

RESEARCH PAPER

## The International Classification of Functioning, Disability and Health and the version for children and youth as a tool in child habilitation/early childhood intervention – feasibility and usefulness as a common language and frame of reference for practice

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### Abstract

Early childhood intervention and habilitation services for children with disabilities operate on an interdisciplinary basis. It requires a common language between professionals, and a shared framework for intervention goals and intervention implementation. The International Classification of Functioning, Disability and Health (ICF) and the version for children and youth (ICF-CY) may serve as this common framework and language. This overview of studies implemented by our research group is based on three research questions: Do the ICF-CY conceptual model have a valid content and is it logically coherent when investigated empirically? Is the ICF-CY classification useful for documenting child characteristics in services? What difficulties and benefits are related to using ICF-CY model as a basis for intervention when it is implemented in services? A series of studies, undertaken by the CHILD researchers are analysed. The analysis is based on data sets from published studies or master theses. Results and conclusion show that the ICF-CY has a useful content and is logically coherent on model level. Professionals find it useful for documenting children's body functions and activities. Guidelines for separating activity and participation are needed. ICF-CY is a complex classification, implementing it in services is a long-term project.

**Keywords:** *Children with disability, ICF-CY, feasibility, logical coherence, implementation*

### Introduction

World-wide, in countries such as Sweden, China, USA, Pakistan, Nigeria, Russia and Kyrgyzstan, non-fatal disabling conditions account for one of the main causes of children receiving early childhood intervention services or habilitation services. Early childhood intervention as well as habilitation services often operate on an interdisciplinary basis. It requires a shared common language between professional groups, and also a shared framework for what constitutes high quality intervention, both in terms of what constitutes goals for intervention and in terms

of how intervention is implemented. Concerning goals for early childhood intervention and habilitation, the last decades have meant a shift from interventions focused on body impairments and typical development (activity) towards child functioning within context, i.e. participation [1]. This shift can also be described as turning from a first generation to second generation perspective on intervention, where the second generation focuses the child in its everyday context [2]. Thus, a trend can be seen turning away from solely child-focused intervention towards involving family members and other persons in a child's natural environments into

intervention decision-making and intervention implementation. One recent development in the field of health and functioning is the International Classification of Functioning, Disability and Health (ICF) [3] and version for children and youth (ICF-CY) [4]. The version for children and youth is based on the same model as ICF with added content adapted to children and youth. ICF is meant to provide a common language to professionals and other stakeholders involved in facilitating functioning for persons with body impairments and activity limitations. It is also meant to provide concepts and terms for describing the functional consequences in everyday life of having body impairments and activity limitations.

## Aim

This article investigates the feasible and usefulness of ICF-CY as a model for generating a common language and a common frame of reference in habilitation and early childhood intervention settings. To reach this goal, a series of studies has been conducted by the CHILd (Children-Health-Intervention-Learning-Development) research group to analyse the utility of the ICF-CY in early intervention and habilitation settings for children. The following three research questions have been asked:

- (1) Does the ICF-CY conceptual model have a valid content and is it logically coherent when investigated empirically?
- (2) Is the ICF-CY classification useful for documenting child characteristics in early childhood intervention and habilitation services?
- (3) What difficulties and strengths are related to using ICF-CY model as a basis for intervention when it is implemented in habilitation services?

## Background

### *Content and logical coherence of the ICF-CY model*

In habilitation and early childhood intervention assessment, instruments are used for several purposes. These instruments are used for determining the children who are eligible for services, for guiding intervention and evaluating the outcome of intervention for individual children obtaining services, and for evaluating the effectiveness of service systems in relation to organisational and national goals. Ideally, the instruments used are derived from a unifying theory or model of human functioning that is functional on several ecological levels from the individual to the societal. It is a prerequisite for

analysing the relationship between evaluating the outcome for individuals, the work of individual professionals, service systems and national policies. However, a unified theory as a basis for habilitation is seldom the case, nor using assessment instruments that are applicable on all ecological levels.

The ICF-CY model can be seen as a conceptual model that has the potential to be applied on several ecological levels and to be used as a basis for generating assessment instruments on these levels. The ICF-CY model was derived from both a traditional ‘medical model’ of human functioning focusing on the consequences in everyday life of having a body impairment, and a ‘social model’ focusing on how society constructs difficulties in participation [5]. The two models were connected by bringing in activity as a unifying construct. Activity is a prerequisite both for identifying the consequences of body impairments on everyday functioning, and for identifying everyday activities in which people with difficulties in functioning cannot participate. The three aspects of functioning in ICF-CY, i.e. body, activity and participation are also related to hindering and facilitating aspects of the environment. To be valid as a conceptual model that can be applied in early childhood intervention and habilitation services the ICF model must: (a) cover the content that is considered as important to assess and intervene with in these services and (b) have a structure that allows for aggregating information from individuals up to societal level. It is important to remember that ICF is not a measurement instrument, but a classification system. Thus, it is impossible to speak of validity in the ICF model. However, it is possible to speak of logical coherence and structural clarity of the ICF conceptual model and of the validity and reliability in instruments constructed on the basis of ICF and ICF-CY.

### *Utility of the ICF-CY for documenting child characteristics*

When intervention for children with disabilities or developmental delay is in focus, a functional perspective can be more appropriate than a developmental perspective [1]. Rather than comparing a child to other children in the same chronological age, the focus is on what is important for everyday functioning for a specific child in the context and developmental level at which the child functions. Thus, for ICF-CY to be a feasible classification it must be possible to describe individual differences in children both in terms of development and functioning with instruments based on the classification. The child version of the ICF was developed to describe domains of functioning and environment in

childhood, especially concerning developmental issues, activities relevant in childhood and the child in the context of its everyday living, i.e. family and school. From a developmental perspective, there are items of functioning on specific developmental levels, for example mouthing, walking and vocalisation for the very young child. Sometimes questionnaire items intended for another age-group than the one a child with developmental delay belongs to might be relevant to use. In addition, several domains of functioning are relevant to all children, independent of age or developmental stage. Universal domains of functioning should be represented by items in all age specific questionnaires. Are instruments based on the ICF-CY model useful to meet new demands of assessment of functioning in everyday life?

Another important question is whether the chapters in ICF-CY are internally consistent, i.e. the items in assessment instruments based on ICF components, chapters and levels below chapters represent the same super-ordinate concept. It is a prerequisite for aggregating data, e.g. on chapter level. It is also of importance to investigate the relationships between codes in different components and chapters. There are, for example, several codes both in the component body and the component activity/participation that can be related to processing time concepts and managing time [6]. Knowledge of such relations facilitates intervention within areas of functioning, e.g. processing and managing time.

#### *Implementing ICF-CY in habilitation services*

In order to be adopted for clinical use, a framework such as the ICF/ICF-CY must be consistent with existing values, easy to understand, learn, use, and to obtain results from. Professionals' prior knowledge of the framework also has to be taken into account [7,8]. Some people may already be familiar with the ICF/ICF-CY and may see the value of it, while others may be skeptical, or do not know about it. Since the ways in which people learn and their willingness to learn seem to depend on their experience of the subject in focus, achievement after training needs to be investigated in relation to previous experiences of, and attitudes to, the ICF/ICF-CY. To ensure that professionals use the framework they must have a basic knowledge of it and understand how to apply it in their everyday work [9,10].

#### **Method**

To respond to the three research questions a series of empirical studies were undertaken, some of these

studies involved collecting new data while others were based on a re-analysis of existing data collected for other purposes. This article is based on data from studies made by members of the CHILD research group published in refereed journals and/or as master theses. All included studies have been reviewed by independent judges and have basic scientific quality. Table I shows the empirical studies on which the work is based, the clinical conditions the participants represent, research questions asked, and the early childhood intervention contexts/habilitation settings from which the participants were recruited. Roman numbers indicate data set, sometimes the same data set have been used for more than one study. In addition, a data set can be used in conjunction with responding to more than one research question.

#### *Content and logical coherence of the ICF-CY model*

To investigate the utility of the conceptual definitions of activity and participation in the ICF model in clinical work with children, the perceptions of well-being of 68 typically developing young children (4–5 years of age) have been compared with the definitions used in the ICF model [11] (data set I). Briefly, the children were interviewed about well-being. Their answers were transcribed and categorised according to the ICF-model in a manifest content analysis [12], and the number of children giving multidimensional responses was counted. Other groups that were asked to define participation were 548 students with disability (7–23 years of age) and persons in their close environment (in total 2000 persons) in an open-ended question [13] (data set IV). Responses were transcribed and analysed using latent content analysis [12]. Individuals were grouped dependent on the categories of the content analysis in which they were represented. The created groups were compared using log-linear analysis. Finally, children and teachers from Pakistan [14] (data set VII) were asked to define participation. Their definitions were transcribed and manifest content analysis was applied.

To investigate the logical coherence of the ICF/ICF-CY model in clinical work with children three different data sets were used [15–21] (data sets III, IV and V). ICF-based protocols were constructed primarily by assigning ICF-codes to items from extant instruments. If necessary the newly constructed ICF-scales were supplemented by newly constructed items based on codes in ICF-CY. Interrater reliabilities for linking items to ICF were satisfactory for all data sets. The logical coherence of the ICF-model was tested by Cronbach  $\alpha$  for newly constructed scales and by confirmatory factor analyses using the three different data sets.

Table I. Studies from which empirical data have been taken to respond to each research questions.

Dataset: Title of published article or master thesis	Clinical condition, age of sample and research questions in original study	Clinical setting and research method
I. Almqvist et al. [11]	Typically developing children (4–5 years of age)  Research questions: – What variations are there in young children’s perceptions, attitudes and self-reported behaviours concerning health? – Are these perceptions related to the four health dimensions body, activity, participation and environment in ICF?	Community based preschools in Västmanland county, Sweden ( $n = 68$ ). A qualitative interview study Data analysis: manifest and latent content analysis. Inter-rater reliability for manifest coding.
II. Almqvist [15]; Almqvist and Granlund [16]	Young children with and without developmental delay (1–5 years of age)  Research questions: – Are patterns of engagement and health evident among subgroups of children aged 1–4 years? – Do children with developmental delay or disability share membership in a group with a specific pattern of engagement? – Does the level of engagement differ by cluster-group membership? – Are there differences in demographics and bio-psychosocial indicators by cluster-group membership? – What are the pathways of engagement? – Do these pathways differ for children with and without developmental delay? – What are the characteristics of children with developmental delay who show stability or change in engagement over time?	Community preschools in Västerås, Sweden ( $n = 1035$ in cross sectional study, 595 in longitudinal study) Quantitative person-based longitudinal study Data analysis: Cronbach $\alpha$ , inter rater correlation, factor analysis, longitudinal cluster analysis
III. Ibragimova et al. [21]	Children in traditional disability categories, i.e. visual disability, intellectual disability, motor disability (0–18 years of age).  Research questions: (1) Do items in the questionnaires as rated by professionals follow the structure of components and chapters suggested in the ICF-CY? (2) Do children in different age groups assessed with the ICF-CY questionnaires differ in their functioning and environment profiles? (3) How feasible is the ICF-CY questionnaire and ICF-CY according to professionals’ ratings and comments?	Convenience samples of Habilitation centres in Sweden – Participants: 130 children and 169 professionals Descriptive questionnaire study Data analysis: internal consistency measured with Cronbach $\alpha$ , construct validity with confirmatory factor analysis
IV. Almqvist and Granlund [22]; Eriksson and Granlund [13]; Eriksson and Granlund [17]; Granlund et al. [18]	Traditional disability categories (7–20 years of age) and a comparison group of same aged children with typical development.  Research questions: – Do students’ conceptions of participation vary with age? – Do concepts of participation vary with the students’ type of disability? – How do important persons in the student’s environment conceive participation and do conceptions of participation vary with role? – Are specific patterns of subject and environmental factors related to participation in school activities? – Is type and/or degree of disability related to participation?	Students receiving services from Swedish Institute for Special Education (SIT) in Sweden ( $n = 448$ ) and students with typical functioning from primary and secondary schools in Västmanland county, Sweden ( $n = 511$ ). Descriptive questionnaire study Data analysis: Cronbach $\alpha$ , inter-rater correlations, inter-rater agreement, qualitative manifest and latent content analysis, log-linear analysis, ANOVA, Scheffé pair-wise comparisons, correlation analysis, factor analysis and cluster analysis Questionnaire items assigned ICF-codes on an item-by-item level. Inter-rater agreement calculated

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Table I. (Continued).

Dataset: Title of published article or master thesis	Clinical condition, age of sample and research questions in original study	Clinical setting and research method
V. Ibragimova et al. [19]; Lillvist [20]	<ul style="list-style-type: none"> <li>- Do subject and environmental factors vary as a function of chronological age?</li> <li>- Do students with disability differ, from students without disability, in how they perceive their participation in school activities?</li> <li>- Do students with and without disability differ in how they perceive the availability of activities?</li> </ul> <p>Children with disabling conditions (0–18 years of age)</p> <p>Research questions:</p> <ul style="list-style-type: none"> <li>- Are the theoretical constructs of ICF-CY valid in categorising items in an assessment instrument, in terms of convergent and discriminant validity?</li> <li>- Can activity and participation be discriminated as two distinct phenomena when rated by caregivers?</li> <li>- What statistical relations can be identified for the ICF items within and between the domains of body, activity/participation and contextual factors when children and youth with disabilities in Russia are surveyed?</li> <li>- What are caregivers' perceptions of interaction with the child?</li> <li>- How are caregivers' perceptions of interaction related to children's body functions, activity/participation and environment as rated in a questionnaire based on ICF?</li> </ul>	<p>Children receiving habilitation services in Leningrad County, Russia. Participants: 135 professionals and 73 parents responded to questionnaire regarding 195 non-speaking children.</p> <p>A descriptive study using both qualitative and quantitative methodology</p> <p>Data analysis: Mixed method. Quantitative scales controlled with Cronbach <math>\alpha</math> and inter-rater correlations, Construct validity analysed with confirmatory factor analysis</p> <p>Qualitative content analysis, controlled for inter-rater agreement followed by group comparisons using ANOVA.</p>
VI. Wilder et al. [23]	<p>Three groups of children and their parents.</p> <p>(a) Pre-symbolic children with profound multiple body impairments, (b) pre-symbolic typically developing infants, (c) age matched children.</p> <p>Research questions:</p> <ul style="list-style-type: none"> <li>- Do parents to pre-symbolic children with multiple body impairments express fewer and less complex emotions (b152) in comparison to children matched for communicative ability or age?</li> <li>- Do parents to children with profound body impairments perceive their children's behaviour style (b126, b140) as different in comparison to the other groups?</li> <li>- Do parents to children with profound body impairments perceive their interaction with their children (a350, d710) as different in comparison to the other groups?</li> <li>- Do parents to children with profound body impairments have other desires for ideal interaction (d710) than the other groups of parents?</li> </ul>	<p>A national convenience sample of 30 families with children with profound multiple body limitations and two control groups of 30 families each. These families have typically developing infants or age matched children respectively</p> <p>A descriptive comparative group design.</p> <p>Data analysis: Cronbach <math>\alpha</math>, Chi 2, ANOVA with Scheffé post-hoc test and correlation analysis</p>
VII. Ali [14]	<p>Children with hearing impairment (7–18 years of age)</p> <p>Research questions:</p> <ul style="list-style-type: none"> <li>- How do parents of children with hearing impairment perceive participation in school?</li> <li>- How do teachers perceive participation of the children with hearing impairment in school?</li> <li>- What are the similarities and differences between teachers and parents perceptions of participation around the same children?</li> </ul>	<p>Children receiving services in a school for the hearing impaired in Lahore, Pakistan.</p> <p>Participants: five parents and five teachers to children with hearing disability.</p> <p>Comparative qualitative group design</p> <p>Data analysis: manifest content analysis based on the ICF participation component</p>

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Table I. (Continued).

Dataset: Title of published article or master thesis	Clinical condition, age of sample and research questions in original study	Clinical setting and research method
VIII. Humayoon [24]	Children with disabling conditions (0–18 years of age) Research questions: – Is the ICF-CY culturally sensitive for application in the psychiatric wards of hospitals in Pakistan? – Is it meaningful to the medical professionals for use in Pakistan? – Is it easy for them to adapt it to daily practice? – Is there a difference in the feasibility of using the ICF-CY in the two neighbouring countries Pakistan and China? – Is there variability in the functional profiles of children in different age groups on the ICF-CY?	Children receiving services from military hospitals in Pakistan. Participants = N 30 psychologists/ psychiatrists in hospitals in Pakistan and n = 120 children in need of special support Quantitative questionnaire study with group comparisons Data analysis: Manifest content analysis, descriptive statistics, Cronbach $\alpha$
IX. Guo [25]	Children with disabling conditions (0–18 years of age) Research questions: – How feasible is ICF-CY for the health professionals in the different kinds of hospitals of China? – What are the differences and similarities in feasibility of the ICF-CY in the two neighbouring countries China and Pakistan?	Children receiving services from hospitals in China. Participants: n = 27 health professionals and 108 children in China and 30 professionals and 120 children in Pakistan Quantitative questionnaire study with two group comparison. Data analysis: Cronbach $\alpha$ homogeneity test, descriptive statistics and <i>t</i> -test
X. Malachy [26]	Children with disabling conditions (0–18 years of age) Research questions: – Is there sufficient information in medical records to code for the various components in the ICF-CY questionnaire? – What are the similarities and differences in the coding patterns for the different health conditions? – Is there a representation of obvious cultural or environmental factors that enhance or limit the functionality of these persons	Children receiving services from a hospital in Nigeria. Participants: data from medical records concerning 20 children and youth with chronic conditions were coded by one coder Document analysis, ratings based on ICF-CY protocol Data analysis: descriptive statistics
XI. Zakirova-Engstrand and Granlund [27]	Children with disabling conditions (5–20 years of age) and their families Research questions: – How well does the ICF-CY document family and societal attitudes toward children with disabilities? – Is the ICF-CY adapted to family environment?	Children receiving services from habilitation units in two cities in Kyrgyzstan ( <i>n</i> = 8 families with children with disabilities) Structured interviews using eco-cultural interview Data analysis: manifest and latent content analysis followed by assigning ICF-codes to meaning units using Cieza et al. (2005) coding rules.
XII. Pless et al. [28], Adolfsson et al. [29], Klang et al. (submitted) [30]	Habilitation professionals working in child and youth habilitation teams in Sweden Aim: to evaluate the effects of an in-service training in using the ICF and ICF-CY on professionals' self-reported knowledge, understanding and use of what they have learnt in everyday work. Research questions: (1) What changes are seen in knowledge about the ICF and ICF-CY, and understanding of the purpose, terms and components of the framework? (2) What changes are seen in use of the components in assessment?	One-hundred thirteen professionals working in 14 habilitation teams evaluation of a pilot course using questionnaires concerning knowledge and use of ICF-CY. Repeated consultation with professionals who review forms implementation Data analysis: Non-parametric and parametric tests and effect size (ES) Manifest content analysis of participants' comments Document analysis of habilitation plans

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Table I. (Continued).

Dataset: Title of published article or master thesis	Clinical condition, age of sample and research questions in original study	Clinical setting and research method
	<p>(3) What differences are seen between the two subgroups?</p> <p>(4) How do habilitation professionals use the ICF-CY over time following in-service training of the ICF-CY?</p> <p>(5) How do habilitation professionals perceive the utility of the ICF-CY over time?</p> <p>(6) How does the use of the ICF-CY correspond with the organisational service goals of child participation in their everyday life contexts?</p> <p>Individual habilitation plans for children with disabling conditions (1–18) and their families (N0245)</p> <p>Research questions:</p> <p>(1) What patterns of change in content occur in professional documentation of individual habilitation plans in relation to components in the ICF-CY?</p> <p>(2) What patterns of change occur in documentation of individual habilitation plans in relation to congruence between assessment and intervention?</p> <p>(3) What is specific to cases where typical and atypical changes have occurred in relation to congruence between assessment and intervention?</p>	
XIII. Eriksson et al. [31]	<p>Pairs of children with and without disabilities in the same classrooms</p> <p>Research questions:</p> <ul style="list-style-type: none"> <li>– Is there an overall difference in participation between groups, do the difference vary dependent on type of activity?</li> <li>– Is there a relation between inclusion and participation?</li> </ul>	<p>Thirty-three pairs of children, aged 7–12, with one child with and one without disability in each pair.</p> <p>Structured observations, structured interviews and self-ratings</p> <p>Data analysis: Cronbach <math>\alpha</math>, non-parametric tests with multiple comparisons and regression analysis</p>

### *Utility of the ICF-CY for documenting child characteristics*

Protocols used in data sets IV [13,15–18,22], VII [14], VIII [24], IX [25], and X [26] also included sections to collect information that may be related to health and disability outcomes (i.e. diagnosis, age and gender) and reliability and validity of the instruments (i.e. type of professional using the protocol, whether the protocol was used by a single professional or in a team setting). Data from these sections were used to investigate the feasibility of the ICF model in habilitation and/or education settings for children in Sweden, Russia, Pakistan, China and Nigeria. In data collection sets of III, IV and V, disability and functioning profiles were calculated for children and the validity and the reliability of the scales used were analysed in relation to the ICF conceptual model. In data set XI [27], the data were used to investigate the applicability of the ICF-CY model to collect data related to a family setting.

### *Implementing ICF-CY in habilitation services*

A project investigating the utility of the ICF-model as a means for collaborative problem-solving involving professionals and family with children with disability has been implemented [28–30] (data set XII). In conjunction with this project an in-service training package for habilitation staff has been developed and piloted using a quasi-experimental pre–post design in which professionals with previous knowledge of ICF-CY were compared to professionals without previous knowledge. Questionnaires were used to assess changes in professionals knowledge and skills in ICF-CY, a qualitative design using self-reports and interviews was used to study the implementation process over time, while a document analysis using manifest content analysis was used to compare the content of habilitation plans before and after in-service training in terms of whether their focus were on body, activity or participation.

## Results

Results will be presented based on the three research questions.

### *Content and logical coherence of the ICF-CY model*

Results from data set I indicate that children's perceptions are possible to categorise according to ICF. The children, 4–5 years of age, provide multi-dimensional responses that can be categorised according to the ICF-model into body, activity, participation and environment dimensions. Most children provide definitions that can be categorised into more than one of these dimensions. Statements categorised as participation or engagement primarily have a positive valence while descriptions of body more frequently have a negative valence.

The responses from 548 children and youth with disability and from persons in their close environment in data set IV when asked to define participation (in total 2000 persons) showed similar results. The definition of participation contains three dimensions, perceptions of motivation and belonging, goal-directed action and perceived availability of environmental opportunities. To note is that the definitions provided by children with disabilities do not vary as a function of type and degree of disability. There is however a trend that the definition vary with age and with role. Younger children stress behaviour while adolescents stress perceptions of control. Persons with disability stress perceptions and behaviour while parents and professionals stress interaction and environment. The definitions of participation by teachers and parents to children with hearing impairments in Pakistan have been investigated (data set VII). The same three dimensions as in the Swedish investigations were identified, perceptions, goal-directed action and perceived availability of the environment. Parents stressed communication, interaction and support more than teachers who stressed learning and applying knowledge and attitudes. This may be a logical consequence of the role of the respondent in relation to the child with disability.

The logical coherence of the ICF model has been investigated by a series of confirmatory factor analyses implemented on three data sets (III, IV, V) based on three different protocols developed from ICF. The rationale is that if the model is logically coherent it will be confirmed by factor analyses even if different instruments and/or different data sets are used for the analyses. In all three sets of data, factor analyses have been implemented on the whole model (three-factor solution representing body, activity/participation and environment), and within each

component (number of factor solutions dependent on number of chapters in component). Chapter scores have been used for the analyses. Dependent on the protocols used in different data collections the number of chapters used in the analyses varies between data sets. The results reveal that the ICF model is fairly strongly confirmed. Chapters representing environment and activity/participation almost entirely fell out in two separate factors confirming the model. Chapters representing the body factor, however, do not as coherently represent one factor of its own. Chapter 1 in the body component, i.e. mental function, consistently fell out in the activity/participation factor.

The within component factor analysis reveals different degrees of consistency with the ICF model for different components. In the body component, the factors identified indicate that chapters tend to group partly after chapters (mental functions in two factors, movement in two factors) and partly dependent on function rather than body systems, e.g. alertness, attention. The chapters in the activity/participation component tend to group into factors dealing with specific functional topics rather than original chapters, e.g. play, routines and interaction. There is however many times an overrepresentation of items from one or two chapters in these factors. In the environmental component items from the chapter attitudes primarily groups into a factor of its own (including also general support). Support from friends and relatives form one factor. The chapter products and technology tend to divide into two factors with availability to activities and assistive technology in separate factors.

In a final analysis, it was investigated if activity and participation could be separated into two factors (dataset V). Carers to children with severe disabilities were asked to rate three aspects of activity and participation: (1) can the child perform the activity (capacity), (2) how frequent does the child perform the activity (performance), (3) how willing is the child to perform the activity (will/motivation). The result reveals that it was difficult for carers to differentiate between these three aspects. Responses were all highly correlated for this group of children. It may be explained a very small behaviour repertoire in this group of children making all three aspects inferred from the same behaviours. The results indicate that engagement and motivation and probably also performance are best rated by the person with disability him- or herself. Future research needs to focus on how to separate activity and participation. Several theoretical suggestions have been provided, e.g. Badley [32], Coster and Khetani [33], McConachie et al. [34] and Whiteneck and Dijkers [35]. These need to be tested and compared with the suggestions for how to separate activity and partici-



pation provided in the ICF-CY manual using empirical data.

#### *Utility of the ICF-CY for documenting child characteristics*

The validity, reliability and utility of instruments/protocols aimed at documenting child characteristics based on ICF-CY have been investigated with several different data sets (III, IV, V, VIII, IX, XIII).

In all data sets both ICF scales constructed by assigning ICF-codes to items from extant instruments and scales constructed directly based on ICF classification codes have had high to acceptable reliability, Cronbach  $\alpha$  values, i.e. they have a good internal consistency and items within the scales seem to measure the same constructs. Inter-rater reliability has been investigated using three data sets (II, IV and V). The inter-rater agreement in scales based on the whole ICF model, based on ratings from parents and rehabilitation professionals regarding children with severe disabilities (data set V), ranged from relatively low in conservative judgement (same scale step is rated by judges) (55%) and was higher in liberal judgement (79%) (one-scale step difference is allowed). The highest agreement between parents and professionals existed for body function scales and the lowest for environmental scales. The results are logical considering the fact that both parents and professional interact with the child but in different environments. The result highlights the importance of collecting assessment data from several sources, including both the child, parents and professionals. This is especially important for activity/participation and environmental factors, which tend to be based on subjective perceptions to a higher degree. In two data sets concerning young children with and without developmental delay (II) and school children with disabilities (IV), the inter-rater correlation between parents, professionals and children's ratings of engagement and frequency of participation respectively was investigated. The result revealed a statistically significant correlation on the 1% level between ratings from the respondent groups for young children (only parents and professionals rated children) and children aged 7–12 years of age. For older children [13–18], the statistical correlation between the respondent group of children and the other two respondent groups was not significant. This indicates that it is important to ask teenagers themselves about their own perceptions of everyday life.

The *content validity* of the ICF-protocols used in data sets (III, VII, VIII, IX, X, XI, XII) has been investigated by analysing the possibility to assign ICF-codes to items from valid and reliable extant instruments used to measuring aspects of function-

ing in children with disabilities (data sets IV and V). The result reveals that it is possible to assign codes to items from extant-rating instruments with a high degree of inter-rater agreement and that the new scales have high internal consistency. In addition, professionals using ICF-CY protocols (III, VII, VIII, IX, X, XI, XII) have been asked about the relevance of the content of the checklist. Results reveal that respondents in different cultures agree on that the ICF-CY is useful for screening purposes, but that in might not be sufficient for guiding professionals in how to proceed with a more in-depth assessment of certain areas covered by ICF. The protocols were considered as more relevant for traditional disability categories of children than for children with other types of clinical conditions, e.g. diabetes. *Concurrent validity* of measures of activity/participation has been analysed using data sets V and XIII. In the analysis of data set V, parents and professionals' responses to open-ended questions about their perceptions of interacting with the children was used to create groups of respondents who primarily described interaction as problematic, neutral or positive. Respondents who perceived the interaction as more positive rated the children higher than the other two respondent groups on the ICF-based assessment protocol, especially concerning mental functions, behaviour style (temperament), interaction and play. The result indicates that the ICF-based protocols produce a picture of the child that corresponds to carers' perception based on interacting with the child. Using data set XIII [35], observers' ratings of children's participation in classroom activities were compared with independent judges' ratings of children's descriptions of their participation in the observed activities using the same rating scale. The result reveals a high inter-rater agreement between observers' ratings of participation and ratings of the children's report on their participation. It indicates that observations can provide valid information on participation but also that children's self-reports of participation are valid as a basis for ratings. Concerning *construct validity* the analyses reported under the heading logical coherence indicate that scales based on ICF generally mirror the basic constructs in ICF and the children themselves identify dimensions in participation covered by the scales. On a detail level, there are inconsistencies within the components indicating that chapters in ICF as well as scales aimed to measure chapter content need to be refined in terms of the functional skills/activities that are measured. Information is lacking regarding how codes associated with the same functional area, e.g. managing time, in different components are related.

Aspects of the feasibility of ICF in clinical practices involving children have been analysed with

different data sets. The clinical feasibility of ICF-CY in assessment as judged by professionals has been investigated using data sets III, VIII, IX, X and XII. The clinical feasibility in differentiating between different profiles of functioning in children with disabilities has been investigated using data sets II, III, IV, V, VI and VIII. Finally, the cultural sensitivity of ICF-CY has been investigated using data sets III, VIII, IX and XI.

The feasibility of the ICF-CY protocols was tested by professionals in Sweden, China and Pakistan. After testing the protocols, the professionals were asked about the applicability of the ICF-CY, both in general and for the checklists constructed for the different age groups 0–3 years, 4–6 years, 7–12 years and 13 and above. A scale from fully applicable [1] to not at all applicable [4] was used. The respondents' most typical rating was 2 'largely applicable' for ICF-CY in general. The rating for applicability for different age groups varied from 'somewhat applicable' [3] to largely applicable [2], with lower ratings for the checklist intended for use with the oldest age group. On an open-ended question, the professionals rather frequently commented that the ICF-CY checklist does not contain enough focused information to guide decisions on what parts of the ICF model to focus on for in-depth assessment of specific children. As a consequence, new ICF-forms are currently under development both in Sweden [36] and in the US [37]. The Swedish forms are aiming at delimiting code sets for supporting children in important everyday life situations, e.g. 'hanging out with friends' for adolescents. The US forms are aimed at identifying important universal code sets for different age groups.

The clinical feasibility in using the ICF components body, activity/participation and environment as a frame of interpretation when studying differences and similarities in communicative functioning between children with profound disabilities, typically developing infants and typically developing children has been tested with data set VI [23]. The result indicates the feasibility of using a profile approach to match body function to activity and participation parameters to identify intervention needs. Profiles of functioning in interaction had a stronger relation to ratings of interaction skills than ratings of use of symbols or ratings of cognitive function. The within group differences in how parents rated their own style of interacting with the children (i.e. an environmental factor for the child) was larger than the between group variance (parent to child with profound disabilities, parent to typically developing infant or parent to typically developing child). The result indicates the feasibility of using the components in the ICF model to obtain multidimensional explanations to child functioning. The data sets II,

IV and V have been used to test the feasibility in using a profile approach to identify groups of children with different patterns of participation, and how these profiles are related to aspects of body function and environment. The results reveal that profiles of participation are related both to body factors and to environmental factors, i.e. they seem to be determined by several factors. They also reveal that traditional disability categories (mostly based on medical diagnosis or body impairments) are relatively weak predictors for profile group membership in activity/participation profiles (see data sets II, IV and V). Data sets III and VIII have been used to investigate whether profile differences between age groups could be detected when ICF-CY checklists were applied in assessment. In the analyses, items common to all age groups were used. The results indicate that it is possible to detect age differences with the ICF-CY checklists. In a comparison of age differences found in children rated by professionals in Sweden and Pakistan (data set VII and VIII) the same patterns of ICF-codes were revealed (e.g. problems with the body function voice and the activity/participation chapter communication was rated more frequently as problems for younger children).

Concerning the cultural sensitivity of ICF-CY, assignment of ICF-CY codes to meaning units from family interviews with families with two different cultural back ground in Kyrgyzstan (data set XI) indicates that the ICF-CY environmental component is applicable in both cultures to describe family context and family accommodations. There was however a lack of detail in chapter 3, Support, in the environmental component that made it difficult to rate barriers and facilitators in terms of immediate family. In data sets III (Sweden), VIII (Pakistan) and IX (China), professionals were asked to rate the cultural sensitivity of the ICF-CY. The results vary from the typical response that ICF-CY is somewhat sensitive (Sweden), to somewhat and largely (China) to largely culturally sensitive (Pakistan). The varying results dependent on country (culture) indicate that cultural sensitivity needs to be further investigated.

#### *Implementing ICF-CY in habilitation services*

In order to be adopted for clinical use a framework such as the ICF/ICF-CY must be consistent with existing values, existing knowledge, easy to understand, learn, use, and to obtain results from. The studies in data set XII describe and analyse the effect of an in-service training intended to support professionals in child- and youth habilitation to use ICF-CY in their clinical work. Effects were evaluated in terms of effects on professionals' knowledge and skills

concerning ICF-CY, diffusion of ICF-CY into clinical work and the effects on the content of habilitation plans. The training was developed based on the content of the ICF-DIN (Disability Italian Network) basic and advanced courses [38]. The content was arranged with regard to the participants being adult learners and that all learning and skills should be transferred to daily work situations. The in-service training constituted of two full days of training, with time for testing participant's understanding and use of the framework, short lectures, discussions of application of ICF-CY on vignettes, training in applying codes and time for discussion of its advantages and disadvantages. It was preceded by a 2-h information meeting with a home assignment and followed by bi-monthly newsletters during 2 years.

The results on professionals knowledge about ICF-CY suggest that a short training package in using the ICF and ICF-CY is an effective method of exposing professionals to the framework, and increasing their knowledge and understanding of it for as long as 1 year after training. This is, especially for professionals who have prior knowledge of the framework and use the framework conceptually after training. The effects on self-reported application of the ICF/ICF-CY framework in everyday work are less impressive. However, professionals who report that they use the framework seem to focus more on assessing the child in relation to performance of activities in everyday environment than those who do not use the framework.

Implementation of ICF-CY into clinical work is, according to the results, a selective process in which participants reported that the ICF-CY was primarily used for practical work, such as habilitation planning, including problem-solving and decision-making, all important parts of the habilitation process. Application of the ICF-CY required development of new routines and adaptations of materials. The use of the ICF-CY appeared to enhance a focus on child participation, corresponding with the overall organisational goal for habilitation. Implementation of the ICF-CY into habilitation services takes time and effort [39]. There were indications that the innovation-decision process was proceeding for the entire two and half-year period the professionals were followed. For the ICF-CY to be used, a lot of effort went into adapting materials, patient records, and strategies for habilitation planning and knowledge transfer. When professionals attempted to apply the ICF-CY into daily work, they realised shortcomings in the organisation and the need to revise routines to fit the innovation represented by the ICF-CY. To direct the process and conduct an effective implementation of the ICF-CY into an organisation, a systematic approach is required [40]. A well-planned process with preparation of materials, such as

checklists for assessment or information folders, and a determined change to ICF-CY-based search terms will probably help to accelerate the process. A key issue in terms of material adaptation is the development of short lists of ICF-CY codes or code sets for specific purposes to facilitate the adaptation of the complex classification.

The comparison of the content of habilitation plans in terms of their focus before, training, and 1 year after training [28] (data set XII) revealed changes in how interventions were framed. After training, professionals' with a higher frequency focused on how a child performs activities in everyday life (activities/participation) and on the physical and social environment of the child (environmental factors). The frequency of interventions focused on body functions did not increase. A comparison of content in habilitation plans in relation to congruence between assessment and intervention indicates that several patterns of congruence exist and these are related to the overall family and child situation and ways of documentation of professional decisions. A wide range of codes from the ICF-CY component activities and participation as well as environmental factors was identified in the content of habilitation plans. It indicates that ICF-CY offers an appropriate language to describe the processes of assessment and intervention in habilitation.

## Discussion

Based on data from several studies, the aim of this article was to investigate whether the ICF-model is a feasible and useful model for generating a common language and a common frame of reference in habilitation and early childhood intervention settings. Overall, the results confirm that the ICF-model and ICF-CY are feasible and useful in early childhood intervention and habilitation services.

The content of the definitions used in the activity/participation component in the ICF theoretical model is confirmed in children's own multidimensional descriptions of well-being and participation. The participation definitions provided by children do however stress the perception of engagement and motivation. Those constructs are not part of the ICF/ICF-CY [34]. It is mentioned in a footnote in the classification manual [3,4] that a third qualifier, in addition to capacity and performance may be created to rate degree of perceived involvement in the situation. The results of the studies, based on children's own statements, indicate the need for this third qualifier, focusing on the perceived or observed degree of involvement or engagement in the life situation.

The logical coherence of the model is confirmed on component level (body, activity/participation and environment) but only partly confirmed within the components, i.e. items are partly grouped according to chapters and partly according to functional activities in factor analyses. The interpretation of these results is open to discussion. Is factor analysis, a statistical method, adequate for confirming or disconfirming a theoretical model? Maybe factor analysis is an adequate model for confirming the overall model on component level but less adequate for confirming chapter content within the components. Chapter content is more dependent on contextual factors and thus the degrees of freedom increases for what chapters should contain dependent on context. In the presented studies, a relatively consistent pattern was that the internal consistency was good to acceptable for the 'ICF-CY chapter scales' created by linking items from extant instruments to ICF-CY. In general, internal consistency was very good for 'body scales' and acceptable for 'activity/participation scales'. For body scales that are less dependent on contextual factors internal consistency was higher than for the contextually more dependent activity/participation scales. Within the activity/participation component internal consistency was higher for capacity ratings than for performance ratings. A conclusion is that on chapter level it may be more important that the content is logically coherent than statistically consistent. Logically coherent content means that items have a conceptual relationship forming the ICF-CY chapter that might not always be seen in empirical data. There are not always a correlation between items and nor a hierarchy between the items measuring the construct. Instead the latent construct is observable through a number of indicators; all of which are imperfect measures of the construct but which together can be summed to obtain a more valid operationalisation. This means that assessment of construct validity based on Cronbach  $\alpha$  or similar measures founded on inter items correlations might be irrelevant. Instead consultations of expert panels, focus groups, literature review, etc will be a more accurate way of making sure including items measure all aspect contributing to the concept of interest [34,41]. In this project, the ICF-CY protocol was field trialled in several countries.

Concerning the ICF-CY's usefulness for documenting child characteristics in early childhood intervention and habilitation services the results indicate that instruments based on the classification can provide a reliable, valid, and clinically meaningful description of functional status, taking into account clinical and everyday environments. The additional information provided by profiling children's functioning within and across components indicates that with the help of ICF-CY based assessments it is possible to provide a more rational

and more meaningful basis for conceptualising treatment needs, allocating resources, and assessing outcomes than diagnosis alone.

Clinical judgment related to the evaluation of a particular client in a particular context seems to be possible with the help of ICF-CY-based instruments. Professionals report that they use a range of assessment approaches (e.g. team-based ratings, clinical interviews, observations, parental ratings, children's self-report) compatible with the ICF-CY model. The relatively similar professional judgments of the feasibility of ICF-CY by professionals from different countries indicate the usefulness of ICF-CY for client evaluation in diverse cultural contexts.

Ratings of child functioning made by carers indicate that it is difficult to discriminate clearly between activity and participation unless self-rated by the child/youth. Thus, it is also difficult to highlight children's own perceptions of participation, i.e. perceived involvement in life situations, unless participation focused self-rating scales are developed. Professionals also indicate that few instruments measuring participation are available. Participation focused assessment materials need to be developed.

The results of the studies are partly able to highlight areas where further development and/or standardisation of assessments based on the ICF-CY model is required, for instance, the role that environmental factors play in the individual's functioning and well-being. The environmental component lacks detail in the possibilities to document environmental aspects especially in chapter 3, *Support and Relationships*.

The results indicate that implementing ICF-CY in clinical practice is a time consuming long-term process. The ICF-CY is a complex classification system and initial adoption of the system is facilitated if intended adopters are given opportunities to familiarise themselves with the system. They also need short lists or code sets easy to use to initiate implementation in their own work. On team and organisation levels implementation need to be supported by a motivated management that create opportunities for implementation by adapting routines and documentation systems. However, also short term in-service training in implementing ICF-CY seems to generate a positive outcome in terms of supporting professionals in providing more assessment and interventions focusing on activity/participation and environment.

## Conclusion

ICF-CY can be used to guide functional status assessment, goal setting and treatment planning and monitoring, as well as for outcome measurement.

Additional work is needed to create reliable and valid instruments that make it possible to discriminate between activity and participation. It is also necessary to conduct research focusing on the feasibility of using ICF-CY, not only as a guide to assessment, but also as a means for evaluating programme routines, programme success and intervention success in working with children and youth in need of early childhood intervention or habilitation services.

### Declaration of interest

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