

#### **Review articles**

# Applicability of the ICF-CY in evaluating children with disabilities and family support: an integrative literature review

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#### **ABSTRACT**

**Purpose:** to verify and update information on the applicability of functional assessment through the International Classification of Functioning, Disability and Health - Children and Youth Version (ICF-CY) in children with disabilities.

**Methods:** a search was carried out on the databases of the Virtual Health Library Research Portal, EBSCOhost and Google Scholar, using a combination of the key words "children with disabilities", "ICF" and "mobility".

**Results:** altogether, 2,773 studies were identified; however, after the filters were applied, only 27 were selected. After an explored analysis of the themes of the articles, this diagnosis revealed four analytical categories: environment (4 articles), quality of movement (3 articles), family (4 articles), and professionals (16 articles).

**Conclusion:** in face of the sufferings experienced by families with disabled people, different possible approaches to this phenomenon were pointed out. Therefore, a greater effort of investigation and intervention in these fields are necessary, further exploring this tool.

**Keywords:** Disability Assessment; Child; Family

## INTRODUCTION

In the beginning of the 1980's, the United Nations revealed that many countries had statistics regarding people with disabilities. As time went by, the progress in this area was small and, as a consequence of the increase in the prevalence of disabilities, the focus on developing health indicators switched from mortality to morbidity and, in more recent years, to the consequences of chronic diseases1.

In 2001, the World Health Organization (WHO) approved a classification system for the understanding of human functioning and disability: theInternational Classification of Functioning, Disability and Health (ICF), which is a method for the identification of structural and environmental conditions and personal characteristics that interfere in people's functioning. The general purpose of this system is to furnish a unified and standardized language by means of a structure which characterizes health and its related conditions, thus helping in communication and in information exchange<sup>2</sup>.

The ICF is organized into four components: Body Function, Body Structures, Activities and Participation, and Environmental Factors. This method offers a classification model which takes into account the presence and seriousness of a health problem, either as an individual or social situation, enabling the a standardized language regarding functioning<sup>2</sup>. Its division is made also in two major parts, the first of them related to the functioning and disability components, in which the aspects of the body, the activities and the participation are dealt with, which may be expressed in negative or neutral terms. The second part encompasses the components related to contextual factors, which include environmental and personal factors, which may be expressed in positive and/or negative terms, according to the influence it has on the person<sup>3</sup>.

Upon adopting the use of the ICF, the clinical practice may improve the multi-professional communication, besides strengthening the position of physiotherapy and occupational therapy within the health staff, improving the effectiveness of the services and the adherence of patients to the treatments3.

In the 1990's, the WHO formed an international group with the purpose of developing a version of the ICF aimed at children and youth, the International Classification of Functioning, Disability and Health -Children and Youth Version (ICF-CY); this version was officially approved in 2007. The objective of the ICF-CY is to make an international comparison of the health

condition of children and youth, and to scan incapacity in children, in order to implement measures that will improve child and youth health and education4.

The ICF-CY evaluates the same components related to health as approached in the ICF. However, this version presents some specificities of childhood and adolescence, such as the child in their family environment, delay in development, the participation and the environment5.

It's important to point out that the ICF transformed the classification method, which used to be based on "consequences of the illness", into a system based on "components of health". This approach identifies what health consists of, whereas "consequences" refers to the impact of illnesses in the health condition of the person. The ICF is the conceptual basis with which to care for people with disabilities.

Approximately 10% of the world population present some sort of deficiency, which characterizes it as a public health issue. For example, when a motor alteration results in the child's disability and limitation to perform activities and tasks in their and their family's daily lives, their functional performance is directly influenced by the characteristics of the physical and social contexts. Hence, assessing the impact that the deficiency causes in the child's and their family's life has been a challenge to the health professionals6.

In the cases of neuromotor alterations, the ICF and the ICF-CY help the health professionals in evaluating the functional registry and intervening in it. Therefore, it contributes to the clinical practice, and enables specific interventions and individual longitudinal follow-up for each patient. The use of the ICF is providential for the true life conditions of patients to become part of the statistics, making it possible to guide policy actions and decisions, define interventions and provide more consistent data regarding the life conditions of people with deficiency, so that these will promote more efficient professional actions7,8.

Considering that the ICF-CY evaluates their functioning in order to gain deeper knowledge of the activities performed and the conditions in which they participate in significant contexts of the child's development9, and thus, intending to reflect on social equity to promote health and development of the children with deficiency, this integrative review had as its aim to verify the main elucidations in the current literature concerning the applicability of the functioning assessment by means of the ICF-CY in children with

deficiencies, in order to offer support to the families in dealing with their necessities.

#### **METHODS**

The protocol of procedure stages in collecting and analyzing data for the integrative review presented in this study is based on Mendes, Silveira and Galvão  $(2008)^{10}$ .

- a) Defining the research question: What have the studies revealed about the applicability of functioning assessment by means of the ICF-CY in children with deficiencies?
- b) Defining the eligibility criteria: in order to be included in this review, the studies had to meet the following inclusion criteria: it had to be published as an original article; it had to be written in Portuguese, English, Spanish or other language; and, it had to address relevant issues regarding the functioning assessment of children with deficiencies.
- c) Searching in sources of published data: a search for electronically published bibliographic data was carried out in the Virtual Health Library Research Portal (VHL), Medical Literature Analysis and Retrieval System Online (MEDLINE), Literature in the Health Sciences in Latin America and the Caribbean (LILACS) and EBSCOhost, as well as Google Scholar search engine.
- d) Developing search strategies: in first place, the search terms were selected, using combinations of the keywords "Children with Deficiencies", "ICF", "Mobility", and the Boolean operator AND in-between the terms previously defines. Then, the articles published in Spanish, English or Portuguese between 2012 and 2017 were selected.
- e) Evaluating eligibility: the articles were scanned, in a review process performed independently in pairs, in order to confirm their eligibility and subsequent selection for this study.

- Search on VHL: in the initial stage of the search, the keywords "Children with Deficiencies" AND "ICF" AND "Mobility" were inserted in the search field (title, summary or subject) of the VHL, which returned 48 texts. After filtering according to date (referring to the years from 2012 to 2017), 29 articles were found. In order to verify the pertinence with the theme, the titles and summaries of the 29 articles were read, of which 18 were excluded due to its incompatibility (i.e., they were not directly related to children with deficiencies, ICF or mobility) and 1 was excluded for being repeated. Thus, 10 articles were selected for full reading.
- Search on EBSCOhost: The keywords "Children with Deficiencies"; "ICF (International Classification of Functioning, Disability and Health)"; and "Mobility" were inserted in the search field of the EBSCOhost, and 395 texts were found. When the date filter referring to the years 2012 to 2017 was applied, 303 articles were found; and, when the consistency with the theme was checked through the reading of the titles and summaries, 297 articles were excluded due to incompatibility of the theme, and 2 for being repeated. Therefore, 4 articles were selected for full reading.
- Search on Google Scholar: the keywords "Children with Deficiencies" AND "ICF" AND "Mobility" were inserted in the search field of Google Scholar, resulting in 2,330 texts found. As the date filter was used, referring to the period between 2012 and 2017, 1,390 articles were found; and, as the consistency with the theme was verified, by reading titles and summaries, 1.376 articles were excluded because of its incompatibility with the theme. Thus, 13 articles were selected for full reading.

On Figure 1, the detailed process of scanning and selecting articles may be verified in the flowchart.

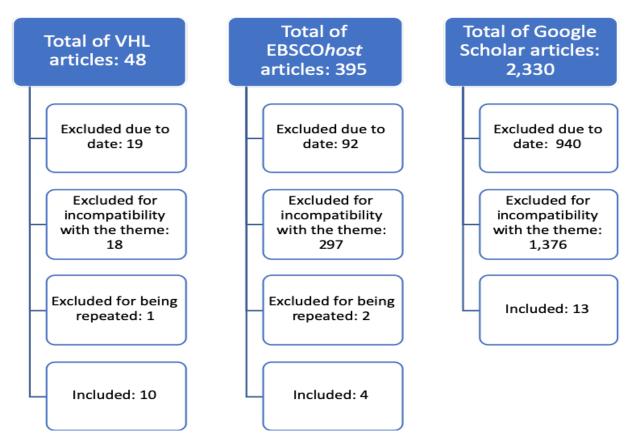


Figure 1. Articles eligibility flowchart

After selecting the eligible articles which constitute the final sampling of this review, the presented aims were explored and, based on the analysis of their content, these articles were classified into categories, according to what was identified in the themes addressed in them.

### LITERATURE REVIEW

The electronic search resulted in 2,773 articles, which were submitted to evaluation to verify the possibility of including them in this review. After filtering them according to the pre-established inclusion and exclusion criteria, a total of 27 articles were considered eligible.

After the exploratory analysis of the theme of the articles, they were grouped in four large categories: 1) environment (four studies); 2) family (four studies); 3) quality of movement (three studies); and 4) professional (sixteen studies).

# Category: environment (four studies)

in the first category, one article aimed at reporting the case of a child with Congenital Zika Syndrome; the child was followed up with the help of the ICF and motor development assessment tools. The second one aimed at analyzing the implications of acquiring physical deficiency as a result of situations one has gone through; the analysis was done with the ICF as a reference, emphasizing the contextual factors. The third aimed at examining the content and reaffirming the validity of the Funded Child Care & Development Options (FUNDES-Child), a child development services foundation for children from newborn to 12 years old and older children with special needs. The fourth one aimed at performing a document analysis of the Brazilian legal framework regarding the policies for people with deficiencies, especially concerning the challenges of evaluating and classifying the deficiency as restrictive to social participation. The results point to the ICF as a remarkable classification method for studying and developing practices, because it's not focused on the illness, but on the context in which the person is. Furthermore, the possibility of evaluating barriers and environmental factors enables the deficiency to be discussed as an issue of social justice and equity, and not only from a biomedical perspective<sup>11-14</sup>.

In the study carried out by Barbosa et al. (2016)11, an investigation protocol was applied to assess behavior condition, reflexes, tolerance and adaptation to handling, muscle tone, adopted posture, and motor development. After follow up, the presence of modifications in the motor behavior was verified, due to changes in environmental factors. Relevant changes were perceived in joint mobility and in the function of the child's muscle tone, as well as improvement in postural reactions of the head, and in control functions of simple voluntary movements.

Hwang et al. (2015)<sup>12</sup> and Toldrá and Souto (2014)<sup>13</sup> question how contextual factors regarding personal and environmental issues reflect on the functioning of children with deficiencies.

Santos (2016)<sup>14</sup>, in his turn, writes about the importance of evaluating the environment in order to promote health, development of children with deficiencies and social equality.

# Category: quality of movement (three studies)

this category gathered researches with the following objectives: to assess the functioning, classify performance and ability, and also investigate the participation of children with Cerebral Palsy (CP); to investigate language issues by means of the components of the ICF, as well as participation and performance/ functioning of children who used supplementary and/ or alternative communication (SAC) in the cognitivelinguistic activities; to evaluate the level of functional independence in the ADLs of a child with CP, before and after a period of functional activities training<sup>9,15,16</sup>.

In the studies carried out by Monteiro et al. (2012)<sup>15</sup> and Romano and Chun (2014)16, the results demonstrated a considerable increase in the level of independence of the child after training on self-care, functional abilities and caregivers assistance. These results point to positive changes in the functional performance of the children as an outcome of a good intervention program based on functional activities. In addition, it may reduce the degree of seriousness which the deficiency represents to these children.

Souza and Alpin (2015)9 used the ICF to evaluate three children diagnosed with Spastic Diplegia Cerebral Palsy, through interviews and functional assessments of the children. In this study, it was highlighted that, when performance was compared to ability, the children revealed a slight increase in performance, enabling limitations of the children in executing tasks to be identified.

## Category: family (four studies)

in this category, the studies aimed at: documenting health and functioning in the daily living of children with cancer, using codes from ICF-CY, as well as identifying a set of encompassing codes which may help in clinical evaluation; elaborating an ICF-CY checklist, based on an investigation of family, clinical and therapeutic dimensions related to this classification, for the follow-up of cochlear implants (CI); exploring the parents' point of view concerning the activities and participation of children with CP in a variety of communicative situations, and the personal and environmental factors that influence it; summarize the experiences and perspectives of youth with CP in order to provide information for the development of rehabilitation and social programs. The results revealed that the children's frustrations, other people's negative attitudes, unknown people and environments are the main obstacles in their parents' perception. The youth, in their turn, identified independence, coping with circumstances and body image as factors that impact their ability to deal with their situation. It was found that the ICF is important for health professionals, parents and teachers, both for assessing and for supporting the health and the day life of children with cancer<sup>17-20</sup>.

The study by Mei et al. (2015)<sup>17</sup> presented the report of thirteen parents of children with CP through individual semi-structured interviews; the identified codes and themes were mapped according to the components of the ICF-CY. The parents' responses reflected the Activity, Participation, and Environmental Factors components of the ICF-CY. The main barriers identified included aspects related to the very interaction between children and parents, people and unknown configurations, and the main facilitators include the support received from the children's family and school, creating a family routine and a positive disposition of the children. In agreement with this study, Lindsay (2016)18 carried out a systematic qualitative synthesis about the experiences and perspectives of youth that live with CP, in which it's made evident the importance of social and environmental inclusion, as well as of the role of family and peers, and social participation, in order to obtain and maintain a good quality of life<sup>18</sup>.

Also regarding family, Morettin (2012) carried out a study with the purpose of developing an ICF-CY checklist for the follow-up of CI users, based on family, clinical and therapeutic aspects. The structuring proved to be positive concerning the investigation of the main factors that may characterize such population.

However, its extensiveness and operationalization may be considered obstacles in health services<sup>19</sup>.

In the research authored by Darcy et al. (2015)20, children diagnosed with cancer and their parents were interviewed, and their answers were codified for the ICF-CY. This study identified a set of extensive codes for child cancer, and most of them are related to activities and participation regarding social relations with relatives, peers, and professionals related to support and independence. These identified codes will be useful for health professionals, parents and teachers in assessing and supporting the health of children with cancer.

# **Category: professionals (sixteen studies)**

This category is composed of two thematic variables: rehabilitation8,21-24 and research25-35.

# CATEGORY: PROFESSIONAL - thematic variable: rehabilitation.

Regarding the rehabilitation variable, the objectives of the studies were: to repot the case of a patient with Nemaline Myopathy (NM), highlighting the main complications and the intervention of physiotherapy; to use the ICF-CY in the Single Health System (SUS, as abbreviated in Portuguese) for the registry of hearing and language development in children in their first year of life; to evaluate the discriminant validity of the Social and Functional Performance protocol for children with Cerebral Palsy (DFS-PC, as abbreviated in Portuguese), in order to verify if it is sensitive to alterations in functional performance and social participation of children with CP, when compared to the typical development; to discuss the practice of the occupational therapist (OT) in neurological rehabilitation, focusing on the use of activities as their intervention tool; to classify the functionality of children with CP by means of the ICF, and evaluate the agreement between assessors8,21-24.

Medeiros et al. (2013)8 developed a study with 12 children diagnosed with CP undergoing physiotherapeutic treatment; the instrument for gathering data was elaborated similarly to ICF. Most of the evaluated children performed the assessed tasks without difficulties, except for jumping, kicking and fine motor activities. Regarding the agreement between assessors, it was evidenced the need of training in order to use the ICF.

In the study written by Bernardi (2017)<sup>22</sup>, specialized audiologists carried out the correlation between questions in a questionnaire for hearing and language monitoring in children in their first year of life, with the ICF-CY codes. Its use enabled the health professionals to broaden their perspective and create or adapt standardized assessment tools based on the ICF-CY; which favors it to be used in clinical practice.

Furlaneto et al. (2014)21 carried out a study describing the clinical evolution and the main complications of the assessment, treatment and physiotherapeutic results. For motor evaluation, both the Motor Function Measure (MFM) and the ICF-CY were used; and the digital manovacuometer, for peak inspiratory pressure. In this study, it was observed that the participants had limitations in transferring body posture, walking and attempting to move an object with the lower limbs, though they had no difficulty in keeping body posture, except in standing position. The physiotherapeutic care was essential to restore the functional and ludic activities of the child, and to help in respiratory disorders.

Stoffel and Nickel (2013)<sup>24</sup> worked on gathering data correlating the structure and terminology of the ICF, the principles of the Model of Human Occupations, and the Motor Learning Approach for Motor Behavior Recovery. The learning and adaptation processes are stimulated by including the performance of daily activities and the development of habits in the routine of the subject with a neurological condition. This inclusion allows the subject to acquire and organize new satisfactory performance standards for their participation.

Zampieri, Santos and Pfeifer (2016)23 used the Social and Functional Performance protocol for children with Cerebral Palsy (DSF-PC, Portuguese abbreviation) with 30 caregivers of children with CP, and 30 who took care of children with typical development. The DSF-PC is considered to be sensitive to detect differences between children with CP and children with typical development, presenting differences in 12 to 16 domains. The study demonstrated that children with CP present a lower level of functional development and lower social participation, when compared to the control group. Hence, it was found that the DFS-PC is considered valid for use with children with CP.

# CATEGORY: PROFESSIONAL - thematic variable: research.

In the theme related to researches, the studies aimed at: demonstrating how the universal language of the ICF-CY may increase the specificity with which researchers and clinics describe the varying manifestations of the Agenesis of the Corpus Callosum (ACC); examining and synthesizing the knowledge available in literature concerning the instruments used in relation to functionality in children with CP; identifying the concepts of outcome measurements in clinical trials in osteogenesis imperfecta (OI), analyzing how these concepts relate to ICF-CY and describing which functioning components are mostly assessed; associating the subcategories of the ICF to the items of the Assessment of Motor Coordination and Dexterity (abbreviated in Portuguese as Acoordem) and determining whether the items of the Acoordem fit into the structure of the ICF; seeing how the content of the deficiency measures differed in five researches in the USA and throughout time; carrying out a systematic review regarding the use of ICF in observational studies; evaluating up to what point the instruments intended for measuring the participation of children are actually effective, and whether their items can be classified according to ICF-CY; cataloging the ICF codes regarding Dentistry; verifying whether the ICF scales and the Gross Motor Function Classification System (GMFCS) are related, and verifying whether the functional objectives are properly related to the two standard measures; examining and comparing the content of the Quality of Life in Short Stature Youth (QoLISSY) questionnaires to the ICF-CY; identifying the most relevant categories of the ICF-CY for evaluating patients<sup>25-35</sup>.

In the study by Kovac and Simeonsson (2014), it was carried out a review of 83 studies about the neuropsychological manifestations and development of Agenesis of the Corpus Callosum (ACC) in children and adolescents. The extension to which the findings about ACC could be documented using taxonomy codes of the ICF-CY was examined. There was a high degree of correspondence between the reported findings and the taxonomy codes of the ICF-CY. This use identifies ICF-CY as a common language for researchers and clinics who work with children with ACC<sup>25</sup>.

Santos et al. (2014)<sup>27</sup>carried out a study with clinical trials performed between 2000 and 2013 in children with osteogenesis imperfecta (OI). The concept of clinical and technical measures and of a standardized

assessment tool (Pediatric Evaluation of Disability Inventory - PEDI) was identified, and the concepts of clinical and technical measures were related to the Functions and Body Structures ICF-CY component, especially Activity and Participation. By means of connecting these outcome measure concepts with the ICF-CY, it was noted that the clinical trials in OI evaluate mainly the Functions and Structures of the Body component<sup>27</sup>.

In the study by Santos et al. (2015)35, five specialists chose a second level list of the ICF-CY, with the most relevant questions for assessing the functioning of children and adolescents with OI. The ICF-CY components with the greatest number of relevant categories for the OI may be elaborated based on the perspective of specialists. This step is important for clarifying what must be evaluated in children and adolescents with OI. Carneiro et al. (2012)32 cataloged the ICF codes referring to Dentistry. In order to choose the topics of each component, three researchers separately elected those they considered pertinent and related to the practice of Dentistry. The ICF is immediately used in many health related fields and must be more closely connected to Dentistry once there are more objectives built around this theme.

Cardoso et al. (2012)<sup>28</sup> made an independent codification of the items in the Acoordem, connecting them to the ICF components, namely: Function of the Body, Activity and Participation, Environmental Factors and Personal Factors. The Structure of the Body component was not related, and three items were not covered by the ICF. The professionals and researchers in the rehabilitation field may use the Acoordem to collect data concerning activity and participation in children with motor coordination problems, since its terminology and scope is in agreement with the biopsychosocial perspective of the WHO<sup>28</sup>.

Chien et al. (2014)31 carried out a systematic study from January, 2000 to May, 2011, made in the terms of the participatory research, outcome measurement and children, aiming to identify the potential participation of those children. The instruments were obtained through identified full text articles and were assessed for inclusion by means of group discussion. These items were also classified in accordance with the rules for correlation with the ICF-CY in order to reflect the content coverage of each instrument. In this study, the participation items in each instrument captured from 3 to 9 domains of the ICF-CY, Activity and Participation. Only the Child and Adolescent Scale of Participation

and the Participation and Environment Measure for Children and Youth covered all the domains. When choosing the participation instrument, the existing differences between the participation items in child participation measures must be considered, as well as their classification in accordance with the ICF-CY<sup>31</sup>.

Verdiani et al. (2016)33 collected and compared the functional objectives outlined by physiotherapists and the ICF codes established by them and the researchers. Once it dealt with a population of children and adolescents with CP, aged from 3 to 17 years, the authors used the ICF-CY to classify the functional objectives However, there were cases in which the proposed objectives had no befitting code in this version; hence, the researchers consulted the full version of the ICF. A good correlation between the measures was noted. Nonetheless, there was significant discrepancy between the codes chosen by the therapists and the researchers. This may be related either to the difficulty in applying the ICF in practical terms, or the therapists' difficulty when outlining the functional objectives.

In the study by Sommer et al. (2015)34, the items of the QoLISSY for children and adolescents and their parents were codified in the context of the ICF-CY. This connection was made in compliance with the standards pre-established by two health professionals experienced in the conceptual bases of the ICF-CY. This linking process indicates that the ICF-CY furnishes a useful reference framework for comparing and examining the content of the HRQoL instruments for short stature children and adolescents and their parents. The connection of the QoLISSY instrument in the context of the ICF-CY translates its content into a universal language.

Brandt et al. (2014)29 used the ICF as a conceptual framework to measure the deficiency. The National Health Interview Survey (NHIS), the Current Population Survey (CPS), the Survey of Income and Program Participation (SIPP), the National Survey of Supplemental Security Income Children and Families (NSCF), and the American Community Survey (ACS) were evaluated regarding coverage of deficiency contents in relation to each of the four ICF components, namely: Body Functions, Body Structures, Activity and Participation, and Environment. The incapacity measures varied from one research to another and from one year to another. The NHIS attained a greater proportion of body functions from the ICF and from the body structures components. The SIPP had greater content of the ICF activities and participation

components, and the NSCF held more components of the environmental factors. It was successfully illustrated the usefulness of the ICF in the content analysis of the deficiency measures<sup>29</sup>.

Castanedal, BergmannII and Bahia (2014)30 carried out a systematic review of articles that used the ICF in observational studies. The most frequent fields of study were rheumatology (24%) and orthopedics (21%); in this case, 83% of the articles were cross-sectional studies. It was found that there was an increase in ICF-related scientific production over the last 10 years and different fields of knowledge are involved in the debate concerning improvements in the information about morbidity.

In the study by Dornelas et al. (2014)26, a search was carried out on electronic databases for articles published between January, 2006 and December, 2012. Based on their findings, the authors proposed instruments that could standardize assessment for classifying the components: Body Function and Body Structure, Activity and Participation, and Environmental Factors. The Body Function and Body Structure component, and the Activity and Participation one, are more frequently classified in agreement with the ICF in children with CP, and they offer a variety of instrumentations for applying the ICF30.

#### CONCLUSION

The ICF-CY does not classify children and youth, as this classification is done through categories within the domains of health. Instead, it intends to describe the situation children or youth find themselves in, within a range of environmental and personal domains and contexts.

The need of previous training to the professionals became evident, for them to apply the ICF-CY properly, as well as awareness of these professionals for this end. In this regard, it is fundamental to create and implement strategies among professionals in order to facilitate and make more practical the use of ICF-CY in the therapist's daily routine. Thus, the possibilities are broadened, as well as the orientations offered to the relatives concerning the care for the patient.

It was found that, due to unfamiliarity, the ICF-CY is still little widespread among therapists who work with youth and children. Among those who know it, its use was partial, i.e., they made use of the ICF for children and youth, but did not use the classification specific for the age group. And little was written describing it as a reorientation tool for the care of children and youth.

It is concluded that the findings of this review point to a small scientific production related to the ICF-CY throughout the last 10 years. Nevertheless, regarding the analyzed works, this classification's usefulness in many fields and sectors is perceivable, and not only in health-related fields. The development of additional studies is suggested, aiming at better knowing secondary data related to functioning and disability of children and youth, through promoting ICF-CY and training for its use, in order to offer support to families in their everyday routine of caring for children and youth with deficiency.

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