and structure patients' goals [11]. Participation is one of the key goals of rehabilitation for disabled children [12–14], and it is vital to identify the most important elements that promote or inhibit their participation [15]. The aim of this study was to (i) identify a set of ICF categories in order to describe the problems, (ii) identify the main needs and goals of these children and (iii) develop an ICF Code Set, useful in goal oriented rehabilitation.

## Methods

### Environment at BHC

BHC is a rehabilitation centre, offering secondary rehabilitation to children, young people and adults with impairments and disabilities [16]. Most of the children referred to the centre have chronic disabling conditions, representing a wide variety of diagnoses, with a predominance of neurological problems. BHC has a holistic approach to disability, seeking to enhance lifelong activity and participation in local environments through a strong interaction between medical, pedagogical and social aspects.

BHC offers a wide range of training and treatment facilities and leisure activities with a large sports hall, swimming and therapy pools, physiotherapy premises, testing laboratories, horse stables with an indoor riding hall and accommodations for different leisure activities. The centre has 200 acres of land at its disposal with a sports stadium, a lake for water sports and fishing, paved paths, cabins, cross country-tracks and an alpine ski hill. The program is intensive and variation in the activities is emphasized. To some extent, the program reflects the Norwegian activity culture with great focus on outdoor activities on a year round basis. The rehabilitation program also contains a large amount of social and cultural activities. A wide range of services is offered, including adaptation of the environmental factors, technical aids and individual instructions.

### Participants

Two hundred and twelve children and their parents were invited to participate in the study during the inclusion period of one year. After being informed about the intention of the study, 160 signed a written informed consent. They were recruited consecutively as they were referred to the centre. The children were aged between seven and 16 years. Almost all were living at home and in contact with their local habilitation services (Table I), and they represented a wide variety of diagnoses with a predominance of neurological problems (Table II).

### Study design

The ICF Core Set Project, initiated in 2001, defined a scientific process in three phases for the development of ICF Core Sets [5]. The core sets were initially defined through elaborate processes with international consensus conferences based on systematic literature reviews, expert surveys (including a Delphi exercise) and empiric data from the ICF-Checklist. In

later projects focus groups/individual interviews were added to cover the Patient Perspective, and cross-sectional studies carried through to enlighten the Clinical Perspective. We adapted the strategy for the development of this code set to the patient population and setting at BHC, by focusing the literature review on goal setting measurements, and restricting the consensus to the multidisciplinary group at BHC (Figure 1). Hence, the design was a prospective study with the intention of establishing a code set, with a triangulation of methods, using a quantitative and qualitative approach. A quantitative approach through a questionnaire represents the perspective of the health professionals, and the qualitative method, based on interviews, allows the children and their proxies to express

Table I. Demographic characteristics of the participating children (n = 160).

	Mean	SD
Age (years)	10.8	2.5
	N	%
Gender		
Girl	65	41
Boy	95	59
Settlement (pattern)		
Urban	91	57
Rural	69	43
Living with		
Both parents	126	79
One parent	34	21

Table II. The distribution of diagnostic groups (n = 160).

Diagnostic groups	%
Cerebral palsy	40
Heredodegenerative diseases	4
Disorders of mental development	14
Blindness	3
Skeletal and muscular malformations	2
Malformations of the central nervous system	17
Chromosomal abnormalities	7
Neurological diseases	5
Sequela of injuries and tumors	8
Total	100

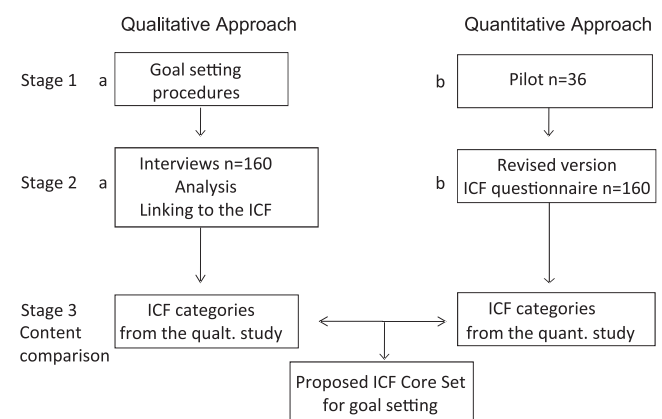


Figure 1. Study design.

their main concerns, needs and goals. This procedure resulted in two preliminary sets of categories, from the quantitative and qualitative method respectively, which were then compared. The comparison created a basis for the proposal of an ICF Code Set for goal setting.

### **Qualitative method**

#### ***Stage 1a: Goal setting procedures: Interviews***

In order to assess the goals of these children, a semi-structured interview was applied at admission, based on a modified version of Canadian Occupational Performance Measure (COPM) [17] for a pediatric population [18]. The interviews were structured in steps, starting with asking the families to identify important issues for their needs and problems in everyday performance and their expectations for the rehabilitation stay. Once the families had identified their needs, the prioritized issues were translated into preliminary main aims for the rehabilitation stay. In the next step, the family prioritized and identified three goals, related to activities problematic to the child, and with a special focus on mobility, play, school activities and leisure activities. Subsequently, these three goals were rated on a 1–10 point scale for importance, performance and satisfaction according to COPM.

The importance of the voice of the children was emphasized. The interviewers, all health professionals, each with a coordinating responsibility for the children during the stay, were trained and experienced in this method.

#### ***Stage 2a: Analysis and linking to the ICF***

A draft, based on the first part of the interview which contained the preliminary main aims, later served as a basis for the identification of ICF categories through the linking process. Two health professionals, both trained in qualitative methods, independently carried out the analysis of the interview data, using the method of “meaning condensation” [19].

In this method, “natural units of meaning”, i.e. a few words or sentences with a common theme, were identified from the interview drafts and then expressed as short and clearly as possible in a “meaning unit” [19]. Three hundred and thirty meaning units were identified by the professionals after comparing results and reaching consensus, and this was the basis for the closing thematic analysis.

Two health professionals, trained in the use of ICF, proceeded with the linking process, utilizing a modified version of established linking rules [20]. They enabled linking meaningful concepts, i.e. meaning units to ICF categories, in a systematic and standardized way. Both linkers conducted this procedure independently, producing two versions which were later compared. In case of disagreement, a third expert was consulted in order to reach consensus. More than 90% of the meaning units could be linked to the ICF.

Since the intention of this study was to establish a brief code set, all categories were linked to the two-level classification of ICF. During the end of the project period, the final official version of ICF-CY was published. Thus we also undertook a second linking process to the full edition of ICF-CY in order

to identify any additional categories for inclusion, not found in ICF or the preliminary ICF-CY versions. The procedure led to the implementation of two additional categories.

### **Quantitative method**

#### ***Stage 1b: Pilot***

Three health professionals, all with several years of experience in working with disabled children, developed a preliminary version of an ICF questionnaire for chronically disabled children, aged seven to 16 years. Based on a narrative literature review of goal attainment instruments, and their experience of reported problems at BHC, they put emphasis on categories from the component Activities and Participation. Relevant categories from the full 2001 edition of ICF were identified based on the consensus of the health professionals.

The preliminary version was tested in a pilot study with 36 children and their parents. Parents were chosen instead of external professional experts in order to strengthen the patient’s perspective.

Some categories from the component Body Functions and Structures were taken out as the parents had problems in giving precise answers to these questions. Another experience from the pilot study was that the parents had problems in interpreting and applying the qualifier of barriers and facilitators in Environmental Factors. We therefore rephrased the questions in the contextual part, asking them to weight the importance of the code by use of the qualifier system, not distinguishing between barriers and facilitators.

#### ***Stage 2b: The revised version of the ICF questionnaire***

The pilot study led to a version with 49 categories, containing 10 codes from Body Structures and Functions, 24 codes from Activity and Participation and 15 Environmental Factors, which were included in a revised questionnaire. This was presented at admission and filled in by the parents, and whenever suitable, by the children, after they had been informed about the intention of the study and the necessity of a written informed consent. The parents were given a short introduction to the use of the generic qualifier in ICF. The questionnaires were administered during a period of one year.

#### ***Stage 3: Correspondence of ICF categories emerging from the interviews and the ICF questionnaire***

The categories emerging from the two approaches were compared. The qualitative part was considered as the basis for the selection of categories in the final code set. In order to identify any additional, important categories, each component of the ICF questionnaire was analyzed according to the severity and number of participants reporting problems. If problems in a category were reported with a higher frequency than the ICF categories drawn from the interviews, they were regarded as potential candidates for the final code set.

These additional categories were then evaluated separately by the three health professionals regarding importance for the goal setting process, and based on consensus, included in the final proposed ICF Code Set.

## Results

### Qualitative approach

Altogether 59 categories at the second level were identified from the interviews and the following linking process. After consensus was established, with a consultation of a third expert, 30 categories remained.

Only four categories emerging from the linking processes were not contained in the ICF questionnaire used in the quantitative approach, as seen in Table III, marked \*. b164 Higher-level cognitive functions were linked to three different meaning units emerging from the interviews, and it obviously reflects an important aspect to be incorporated in the questionnaire. The three other categories, b730 Muscle power function, b735 Muscle tone function and b760 Voluntary movement were included in the pilot version of the questionnaire, see Stage 1b, and later removed.

### Quantitative approach

Problems were reported in all suggested categories within the ICF questionnaire. The frequency within each category is given in Table IV, and gives a strong indication of the extent of the problem. Attention functions and Exercise tolerance functions were the most prominent problems within body functions, reported in 84 and 85% of the participants, respectively.

Participating in sports and Recreation and leisure were the most frequently reported problems in the component of Activities and Participation, reported by 85% of the subjects, respectively. Social security and Education and Health services

represented the main challenges among the environmental factors for the children in the present study.

### Correspondence of categories emerging from the interviews and the questionnaire

There was an evident discrepancy between the results from the qualitative and quantitative study in the component of Body Functions and Structure as seen by comparing Tables III and IV. In addition to the nine categories from the qualitative study, two categories, b114 Orientation functions and b140 Attention functions, both represented with the high percentage reported in the ICF questionnaire, were added to the proposed code set.

In the component of Activities and Participation and Environmental Factors, 16 categories came forth from the interviews, as seen in Table IV, marked \*. In the same component, several categories emerged with high frequency in the questionnaire, not identified in the interviews. Five of these categories were added as candidates for the code set, based on the frequency. These categories included d230 Carrying out daily routine, d430 Lifting and carrying objects as well as d455 Moving around (other than walking). Also, d470 Using public transportation and d820 Education were challenges, not identified in the interviews. In Environmental Factors, Social Security and Educational and Training Services emerged with a high frequency.

On the basis of the comparison of the results from the qualitative and quantitative study, we suggest the following ICF Code Set for goal setting (Table V).

## Discussion

Based on the ICF model, and through a combination of qualitative and quantitative approach, we developed an ICF Code Set for use in the goal setting process for children. This procedure implements the bio-psycho-social aspects of rehabilitation, as well as the individual preferences of the children, and a normative, clinical evaluation of problems and needs.

ICF is increasingly used as the framework for goal setting in rehabilitation [2,11]. Martinuzzi et al. state that "ICF provides the most adequate framework to describe the conditions of persons towards whom rehabilitative efforts are concentrated" [1]. The ICF concept allows both individual, as well as contextual factors to be taken into consideration, which is mandatory in rehabilitation. The relevance of the huge number and the variety of the ICF categories is also expressed by the fact that Lohmann et al. found that more than 90% of all patient goals in their study could be linked to ICF [11]. We found the same in our study.

The triangulation of methods, broadly defined as "the combination of methodologies in the study of the same phenomenon" [19,21,22], was found important, seeing the health professionals' perspective being enriched and deepened by the patients' preferences.

A partial aim of this study was to identify a set of ICF categories to describe the problems of the population at hand, the children with disabilities accepted for a stay at BHC. This was

Table III. Qualitative study.

ICF categories	
b126 Temperament/personality	d450 Walking
b130 Energy and drive	d465 Moving around using equipment
b147 Psychomotor functions	d475 Driving/moving vehicles
b152 Emotional functions	d510 Washing oneself
b164 Higher-level cognitive functions*	d530 Toileting
b455 Exercise tolerance functions	d540 Dressing
b730 Muscle power functions*	d550 Eating
b735 Muscle tone functions*	d710 Basic interpersonal interaction
b760 Control voluntary movement*	d750 Informal social relationships
d155 Acquiring skills	d920 Recreation and leisure
d410 Changing basic body positions	e115 Prod. for personal use in daily living
d415 Maintaining a body position	e120 Products for indoor/outdoor mobility
d435 Moving objects with lower extremities	e320 Support and relationship friends
d440 Fine hand use	e355 Support health professionals.
d445 Hand and arm use	e580 Health services

ICF categories at the second level to which the meaning units from the goal setting interviews were linked.

\*Categories emerging from the linking process not contained in the ICF questionnaire.



Table IV. Quantitative study.

ICF code	ICF category title	0	1	2	3	4	N.a.	%
b114	Orientation functions	52	50	34	22	2		68
b126*	Temperament/personality	39	58	38	23			75
b130*	Energy and drive	32	64	37	27			80
b140	Attention functions	25	41	48	44			84
b144	Memory functions	58	43	41	18	2		59
b147*	Psychomotor functions	59	44	29	26			63
b152*	Emotional functions	53	46	40	20	2		67
b455*	Exercise tolerance functions	23	36	72	28	1		85
b530	Weight maintenance functions	63	52	27	15			61
b550	Thermoregulatory functions	76	41	28	15	3		53
d155*	Acquiring skills*	35	41	48	26	3		85
d230	Carrying out daily routine	28	60	43	28	1		83
d310	Communication receive/speak	62	41	32	23	2		61
d410*	Changing basic body positions	62	51	24	20	3		61
d415*	Maintaining a body position	88	53	13	6			45
d430	Lifting and carrying objects	54	47	32	24	2		66
d435*	Moving objects lower extreme	40	39	40	31	10		75
d440*	Fine hand use	45	45	47	21	1		72
d445*	Hand and arm use	28	45	56	31			83
d450*	Walking	47	32	37	29	20		62
d455	Moving body, not walking	34	37	39	30	19		78
d465*	Moving around walking equipment	22	34	14	3	2	85	33
d470	Use public transportation	25	30	21	41	2		81
d475*	Driving/moving vehicles	32	32	20	23	7	93	51
d510*	Washing oneself	56	44	33	23	4		65
d530*	Toileting	65	33	32	20	10		59
d540*	Dressing	39	52	38	22	8		76
d550*	Eating	75	57	21	5	2		53
d710*	Basic personal interactions	64	44	35	15	1	92	60
d750*	Informal social relationships	54	38	40	26	2		66
d811	Play with others	56	37	47	19	1		65
d820	Education	30	30	45	41	12	1	81
d920*	Recreation and leisure	25	40	61	38	4		85
e115*	Products in personal use	25	35	29	5		66	43
e120*	Products mobility	18	27	18	7	1	90	32
e140	Products culture/recreation/sports	11	28	29	8	1	83	41
e150	Official buildings	8	20	31	20		81	44
e210	Nature environ./land forms	20	29	40	30		40	63
e320*	Support/relationships friends	37	46	43	29	3	2	76
e355*	Support/relationships health professionals	45	61	41	11	1		72
e360	Support/relationships other professionals	45	71	34	8	2		72
e420	Attitudes friends	38	55	45	20	2		76
e450	Attitudes health professionals	47	70	36	5	1		70
e455	Attitudes other professionals	50	75	24	9	2		69
e460	Attitudes society	34	56	55	14	1		79
e570	Social security services	23	48	51	27	3	4	83
e580*	Health services	28	64	50	10	2	3	81
e585	Education and training services	29	64	46	14	2	3	80

ICF categories reported in the questionnaire with the numbers of subjects reporting each of the qualifiers. The right column representing the percentage of subjects reporting any level of problem. For the environmental factor, the percentage reporting facilitators and barriers are summed and given as percentage of the study population. The qualifiers represent 0 = no problem, 1 = mild problem, 2 = moderate problem, 3 = severe problem, 4 = complete problem, N.a. = not applicable, % = percentage of subjects reporting from mild to total problems within the category. For environmental factors the qualifiers represent either a barrier or facilitator, graded from 0 to 4.

\*Represents categories also identified in the qualitative study.

Table V. Suggested ICF categories for the code set for goal setting in disabled children.

Body Functions and Structures	Activities and Participation	Environmental Factors
b114 Orientation functions	d155 Acquiring skills	e115 Products for personal use in daily living
b126 Temperament/personality	d230 Carrying out daily routine	e120 Products in/outdoor mobility
b130 Energy and drive	d410 Changing basic body position	e320 Support/relationships friends
b140 Attention functions	d415 Maintaining body position	e355 Support/relationships health professionals
b147 Psychomotor functions	d430 Lifting and carrying objects	e450 Support/relationships other professionals
b152 Emotional functions	d435 Moving objects lower extreme	e570 Social security services
b164 Higher cognitive functions	d440 Fine hand use	e580 Health services
b455 Exercise tolerance functions	d445 Hand and arm use	e585 Education and training services
b730 Muscle force	d450 Walking	
b735 Muscle tone	d455 Moving body, not walking	
b760 Voluntary movements	d465 Moving around walking equipment	
	d470 Use public transportation	
	d475 Driving/moving vehicles	
	d510 Washing oneself	
	d530 Toileting	
	d540 Dressing	
	d550 Eating	
	d710 Basic personal interactions	
	d750 Informal social relationships	
	d820 Education	
	d920 Recreation and leisure	

carried out through a questionnaire for quantitative analyses, which represented the health professionals' perspective. This is important, because individual wishes and subjective apprehensions may not cover the problem profile relevant for the rehabilitation goals. Thus, a broader examination of problems within relevant areas, based on normative judgment may represent a relevant adjustment.

The quantitative approach revealed a broad range of problems in functioning. Some of these were not always defined as intervention goals in the interviews. This reminds us of the limitations of a sole professional judgment of what would be the needs of each individual, and underlines the necessity of implementation of the patient perspective in goal setting in rehabilitation. The definition of problems in the group should be considered as a necessary step towards the identification of goals in the rehabilitation process.

It is important to distinguish between the two concepts, "problems" and "needs" [23]. In a clinical setting, there is no absolute need to know the total problem profile of the patient population, but rather to identify the problems in functioning that matters most to the patients.

The definition of needs should be based on the experience of problems, important to the child and possible to diminish [9]. What should be defined as a goal would then be flavored both by the individual preferences and aspirations, and the access to relevant measures and the feasibility of eventual rehabilitative efforts.

The implementation of patient preferences in the code set was taken care of by the qualitative approach [24].

We chose to use the COPM as basis for the qualitative interview, in order to identify the needs. The instrument is well known and in regular use at BHC. A content comparison with the ICF has shown that it was possible to link all items

to the ICF [25]. McDougall et al. explored the combined use of the ICF-CY and Goal Attainment Scaling (GAS) for pediatric practice [26], and stated that COPM may be preferred, being less time-consuming, and when patients' goals fell in the areas of self-care, activity and leisure. The instrument has a special focus on the Activity and Participation components in tune with the specific concept of BHC, which to a large extent is based on physical activity and social participation. As stated by Martinuzzi et al. [1], the intervention in rehabilitation is rarely on disease and its treatment, but almost always on functioning and well-being. Goal setting in rehabilitation therefore appears to be moving from the Body Function and Structure domain of the ICF, towards the Activity and Participation domain.

In ICF linking rules [20], "meaningful concepts" were applied when linking the ICF to specific terms or items, e.g. found in measurements or questionnaires. In qualitative data the concepts are identified within "meaning units". A "meaning unit" is defined as a specific unit of text of either a few words or a few sentences with a common theme [19].

The proposed code set is dominated by categories in the component of Activity and Participation, and by a relatively low number of categories from the Body Function and Structure domain. This may strengthen the external validity of the code set by diminishing the focus on strictly medical aspects. The philosophy and treatment approach at BHC is well known among many of the parents of the children referred to the institution, which to some extent probably influenced the presentation of needs and goals in the interviews. Thus, it was expected that their preferences would be most dominant in areas where they could expect to enhance functioning in mobility through intensive physical training, testing new technical devices and adapting new skills.

The importance of physical activity is also stressed by Schenker et al. [27], who found that this is the most important factor of overall participation in children with cerebral palsy in mainstream schools. In general, this is supported by others [12,15,28] who claim that peer relationship and shared participation in games and play is important in any child's life. Choosing and participating in leisure activities is a basic health-promoting requirement for all.

Environmental factors may often contribute to the restriction of physical and social activity among children with disabilities [29,30] and the philosophy of the institution is that these restrictions may be reduced not only by improved physical activity, skills and attitudes, but also by environmental adaptations. Thus, products for daily living, mobility and sports, as well as social integration and social services and systems were found to reflect areas of categories suitable for inclusion in the code set. This is also in accordance with findings from other studies [29,31,32].

Some additional categories from the Body Function and Structure domain were included in the quantitative pilot study, but were later taken out as the parents had problems in giving precise answers to these questions, and as such information also could be found in the medical record. This might represent a selection bias of categories, which could be omitted in future studies by also linking the medical records to ICF.

Although the patient population spans a wide range of physical disabilities, a significant proportion of cognitive and emotional needs emerged during the interviews. The importance of cognitive factors in physical disability is well known from larger surveys and studies of similar populations [33–35]. The mental aspect will obviously influence participation, and may be expected to play an important role in the rehabilitation process.

Pain and fatigue are frequently reported symptoms among children with chronic disabilities, mostly related to the severity of motor impairment [36]. None of these issues came forth in the interviews.

We consider 40 categories to be a feasible size of a code set for our clinical setting. Focusing on activities and participation may increase the generalization otherwise limited across diagnosis and etiologies, but children in other settings and countries may have another focus and experience other problems and needs. However, the procedure of developing a code set for goal setting may be adapted to other populations and settings. From our understanding, this would in correspondence with the request from WHO to implement the use of ICF in health services and research all over the world.

## Conclusion

Through a triangulation of methods, we developed a tailored code set for the goal setting process in rehabilitation for children with a disability, taking into account both individual preferences and the health professionals' perspective. The combination of perspectives was valuable in the research and would also be useful in the treatment process. Although the external validity is limited, our methodological

procedures may have relevance for the implementation of ICF in other clinical settings and populations.

**Declaration of Interest:** The authors report no conflicts of interest.

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