



**Linking autism measures with the ICF-CY: Functionality beyond the borders of diagnosis and Interrater agreement issues**

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Table 1: Cohen's Kappa values for ICF-CY codes mapped with ADOS

<b>ICF-CY codes mapped with meaningful concepts (Body Functions):</b>	<b>Kappa Cohen (N=44)</b>	<b>ICF-CY codes mapped with meaningful concepts (Activities and Participation):</b>	<b>Kappa Cohen (N=44)</b>
b114 – Orientation Functions	1	d161 – Directing attention	0
b122 – Psychosocial Functions	0	d250 – Managing one's own behavior	0.66
b126 – temperament Functions	0.66	d315 – Receiving non-verbal messages	0
b130 – Energy and drive functions	0	d330 - Speaking	0.51
b147 – Psychomotor Functions	0.38	d331 – Pre-vocalizations	0.79
b152 – Emotional Functions	0.65	d335 – Producing non-verbal messages	0.40
b160 – Thought Functions	0.65	d350 - Conversation	0.78
b164 – Higher cognitive functions	0	d571 – Looking after one's safety	1
b167 – Language Functions	0.85	d710 – Basic Interpersonal Interactions	0.47
b330 – Fluency and Rhythm of speech functions	0	d720 – Complex Interpersonal Interactions	1
b765 – Involuntary movement reactions functions	0.32	Nd – Non definable	0

Table 2: Cohen's Kappa Values for ICF-CY codes mapped with CARS

<b>ICF-CY Codes mapped with meaningful concepts (Body Functions):</b>	<b>Kappa Cohen (N=55)</b>	<b>ICF-CY Codes mapped with meaningful concepts (Activities and Participation):</b>	<b>Kappa Cohen (N=55)</b>
b117 – Intellectual Functions	0.13	d130 - Imitation	1
b122 – Psychosocial Functions	0	d131 – Pre-vocalization	1
b125 – Intrapersonal dispositions	0	d160 – Directing attention	0
b126 – Temperament and personality functions	0	d230 – Managing routines	0
b130 – Energy and Drive Functions	0	d240 – Handling stress and other psychological demands	0
b140 – Attention Functions	0	d250 – Managing one's own behavior	-0.02
b147 – Psychomotor functions	0	d315 – Receiving non-verbal messages	-0.02
b152 – Emotional Functions	0	d330 - Speaking	0.79
b156 – Perceptual Functions	0	d335 – Producing non-verbal messages	0.48
b160 – Thought functions	0	d415 – Maintaining a body position	0
b167 – Language Functions	0.19	d571 – Looking after one's safety	-0.02
b280 – Sensation of pain	1	d710 – Basic Interpersonal Interactions	0,54
b765 – Involuntary Movement Functions	0.26	d720 – Complex Interpersonal Interactions	-0.02
b770 – Gait pattern functions	0	d880 – Engagement in play	0
		nc	1

Table 3: ADI-R meaningful concepts linked with the ICF-CY

	N	Nc (Not covered)	Nd (Non- definable)	Activities & Participation	Body Functions	Environmental Factors
<b>Items</b>	93	28 (30.1%)	33 (35.5%)	48 (51.6%)	52 (55.9%)	1 (1.1%)
<b>Meaningful Concepts</b>	214	28 (13.1%)	84 (39.3%)	67 (31.3%)	62 (28.9%)	1 (0.5%)

Table 4: ADOS' meaningful concepts linked with the ICF-CY

<b>Meaningful concepts</b> N=44	<b>Nc (Not-covered)</b>	3 (6.8%)
	<b>Body Functions</b>	21 (47.7%)
	<b>Activ./Part.</b>	19 (43.2%)
	<b>Environmental Factors</b>	0

Table 5: CARS' meaningful concepts linked with the ICF-CY.

<b>Meaningful Concepts</b> N= 55	<b>Nc (Non-covered)</b>	1 (1.9%)
	<b>Body Functions</b>	49 (96.1%)
	<b>Activities and Participation</b>	22 (43.1%)
	<b>Environmental Factors</b>	0

Table 6: Codes from the ICF-CY code set for ASD (Castro & Pinto, in prep.) identified in each measure.

CODE-SET CHAPTERS	Number of codes from the code-set found in each measure		
	ADOS	ADI-R	CARS
<b>ACTIVITIES &amp; PARTICIPATION</b>			
d1 Learning and applying knowledge (5*)	3	4	3
d2 General Tasks and Demands (5*)	3	1	2
d3 Communication (6)	5	6	3
d5 Self-care (4)	2	1	1
d7 Interpersonal Interactions (4)	3	2	1
d8 Major Life domains (3)	1	1	0
d9 Community, Social and Civic Life (1)	0	0	0
<b>BODY FUNCTIONS</b>			
b1 Mental Functions (11)	9	8	9
<b>ENVIRONMENTAL FACTORS</b>			
e3 Support and relationships (7)	0	0	0
e4 Attitudes (8)	2	0	0
e5 Services, Systems and Policies (4)	0	0	0

\* Number of codes-sets found by experts to be essential for assessment of ASD in the ICF-CY chapter

Table 7: Frequency of meaningful concepts coded with the code-set codes in each measurement.

Code-set	Meaningful concepts		
	ADI-R	ADOS	CARS
d120	0	0	0
d130 - Imitation	2	0	4
d131 – Learning through actions with objects	0	2	2
d132 – Acquiring information	0	1	0
d133 – Acquiring language	0	1	0
d135 - Rehearsing	0	0	0
d137 – Acquiring concepts	0	0	0
d155 – Acquiring skills	0	0	0
d160 – Focusing attention	1	0	3
d161 – Directing attention	0	1	0
d163 - Thinking	2	0	0
d175 – Solving problems	0	0	0
d177 – Making decisions	0	0	0
d210 – Undertaking a single task	0	0	0
d220 – undertaking a multiple task	1	0	0
d230 – Managing routine	1	0	1
d240 – Handling stress and other psychological demands	0	0	1
d250 – Managing one’s own behavior	7	1	0
d310 – Receiving spoken messages	3	2	0
d315 – Receiving non-verbal messages	1	1	1
d330 - Speaking	8	11	2
d331 – Pre-vocalization	0	7	0
d335 – Producing non-verbal messages	12	17	3
d350 - Conversation	1	2	0
d530 - Toileting	3	0	0

d540 – Dressing/undressing	0	0	0
d550 - eating	0	0	0
d571 – Looking after one’s safety	1	1	1
d710 – Basic Interpersonal Interactions	12	19	4
d720 – Complex Interpersonal Interactions	10	1	0
d750 – Informal Social relationships	3	0	0
d760 – Family relationships	0	0	0
d810 – Informational Education	0	0	0
d815, d816 – Preschool education/life	0	0	0
d880 – Engagement in play	3	1	0
d920 – Recreation and leisure	0	0	0
b114 – Orientation functions	0	4	1
b117 – Intellectual Functions	0	0	1
b122 – Psychosocial Functions	9	13	2
b125, b126 – Intrapersonal dispositions and temperament Functions	6	0	6
b140 – Attention Functions	1	3	3
b144 – Memory Functions	1	0	0
b147 – Psychomotor Functions	3	3	7
b152 – Emotional Functions	3	4	6
b160 – Thought functions	8	3	1
b163, b164 – Basic and Higher level cognitive functions	2	2	0
b167 – Language Functions	17	15	6
e310 – Support of the immediate family	0	0	0
e315 – Support of the extended family	0	0	0
e320 – Support of friends	0	0	0
e325 – Support of acquaintances, peers, colleagues	0	0	0
e330 – Support of people in position of authority	0	0	0
e340 – Support of personal care providers and personal assistants	0	0	0
e355 – Support of health professionals	0	0	0
e410 – Individual Attitudes of immediate family members	1	0	0
e415 – Individual Attitudes of extended family members	0	0	0



e420 - Individual Attitudes of friends	0	0	0
e425 – Individual Attitudes of acquaintances, peers, colleagues	0	0	0
e430 – Individual attitudes of people in position of authority	0	0	0
e440 – Individual attitudes of personal care providers and personal assistants	1	0	0
e450 – Individual attitudes of health professionals	0	0	0
e455 – Individual attitudes of other professionals	0	0	0
e570 – Social security services, systems and policies	0	0	0
e575 – General social support services, systems and policies	0	0	0
e580 – Health services, systems and policies	0	0	0
e585 – Education services systems and policies	0	0	0

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3 Abstract

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5 Purpose: This study aims to: (1) link measurements used in the diagnosis of children  
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7 with Autism Spectrum Disorders (ASD) with the International Classification of  
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9 Functioning, Disability and Health – Children and Youth Version (ICF-CY) and (2)  
10  
11 analyze issues concerned with interrater agreement within this process.

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14 Method: Three instruments for ASD diagnosis were linked with the ICF-CY using  
15  
16 deductive content analysis.

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18 Results. Correspondences between items' content and ICF-CY dimensions were  
19  
20 identified for all ICF-CY components, except for environmental factors. Interrater  
21  
22 agreement varied with the content of the units analyzed.

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25 Conclusion. The linkage between the ICF-CY and the analyzed measures provides a  
26  
27 way to document assessment-intervention outcomes using a common language, as  
28  
29 well as to integrate diagnostic and functional data. Diagnostic measurements provide  
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31 functional information beyond the diagnostic criteria defined for autism. A functional  
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33 perspective is added to diagnostic outcomes, thus better informing educational and  
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35 rehabilitation practices for children with ASD.  
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## Introduction

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

The International Classification of Functioning, Disability and Health- Children and Youth Version (ICF-CY) [1] is part of the “Family of International Classifications” of the World Health Organization (WHO), along with the International Classification of Diseases and Related Health Problems, 10th version (ICD-10) [2]. WHO recommends the use of both classifications in clinical practice and service delivery, as they focus on different but complementary aspects of health. While the ICD-10 classifies symptoms grouped by diagnostic categories, the ICF-CY classifies specific characteristics of functioning within a given health status. The publication of the ICF [3] and the ICF-CY [1] reflects a shift in the purpose of classifications from the medical model perspective advocated by the ICD to a biopsychosocial model of disability [1]. In this paper, particular interest has been given to mapping content of extant diagnostic measurements for Autism Spectrum Disorders (ASD) with the ICF/ICF-CY classification system. This study intends to illustrate the complementary nature between this classification and medical classification systems such as the ICD and the Diagnostic and Statistical Manual of Mental Disorders (DSM) [4].

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3 Main ICF-CY lines of research  
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7 The ICF [3] and the ICF-CY [1] have been applied in many countries in research, as  
8 well as in clinical and educational practice. As the most recent classification system of the  
9 WHO, the ICF and ICF-CY classify aspects of functioning independently of diagnostic  
10 categories. Based on a biopsychosocial model, the ICF/ICF-CY classification approaches  
11 disability from a multidimensional perspective. This classification focuses on biological,  
12 psychological and social/environmental aspects of functioning, and thus is intended to  
13 complement the WHO's medical classification system, the ICD-10 [2]. The ICD-10 classifies  
14 disability within a medical model by grouping individual symptoms into categories. By  
15 considering disability as a result of person-environment interactions, both the ICF and the  
16 ICF-CY document various dimensions of human functioning, organized in three components:  
17 (a) Body Functions and Body Structures; (b) Activities and Participation and (c)  
18 Environmental Factors [1] [3].  
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34 Literature has been focusing on different aspects regarding the application of the ICF  
35 and the ICF-CY, namely: (a) the theoretical background of the ICF and the ICF-CY, (b) the  
36 conceptual distinction between Activity and Participation, (c) the practical utility of the ICF  
37 and ICF-CY for rehabilitation/health/education services, (d) the validation of the structure and  
38 components of the ICF and ICF-CY (d) the development of new measures, and (e) the linkage  
39 of extant measures with the ICF and ICF-CY.  
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47 Regarding the conceptual framework of the ICF/ICF-CY[5] refers to the shift in  
48 paradigm that led to the development of the biopsychosocial model of disability, as it is  
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3 known today through its operationalization in the ICF/ICF-CY model and taxonomy. The  
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5 predominant framework of disability beginning in the nineteenth century, the medical model,  
6  
7 conceptualized disability as a deficit within the individual. In response to the existing reliance  
8  
9 on medically-based interventions for disability, the social model of disability began to take  
10  
11 root in the 1960s. According to this model, disability results not from individual functional  
12  
13 limitations, but from the inability of society to accommodate these limitations. Subsequently,  
14  
15 in the 1990s, a group of studies began to integrate principles of the medical model with  
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17 principles of the social model of disability into a functional framework, the biopsychosocial  
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19 approach to disability. Such issues about the need for a multidimensional framework to  
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21 conceptualize disability [6] that were raised in the 1970s by Engel [7] received several  
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23 contributions from authors who underlined the relevance of considering contextual factors  
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25 and person-environment interactions as developmental components. The Bioecological [8]  
26  
27 and the Transactional Models of Human Development were important contributors to the  
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29 biosychosocial formulation [9] [10]. These approaches are the framework for the  
30  
31 establishment of the ICF/ICF-CY [11] [5].  
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36 Another group of studies addressed the conceptual distinction between the *Activity*  
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38 and *Participation* constructs, arguing that, in spite of the fact *Activity* and *Participation*  
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40 domains are fused together in the same ICF/ICF-CY component, they should be defined  
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42 differently. WHO [3] defined Activity as the “execution of a task” and Participation as  
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44 “involvement in life situations”. Badley [12] suggested Participation is more context-  
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46 dependent and socially-oriented than Activity, while activity (execution of a task) may  
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48 influence the level of participation in a life situation. McConachie [13] suggested that  
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3 Participation implies volition, being closer to behaviors involving choice, while Activity is  
4 closer to automatic behaviors related to daily routines. Other studies have investigated which  
5 instruments, in general, are more likely to assess participation issues [14], while new  
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10 measures of participation are also being developed [15] [16].

11 Applied research studies, although still scarce, have suggested ways to implement the  
12 use of the ICF/ICF-CY in rehabilitation or educational services [17] [18]. These studies  
13 demonstrated the ICF/ICF-CY framework can serve as a valuable tool for service  
14 implementation, by illustrating how the classification may be used in documenting  
15 assessment outcomes and in planning and monitoring interventions.  
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22 Ibragimova, Granlund and Bjorck-Akesson [19] studied the logical coherence,  
23 developmental issues and clinical use of the ICF with professionals providing interventions to  
24 children with disabilities. The authors concluded through factor analysis that data based on  
25 the clinical usage of the ICF appropriately corresponded with the original ICF three-factor  
26 structure. The authors also found that the ICF enabled the distinction among different levels  
27 of functioning. Thus, it provided the identification of patterns of functioning among children  
28 in different age groups: children younger than three years old, children three to seven years of  
29 age, and children seven to 12 years of age.  
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40 A few studies have been conducted to develop measures for diverse health conditions  
41 (e.g., ankylosing spondylitis and multiple sclerosis) based on the ICF version for adults [20]  
42 [21]. However, studies focusing on the development of new measures based on the ICF-CY  
43 are still rare. In the childhood field, Bedell, Khetani, Cousins, Coster, and Law [22] studied  
44 parents' perspectives in order to inform the development of new measures of Participation  
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3 and Environment for children and youth. Nevertheless, more studies are necessary in order to  
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5 support the development of new measures based on the ICF-CY taxonomy.  
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8 Although also rare, there are already a number of studies that link existing measures  
9  
10 with the ICF-CY version [23] [24]. These studies have demonstrated that some of the content  
11  
12 of extant measures used to assess child functioning (e.g., Carolina Curriculum for  
13  
14 Preschoolers with Special Needs) can be mapped to the ICF-CY components (Body  
15  
16 Functions, Activities and Participation, and Environmental Factors). By focusing on this line  
17  
18 of research, the present study has added value to document functioning aspects in currently  
19  
20 used diagnostic/assessment measurements for children, thus contributing for planning  
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22 interventions in early childhood intervention and special education for young children with  
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24 ASD.  
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28 Based on the Transactional Model [10] of development and on the biopsychosocial  
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30 model of disability, in the present study it is assumed that diagnostic categories are best  
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32 conceived as a starting point for the assessment-intervention process and would benefit from  
33  
34 additional information regarding children's functioning in their real life environments. The  
35  
36 World Health Organization states ICD-10 diagnostic criteria serve purposes related to the  
37  
38 analysis of general population health, namely the monitoring of the incidence and prevalence  
39  
40 of diseases and the creation of a common language for legal documents and  
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42 mortality/morbidity statistics [25]. Diagnoses are relevant as they establish the main  
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44 developmental domains where there is a significant statistical probability of functional  
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46 problems to occur. Although the DSM-IV-TR already considers factors of the environment  
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48 and individual functional delays (Axis IV and V), it fails to document specific and detailed  
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3 aspects of the child's participation in daily life situations and to account for more specific  
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5 environmental aspects that influence participation using a common language. Another type of  
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7 classification was necessary to address these issues in a complementary way with the WHO's  
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9 ICD-10. Also, in the US and Canada, as well as in some EU countries, diagnosis is a  
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11 necessary condition for children to receive any sort of educational intervention or  
12  
13 rehabilitation services. However, according to the World Health Organization, establishing a  
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15 diagnosis is a necessary but not sufficient condition, since diagnostic procedures/tools may  
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17 not provide a complete set of information for educational and developmental interventions in  
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19 children's daily life situations [25], in a language that may be understood across disciplines.  
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#### 25 A Biopsychosocial Approach to Autism Spectrum Disorders

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27 Autism Spectrum Disorders are classified under the Mental and Behavioral Disorders  
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29 (Chapter V) in the ICD-10 and coded as F84 – Pervasive Developmental Disorders. In the  
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31 DSM-IV-TR, ASD are classified within the Pervasive Developmental Disorders (PDD).  
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33 These include Autistic Disorder, Pervasive Developmental Disorders, Not Otherwise  
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35 specified (PDD-NOS), Asperger's Disorder, Rett's Disorder, and Childhood disintegrative  
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37 disorder. This variability of types of pervasive developmental disorders reflects the  
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39 uniqueness of this population, underlining the relevance of studying these types of disability  
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41 in light of the Biopsychosocial Model. In fact, there are several disparities in functioning of  
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43 children diagnosed within this group [26] [27]. Numerous intervention programs have been  
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45 designed for individuals with ASDs [28]. However, according to Etscheidt [29] the structured  
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47 nature of such programs may restrict the individualization of the intervention procedures. The  
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3 diagnostic criteria perhaps may be complemented by the functional information documented  
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5 with the ICF-CY classification system, thus enabling the individualization of programs by  
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7 identifying unique differences in functioning. In fact, the ICF/ICF-CY taxonomy provides a  
8  
9 common language to describe specific functional characteristics of individuals within  
10  
11 diagnostic categories and, according to this perspective, both classifications (ICF and ICD)  
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13 are useful and should be applied in a complementary way to document the person's  
14  
15 functioning within a holistic perspective. In line with this approach, Baron and Linden [30]  
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17 proposed the integration of the ICD and the ICF language - while the ICD categorizes  
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19 symptoms into diagnostic categories, the implications of these symptoms on individual  
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21 functioning can be identified through the ICF taxonomy.  
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25 The complementary usage of diagnostic classifications with the ICF-CY is in line with  
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27 the Biopsychosocial Model and its assumptions of framing the individual within all  
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29 dimensions of life. According to Simeonsson et al. [11], the purposes of a classification  
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31 system are to serve both as a framework to identify variables as part of the development of  
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33 assessment measurements for children and as an organizing tool to document dimensions  
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35 assessed in extant measurements by linking assessed variables with the ICF language. Thus,  
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37 the ICF has an important application in contributing to the "growing interest in identifying  
38  
39 children on the basis of functional profiles rather than diagnostic labels" [11, pp. 607].  
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#### 44 45 Study Aims

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47 The present study aims to link extant measurements used in the diagnosis of Autism  
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49 Spectrum Disorders (ASDs) in children, with the ICF-CY classification system, in order to  
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3 identify functional aspects of these tools that may improve the documentation of children's  
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5 functioning and complement diagnostic information to inform educational interventions.  
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7 Three specific goals were formulated: (1) to identify the functionality dimensions assessed by  
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9 three ASD diagnostic instruments, (2) to study the agreement-level between ICF-CY trained  
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11 researchers when assigning content to the ICF-CY functioning dimensions, and (3) to  
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13 document items that assess functionality aspects regarded as "essential" for the assessment-  
14  
15 intervention process with children with ASDs. These essential aspects to be considered in the  
16  
17 assessment-intervention with these children were described by international experts in the  
18  
19 field, when asked to define the code set of ICF-CY codes for ASDs from ages zero to six  
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21 [31].  
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## 27 Method

### 31 Design

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33 This study follows a mixed method approach, specifically a sequential exploratory  
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35 design [32], in which the quantitative results assist the qualitative data interpretation.  
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37 Therefore, each step of the procedure is characterized by an initial phase of qualitative data  
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39 collection and analysis, followed by a quantitative phase. The results are then interpreted  
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41 through an integration of the conclusions from the qualitative and quantitative phases.  
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### 47 Measures

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3 The measures were selected based on a previous study conducted by our team where  
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5 33 school records of children referred as having some characteristics on the autism spectrum  
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7 from 2 to 6 years of age were analyzed [33]. Within this study, six formal assessment  
8  
9 measures were identified as sources of information regarding these children's assessments.  
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11 Three of those measurement tools are widely used as diagnostic tools for ASDs in preschool  
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13 children and were linked to the ICF-CY classification system in the present study: the Autism  
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15 Diagnostic Observation Schedule (ADOS) [34], the Autism Diagnostic Interview Revised  
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17 (ADI-R) [35] and the Child Autism Rating Scale (CARS) [36]. The ADOS is a semi-  
18  
19 structured, standardized tool for the assessment of communication, social interaction, play and  
20  
21 imaginative use of materials in toddlers from 24 months up to adulthood. It consists of four  
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23 modules, each with its own protocol, which can be administered in 35 to 45 minutes. A  
24  
25 trained examiner must choose the module that is more adequate, based on the child's  
26  
27 expressive language level. The authors suggest that the Vineland Adaptive Behavior Scales  
28  
29 [37] could be useful for initial screening of the expressive language level of the child. Each  
30  
31 ADOS item has a coding system. Final algorithms identify the cut-off for an ASD [34]. The  
32  
33 ADI-R often complements the assessment of the ADOS. The ADI-R is a structured interview  
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35 for parents or caregivers and comprises 93 items. The instrument is designed to collect the  
36  
37 full developmental history of the individual and focuses on three domains of functioning –  
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39 language/communication; reciprocal social interactions; and, restricted, repetitive and  
40  
41 stereotyped behaviors and interests. These are the domains specified as diagnostically relevant  
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43 in the ICD-10. Approximately half of the items are scored in the algorithm form. The  
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45 instrument is valid for adults and children with a minimum mental age of two [35].  
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3 The Childhood Autism Rating Scale (CARS) comprises 15 items designed to assess  
4 the level of autistic characteristics on a seven-point scale, from normal to severe. Raters are  
5 professionals who work with the child. The purpose of the assessment is to distinguish  
6 children with autism from children with other developmental disabilities. Scores range from  
7 15 to 60. Scores of 30 or higher are considered to be on the autism spectrum [36].  
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#### 14 Procedure

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18 Two independent researchers with wide knowledge and training in the ICF-CY model  
19 and classification system independently linked each ASD measurement's items with the ICF-  
20 CY functioning dimensions. This linkage process followed a manifest/deductive content  
21 analysis procedure, as well as an adaptation of the "linking rules" developed for the specific  
22 purpose of connecting content with the ICF [38], as described in the procedure conducted by  
23 Castro, Pinto and Maia [23]. The principles of content analysis described by Granheim and  
24 Lundman were also applied [39]. Therefore, the process followed the following steps. First,  
25 within each Unit of Analysis (the instruments' items), researchers identified units of meaning,  
26 (i.e. words, sentences or paragraphs) that are "codable" considering the ICF-CY taxonomy as  
27 a pre-defined matrix of categories. These units of meaning were then matched to ICF-CY  
28 dimensions of functioning by being assigned a code based on the ICF-CY taxonomy. The  
29 notion of 'unit of meaning' is similar to the one of 'meaningful concept' explained by Cieza  
30 and collaborators [38]. Each unit of meaning could be mapped to one or more ICF-CY  
31 dimensions. Also, according to the linking rules, the units could be coded as non-definable  
32 (nd), in case there was no ICF-CY dimension that adequately matched their content. Such  
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3 items provided valuable information for ICF-CY improvement, as they illustrate aspects of  
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5 functioning that the classification is not able to address. Additionally, the meaning units could  
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7 also be coded as non-covered (nc) in cases where the information conveyed in the item was of  
8  
9 a nature that did not allow its classification (e.g., time is not classified within the ICF-CY  
10  
11 model). After the independent linkages were completed, the two researchers discussed  
12  
13 differences in their coding, in order to obtain consensus regarding a final set of codes. In case  
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15 researchers could not reach consensus, a third researcher, also knowledgeable on the ICF-  
16  
17 CY, determined the final code.  
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21 For the ADI-R, a slightly different procedure was followed in the linkage process.  
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23 Since the ADI-R is a semi-structured interview the information gathered through  
24  
25 parent/caregiver responses provides more functional information than what the formulated  
26  
27 item/question provides. Thus, the functional information the content of each item/question of  
28  
29 this interview provides is the minimum amount of functional information that may be  
30  
31 gathered, Parent/caregivers' response may provide even more functional information, beyond  
32  
33 what is written in the question at stake. Similarly to the procedure used for the ADOS linking  
34  
35 process, each item of every ADI-R module was linked to the ICF-CY through deductive  
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37 content analysis. However, observation of child behavior might enable the coding of other  
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39 functional characteristics that the item, as it is written, does not directly assess. The ICF-CY  
40  
41 dimensions that are present in each ADOS item comprise the minimal functional information  
42  
43 that the item enables observers to collect, but observation of child behavior triggered by that  
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45 item may provide the observation of other functional characteristics. Lastly, each CARS item  
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47 was analyzed and the meaningful concepts identified were directly linked to the ICF-CY  
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3 dimensions. Due to the fact that CARS is a rating scale, it was not expected to provide as  
4  
5 much functional information as the ADI-R (interview) or the ADOS (observation measure).  
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7 Final codings of ICF-CY components (Body Functions & Body Structures, Activities &  
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9 Participation, and Environmental Factors) were then quantified and descriptive statistics were  
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11 computed.  
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## 20 Results

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23 Interrater agreement was computed for each ICF-CY code that was mapped with the  
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25 instruments' items, based on the percentage of agreement between the two raters in each  
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27 measure, as well as on the unweighted Cohen's Kappa coefficient. Mean Kappa values is .43  
28  
29 for ADOS and .22 to CARS, but this fact is not very meaningful, because there is much  
30  
31 variety on kappa levels among different ICF-CY dimensions. This fact reflects an important  
32  
33 issue related to the ICF-CY content: the level of Kappa appears to be more dependent on the  
34  
35 content of the ICF-CY functioning dimension at stake than on the ability of the raters to code  
36  
37 meaning units following similar criteria. In fact, certain ICF-CY functionality dimensions  
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39 were frequently coded with higher levels of agreement than others, illustrating that some ICF-  
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41 CY dimensions might need clearer definitions in order to be applied similarly by different  
42  
43 coders. Tables 1 and 2 show the values of Kappa for each ICF-CY code mapped with the  
44  
45 ADOS and CARS, respectively. For the ADOS, the percentage of agreement between the two  
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47 coders in at least one ICF-CY code per unit of meaning was 84.1%. Kappa values ranged  
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3 from 0 (no agreement) to 1 (total agreement). For CARS, the percentage of agreement  
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5 between the two coders in at least one ICF-CY code per unit of meaning was 43.7%.  
6  
7 Concerning the ADI-R, as it has an interview format, it was not feasible to follow the  
8  
9 independent rating procedure, and reliability was based on discussion of criteria between the  
10  
11 two raters.  
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16 *Insert table 1 about here*  
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18 *Insert table 2 about here*  
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23 Results regarding the process of linkage of the ADI-R with the ICF-CY show that the  
24 majority of meaningful concepts identified in this measurement's items are Body Functions  
25 (55.9%) and Activities/Participation (51.6%). *Non-definable* concepts were also found in a  
26 high percentage (39.3%). Among the non-definable meaningful concepts we found: (a) age  
27 (conceptually considered as a Personal Factor within the ICF-CY model; yet, not coded) and  
28  
29 (b) some definitions which are not coherent between the ICF-CY and the ADI-R (e.g.  
30  
31 "stereotypies" are defined as "voluntary movements" in the ADI-R and as "involuntary  
32  
33 movements" in the ICF-CY). Only one dimension of the Environmental Factors component  
34  
35 was matched to the contents of the interview, and it is related to the attitude of the  
36  
37 parent/caregiver towards the child's functioning. Table 3 summarizes the results concerning  
38  
39 the ADI-R content analysis' process.  
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49 *Insert table 3 about here*  
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5 Results of the linkage process between the ADOS and the ICF-CY are summarized in  
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7 Table 4. Similar to ADI-R, the majority of the meaningful concepts identified are Body  
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9 Functions (47.7%) followed by the Activities/ Participation (43.2%). There are no  
10  
11 Environmental Factors assessed through the use of this measure, and 6.8% of the meaningful  
12  
13 concepts are *non-definable*. The *non-definable* concepts were “unusual sensory interest”,  
14  
15 “offering information” and “reports events”. Although the definitions of some ICF-CY codes  
16  
17 were found to be close to the meaning of these concepts, there did not seem to be a perfect  
18  
19 match between such concepts, regarding the context in which they were presented in the item,  
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21 and the ICF-CY codes. The decision of coding them *non-definable* aimed to provide  
22  
23 information on aspects of the classification that may need further improvement.  
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30 *Insert table 4 about here*  
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34 Results of the linking process between CARS and the ICF-CY classification system  
35  
36 are summarized in Table 5. The majority of the meaningful concepts identified are Body  
37  
38 Functions (96.1%). Additionally, 43.1% of the items were linked to the  
39  
40 Activities/Participation component. No Environmental Factors were found in any of the  
41  
42 meaningful concepts identified. One meaningful concept was coded as “nc” (not covered).  
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44 The item was related to the examiner’s judgment regarding the child diagnosis, which cannot  
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46 be coded using the ICF-CY classification system.  
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*Insert table 5 about here*

In another study conducted by our team [31], experts in the field of ASDs at the national and international levels identified a set of ICF-CY codes found to be essential for the assessment-intervention process with children with ASD. Their response to a set of enquires in the scope of a Delphi procedure provided a “code-set” of ICF-CY codes for young children with ASD. Table 6 illustrates the number of functionality dimensions assessed by each of the three analyzed measures that are part of such “code-set”. The dimension of the Community, Social and Civic Life (d920 – Recreation and Leisure) which is included in the “code-set” as it was considered as essential by experts, is not assessed by any of the analyzed measures. The same happens with the Environmental Factors component of the ICF-CY. However, we can observe that all three measures assess most of the Mental Functions (b1) within the Body Functions component considered essential by experts, as well as the dimensions of Learning and applying knowledge (d1) within the Activities & Participation component. We may conclude that the three measures analyzed in the present study are child-focused and diagnostic oriented.

Communication dimensions of functioning are extensively assessed by ADOS as well as by ADI-R, but not so much by CARS. Interpersonal Interaction is frequently assessed by ADOS, but less so with ADI-R and CARS. Table 6 shows the frequencies of meaningful concepts linked with the ICF-CY codes that were included in the code set for ASD, in each measure analyzed, per ICF-CY component, while table 7 shows frequencies of ICF-CY dimensions included in the code-set that were linked to the analyzed measures.

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5 *Insert table 6 about here*  
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## 11 Discussion and Conclusion

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16 Results show all three analyzed measurements for the diagnosis of ASDs provide  
17 information on functional aspects that are not documented in the final coding of each  
18 measurement, because they go beyond the boundaries defined by formal diagnostic criteria.  
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20 Thus, these instruments may provide a way to document functional aspects in a common  
21 language that may inform specific, individualized educational interventions. However, the  
22 ICF-CY proved to be an important tool for the identification and documentation of these  
23 functional aspects in a complementary way with these instruments. As illustrated in the  
24 results section, the ADOS and the ADI-R provide a great deal of information regarding  
25 Activities/Participation, while CARS is much more focused on Body Functions. Therefore,  
26 the ADOS and ADI-R, beyond their utility in diagnosing ASDs, may also have the potential  
27 to create opportunities for the assessment and identification of specific and individualized  
28 functionality aspects of the child. In turn, these aspects may be documented using the ICF-CY  
29 language and taxonomy. Using diagnostic measurements along with the ICF-CY  
30 classification system may help to highlight the wide functional disparities among children  
31 diagnosed with ASDs and to individualize the assessment-intervention process. According to  
32 the diagnostic criteria for ASDs in ICD-10, the three main areas of functioning deficits in  
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3 children with this health condition are Language/Communication, Social Interaction and  
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5 Restricted or Repetitive Behavior/Interests. These areas are considered in the diagnostic  
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7 measurements as a starting point in the process of assessing a child with ASD, because they  
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9 define, according to the ICD and the DSM, the domains where functional problems will be  
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11 more frequent. However, the ICF-CY classification system helps identify specific features of  
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13 functioning within these areas that might differ among children with this same diagnosis. In  
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15 this way, the ICF-CY provides a way to document assessment-intervention outcomes with a  
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17 common language, as well as to integrate medical and functional approaches, even when a  
18  
19 structured intervention program is being applied. The ICF-CY classification system is not  
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21 incompatible with a diagnostic approach, neither with the administration of standardized  
22  
23 intervention programs. On the contrary, it may highlight the uniqueness of each child,  
24  
25 especially when the classification system is linked with the assessment measurements used.  
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27 The fact that not all dimensions of functioning within the ICF-CY have the same level of  
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29 interrater agreement when assigning them to instruments' items, may be illustrative of the  
30  
31 complexity of the Classification, reflecting the multidimensionality of reality, thus  
32  
33 encompassing a spectrum of more straightforward function concepts and more abstract ones.  
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35 Nevertheless, "a classification is a way of seeing the world at a point in time" [40, p.3] and  
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37 will certainly benefit from improvements informed by research outcomes.  
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45 Some limitation of this study should also be pointed out. The study highlights the ICF-  
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47 CY dimensions that may be documented based on instruments used for diagnosis of children  
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49 with an ASD, thus providing an opportunity for the integration of the medical model with the  
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3 functional approach. However, it is important to note that researchers found numerous  
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5 meaningful concepts in the analyzed measures which were not definable based on the ICF-CY  
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7 taxonomy. For instance, there was no coherence on the definitions of “stereotypic  
8  
9 movements” between the ICF-CY and the ADI-R and whether these are considered as  
10  
11 voluntary or as involuntary movement reactions. This means that the instruments and the  
12  
13 classification were developed based on a different rationale, making it difficult to use them in  
14  
15 a complementary manner. Future revisions of the ICF-CY should include the improvement of  
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17 definitions to clarify concepts to which they refer, by making them compatible with extant  
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19 measurements. Also, data concerning interrater agreement illustrates that some ICF-CY  
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21 dimensions (e.g. b122 – psychosocial functions) often do not allow the raters to agree on their  
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23 application when coding content, while others seem to have good levels of agreement,  
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25 repeatedly (e.g. d710 – Basic Interpersonal Interactions). This fact reflects a need for further  
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27 improvement in some ICF-CY definitions.  
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32 According to [41] qualitative studies should engage in at least two of the eight  
33  
34 formulated procedures to ensure trustworthiness of results. The methodology used in this  
35  
36 qualitative study included some standards to ensure the trustworthiness of the results  
37  
38 obtained. Considering the standards of quality and verification defined by Lincoln and Guba  
39  
40 [42] the study procedure included: (a) peer review: a third researcher reviewed the codings of  
41  
42 the first two independent researchers to help obtain consensus on final coding; (b) external  
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44 audit of process and outcome: all of the procedures were supervised by an external expert in  
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46 child development and psychopathology.  
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3 Generally, the study highlights important aspects regarding the integration of the  
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5 medical approach with the functional approach on the assessment-intervention of children  
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7 with ASDs. However, future research should encompass methods to enable the development  
8  
9 of new tools based on this linkage between diagnostic measures and the ICF-CY classification  
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11 system. New tools should be available for professionals of education and rehabilitation  
12  
13 services based on the functional and environmental aspects of ASDs.  
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