Updating Annex 5: ICF, people with disabilities and UN CRPD: implications for statistics and policies monitoring.

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Abstract

The definition of "persons with disabilities" given by the UN Convention on the Rights of Persons with Disabilities (CRPD) poses a challenge. Without questioning bodily impairment (seen as a precondition), the UN definition focuses on "disabilities" as negative outcomes and describes the restriction to participation and inclusion in society as the result of the presence of barriers and discrimination. ICF also provides a conceptual framework for understanding disability. According to the ICF model, disability and functioning are the negative and positive outcomes of the interactions between an individual with a health condition and contextual factors. Since ICF and UN CRPD are the two pillars of a modern way to approach disability, the practical and political implications of the new definitions are various, first of all for people who "remain" with disabilities.

Introduction

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) states that: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1). Such a definition allows to outline a concept of disability, which, without questioning the physical/mental impairment (seen as a precondition), focuses on the consequences that people with disabilities face in their daily life because of the presence of barriers and discrimination. The consequences, according to the UN definition, are negative and they regard the restriction to participation in life on an equal basis with other persons. Thus, although the UNCRPD does not explicitly define what disability is, it suggests (preamble) that disability is the negative consequence of an interaction between a person with impairments and the attitudinal and environmental barriers. In the UN definition of persons with disabilities, disability has the value of an outcome. A term that clearly shows the real novelty of this definition: that is, that when we talk about people with disabilities, we talk about people with a negative outcome that describes their restriction to participation**.**

To put disability in a framework of human rights produces a new approach to the condition of persons with disabilities. Any barrier or discrimination is responsibility of the society; thus, removing disability is a process in which the individual characteristics (impairments) and the barriers have the same importance. The prevention of disability must be developed taking into account both factors. For this reason, it is important to maintain this important meaning in any definition.

The paper aims to provide some starting points for discussion on the possible implications of such a novelty.

ICF levels of functioning and disability: how is it possible to operationalize the differences between functioning and disability? The operationalization of disability/ties as negative interaction/s.

ICF describes disability as an **umbrella term for impairments, activity limitations, and participation restrictions** (acronym: ImAliPar, imalipar). In the ICF model of disability, impairments, limitations, and restrictions refer to the "interaction between an individual and that individual's contextual factors". Thus, the term disability **refers to the "negative interaction between** an individual and that individual's contextual factors" (acronym: NeIntICoF, neinticof). Therefore, the umbrella term 'functioning' is used to describe the positive interaction between an individual and that individual's contextual factors (acronym: *Picof*).

The terms used in the specific language do not have this meaning. The use of the English terms "disability" and "disabilities" does not eliminate the language barrier to a complete understanding of the bio-psyco-social model of disability. It is necessary to find new "trans-language" terms. Imalipar, Neinticof and Picop are here used as neutral and very bizarre terms to describe the new concepts and overcome the language barrier.

However, the issue of what a positive interaction is and what a negative one is, is not completely dealt with in the "red book". The schema suggested in Annex 2 (ICF, pag. 223) is not sufficient to solve the problem of how to distinguish positive from

negative interactions. The WHO/ESCP training manual for statistics on disability quotes that **"**The ICF is flexible and places no limitation on scope or coverage. Instead, the ICF provides a complete descriptive framework for all aspects of human functioning, a framework that systematically organizes these data. Nonetheless, decisions about scope and coverage are essential, unavoidable, and have a profound effect on the usefulness of resulting data. *These decisions should be driven by the purposes of data collection, and therefore the needs of the ultimate data user."*

Data from national research show that "Although components of the ICF were identified across all data sources, the extent to which they were operationalised and the nature of their use differed greatly" (o'Donovan an Good, 2010).

In the WHO/ESCAP disability statistic manual, it is also clarified that "the ICF does not establish a priori thresholds. The user can determine, for specific purposes and on whatever grounds are relevant to those purposes, where the threshold should be placed for each domain of functioning…. Thresholds can be left to the analysis stage… , thus making the data more flexible, … The data remains comparable though, and in fact is effectively more comparable across sources, by simply applying the same threshold to multiple population samples".

This flexibility is one of the reasons why it is not possible to compare disability statistics and data all over the world (Leonardi et al, 2010). Since disability, like health, lies on a continuum, there is no definitive answer to the question: 'What is the level of functioning, for a specified domain, below which a person can be said to have a disability (or be unhealthy)?'. Of course, at the extremes (total lack of functioning, or complete functioning for a specific domain) the thresholds are logically determined. But, in principle, any line on the continuum could be the threshold one might use to make the cut between 'disability' and 'no disability' (or health and ill-health). Honestly speaking, we think that some suggestions could be useful to data collectors since they influence policy makers. The first suggestion is that we should not use the term disability but its meanings, ie "negative interaction between…" or "negative outcome". The following Table shows how it would be possible to face these problems. In an attempt to solve this enigma, a matrix was realized and here presented for discussion.

Positive aspects = Dimensions of Functioning	**Value of the first qualifier (extent or magnitude of a problem)***		**Negative aspects = Dimension of disability**	**Value of the first qualifier (extent or magnitude of a problem)**		**Severity.. OF WHAT?** Severity of disability = "severity" of the negative interactions etc. = severity of Neinticof**
	Without doubts	Possible		Without doubts	Possible	
Body functions	0	1	Impairments	1		LOW

integrity						
			Impairments		2, 3	MEDIUM
			Impairments	4		HIGH
Body structures integrity	0	1	Impairments	1		LOW
			Impairments		2, 3	MEDIUM
			Impairments	4		HIGH
Activities	0	1	Activities limitations	1		LOW
			Activities limitations		2, 3	MEDIUM
			Activities limitations	4		HIGH
Participation	0	1	Participation restrictions	1		LOW
			Participation restrictions		2, 3	MEDIUM
			Participation restrictions	4		HIGH

* accepted value are 0,1,2,3,4.

** ICF defines disability as the umbrella term that denotes the negative aspects of the interaction etc….

When can an interaction between an individual and his/her environment be defined negative? (When can an interaction between an individual and his/her environment be defined positive?)

Since ICF is one of the pillar of a modern way to approach disability, our proposal is to update some terminological issues, ie the terms disability and functioning used in ICF (Annex 1), in order to clarify and operationalize the novelty of the concepts used in the bio-pycho-social model of functioning.

an interaction can be defined negative if	an interaction can be defined positive if
the extent of the problem is mild to complete (first ICF qualifier 2, 3, 4) and the environmental factors act as barriers (.1 to *.4?).* and/or the environmental factors are mild facilitators (+1 or +2) and/or the environmental factors are absent *(+0?, .0?).* It is possible to use the values .0 and +0.	The extent of the problem is absent or light (first ICF qualifier 0,1) and the environmental factors act as facilitators (+1 to +4) and/or the environmental factors are absent *(+0?, .0?).* It is possible to use the values .0 and +0.

To do that, it would be necessary to combine environmental factors to each ICF category (BF, BF, A&P) chosen to evaluate an individual.

If a negative interaction in a specific domain (ie. specific A&P category) were carefully considered an outcome of the intervention/aid/support systems (formed by a mix of public services and private actions), the interactions described using the ICF with respect to multiple domains and multiple categories in all the ICF components could be considered outcome indicators.

In the light of this, a functioning/disability individual profile may be used to analyze the capacity of the intervention/aid/support systems to produce or not positive interactions, ie bad or good outcomes.

In the light of the bio-psyco-social model of functioning and according to ICF, when can a negative interaction be defined "severe"?

Our proposal is that a negative interaction can be defined severe if the value of the first qualifier is 4

and

the environmental factors act as barriers (.3? *.4?)*

and/or

the environmental factors are absent *(+0?, .0?).*

How many ICF categories are needed to describe functioning and disability in the same individual?

It depends on decisions about the scope and coverage of data collection, and it has a profound effect on the usefulness of resulting data. The list of categories from all the ICF components that data collectors choose must be useful to describe positive and

negative interactions as a continuum in the same individual or in the same sample. In some Italian trials coordinated by WHO-FIC CC, a common ICF based assessment framework is used, in order to become a standard (Frattura et al, 2011 a, b)

Is there any difference between disabled people and persons with disabilities ?

The problem of how to refer to individuals who experience some degree of functional limitation or restriction remains in spite of ICF (ICF, Annex 5, pag 242). There is no universal practice for WHO to adopt the term "people with disabilities" or "disabled people" and it is not appropriate for ICF to rigidly adopt one rather than another approach. Nevertheless, UN CRPD suggests a term to adopt, "persons with disabilities", and stimulates ICF developers and users to deal with this term and the consequences of its use when the bio-psycho-social model of ICF is recommended for monitoring UNCRPD (Griffo et al, 2009, Bickenback, 2011) or for speaking about disability all over the word (WHO/World Bank, 2011). ICF is adopted as the conceptual framework for the World Report on Disability. Defining disability as an interaction means that disability is not an attribute of the person. "The universal approach may seem unconventional or difficult to operationalize, because traditionally we think of disability, not as a matter of more or less, but as a matter of 'yes or no': you are either disabled or not". The issue of how to refer to individuals is really difficult if also the World Report on Disability uses both terms, in spite of the statement by which "defining disability as an interaction means that disability is not an attribute of the person". The problem could be overcome if the implications of the "old term" disability were completely accepted: the problem is not to define an individual, but is to describe and define positive and/or negative interactions.

The Report quotes that "The threshold in each case divides everyone into two classes, those who are disabled (in a certain domain) and those who are not". The question "can disabled people be considered persons with disabilities?" still remains. If the term disabled is considered an attribute of an individual and the term disabilities is used to describe the "*negative interactions between …*" according to ICF, or the negative outcomes according to UNCRPD, then we can say that there is a great difference between the terms "disabled people" and "persons with disabilities". Although "the threshold is arbitrary, and the truth of the matter is that disability, like human functioning, is a continuous not a dichotomous phenomenon" (WHO/ESCAP, 2008), without an agreement on how to read/understand an individual functioning profile coded into ICF, the comparability of data collected using ICF will remain very low.

Another problem is the dynamic character of the condition of disability. An ICF based functioning profile makes in any case a static picture of an assessed person, but the condition of disability can be a process of reduction or increase (Alves et al, 2010). So it is important to describe the situation in the continuum of life, if the person is in a process of empowerment or of impoverishment.

Two case vignettes of persons receiving health and social care are presented to show a way to describe the continuum of functioning and disabilities in an individual profile at a point time. Details are shown in Annex 1. The data are coded into ICF and three qualifiers are used for performance, capacity and performance without assistance. The original data was collected in a national survey conducted by the Italian WHO-

FIC CC (Francescutti et al, 2009, 2011). A new analysis was carried out in order to provide some inputs for an updated discussion, using a new ICF based assessment framework and a specific ICF based web application (Frattura et al, 2011 a), b).

Conclusions

The consequences of the new definitions of disability (according to ICF) and persons with disabilities (according to UNCRPD) are various.

From the public policy point of view, the 'disability' indicator of a country, which should better be defined, points out to what degree "persons with impairments" cannot participate in life and are violated in their human rights. The more the disability, the more segregating a nation/region/town will be. In contrast, the less the disability, the more inclusive a nation/region/town will be. The aims of public policies are to fight disability and to have people with long-term impairments live without disability. Reducing disability is an economical convenience and an indicator of respect of human rights.

From the epidemiological point of view, people with disabilities are the only 'excluded' persons and the barriers are the determinants/risk factors.

From the public services point of view, the aim of individualized care plans is to eliminate/reduce disability, whereas the objectives are to introduce what the UN Convention calls "reasonable accommodations".

"Europe without barriers" and "world without barriers" only mean "Europe and world without persons with disabilities".

If the discriminant between persons with disabilities and persons not yet with disabilities (the WHO stresses that disability is an experience of all human beings) is not bodily impairment but exposure to barrier factors/non barrier factors/facilitators, an ICF/UN CRPD-based epidemiology/statistics on disabilities seen as negative outcomes has to analyze the role and the effect of barrier factors and facilitators.

Some questions could guide new studies:

First of all: How many are the persons with disabilities (IE: with *neinticof*), described using an ICF-based assessment framework, and which are the barrier and discriminatory factors that are the determinants of their condition?

If a person with a physical impairment lives in a society without barriers and discrimination and can fully and effectively participate in society on an equal basis with others by means of appropriate support, can he/she still be considered a person with disability (IE: with *neinticof)*?

If the condition of disability of a person with impairments is associated with the presence of barrier factors, how do the number of people with disabilities (IE: with *neinticof*) and the type of disabilities (IE: with *neinticof*) change with the changing of barrier factors?

If, factors that do not constitute a barrier are present in the life of a person with impairments (because they are facilitators), can that person be

considered without disabilities (IE: with *picof)*?

It is evident that, if the discriminant between persons with disability and persons not yet with disabilities is the exposure to barrier factors/non barrier factors/facilitators, an epidemiology of disability (seen as the outcome of the interaction between a person with health conditions and the environment) and a welfare system aiming at verifying if and to what extent disability has been intercepted and reduced have to analyze the role and the effect of barrier factors/non barrier factors/facilitators. At the same time, because the relationship between people with long-term impairments and environment may change over time, it is necessary to collect information for all the phases of a person's life so that it is possible to see the appearance/reduction/disappearance/presence/absence of disability in the life of a certain person or population.

The terms "disability" and "disabilities" continue to be translated into national terms maintaining old meanings related to bodily impairments. Old terms do not facilitate their use with a new meaning. New neutral terms may be useful.

Annex 1

References:

Alves I., Bosisio Fazzi L., Griffo G., *Human Rights, Persons with Disabilities, ICF and the UN Convention on the rights of persons with disabilities*, Lamezia Terme (CZ) 2010.

Bickenbach J. Monitoring the United Nation's Convention on the Rights of Persons with Disabilities: data and the International Classification of Functioning, Disability and Health, BMC, 2011

Francescutti C, Frattura L, Troiano R, et al . Towards a common disability assessment framework : theoretical and methodological issues for providing public services and benefits using ICF. Disability and Rehabilitation 2009; 31 (S1): S8-S15

Francescutti C, Gongolo F, Simoncello A, Frattura L. Description of the person-environment interaction: methodological issues and empirical results of an Italian large-scale disability assessment study using an ICF-based protocol. BMC, 2011

Frattura L, et al. Information systems learn to speak ICF. WHO-FIC Network annual meeting, 2011a

Frattura L, et al. ICF implementation in regional policies: the case of the Friuli Venezia Giulia Region, Italy, WHP-FIC Network annual meeting, 2011b

Griffo G., et al. Moving towards ICF use for monitoring the UN Convention on the rights of persons with disabilities: the Italian experience. Disability and Rehabilitation, 2009, 31 (S1): S74-S77

Leonardi M, et al. Integrating research into policy planning: MHADIE policy recommendations. Disability and Rehabilitation, 2010; 32 (S1): S139-S147

O'Donovan MA, Good A. Towards comparability of data: using the ICF to map the contrasting definitions of disability in Irish surveys and census, 2000-2006, Disability and Rehabilitation, 2010; 32 (S1): S9-S16

UN Convention on the rights of persons with disabilities. New York, United Nations, 2006. httpo://www.un.org.disabilities/

WHO and World Bank. The world report on disability, WHO 2011

WHO/ESCAP. Training Manual on Disability Statistics, 2008

WHO. International Classification of Functioning Disability and Health, Geneva 2001

From national terms to new "trans-language" terms: same examples

National terms	*From acronyms to new" trans-language" terms ?*
Handicap, personnes handicapées	imalipar, avec imalipar neinticof, avec neinticof
Discapacitad, las personas con discapacitad	neinticof, con neinticof ….
Disability, persons with disabilities	neinticof , with neinticof …..
Disabilità, Persone con disabilità	neinticof, con neinticof
Invalidnosti, invalidne osebe	……..
Behinderung / Menschen mit Behinderungen	……

Comparison between two functioning profiles of persons with different health conditions and environmental factors

A) Aggregated data by ICF Component

Figure 1 Sylvia: Functioning and disability continuum in an individual profile – BF

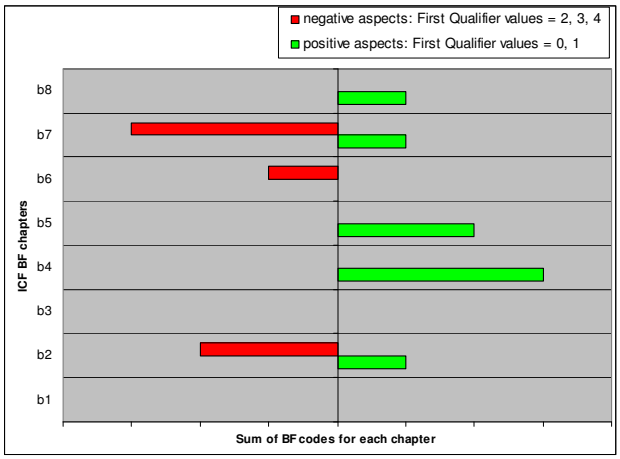


Figure 2 Jessica: Functioning and disability continuum in an individual profile – BF

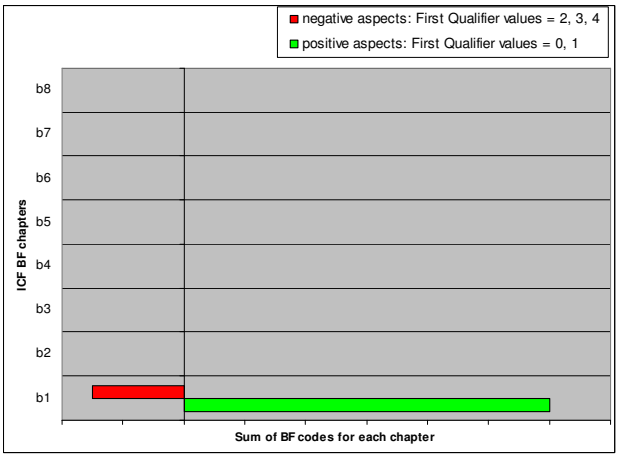


Figure 3 Sylvia: Functioning and disability continuum in an individual profile – BS

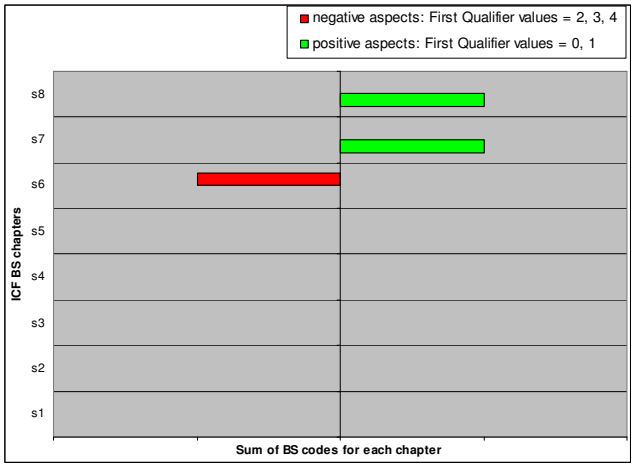
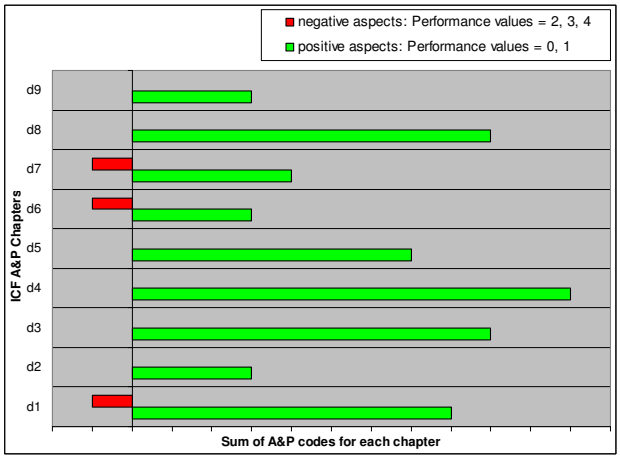


Figure 4 Jessica - Functioning and disability continuum in an individual profile – BS

No problems

Figure 5 Sylvia: Functioning and disability continuum in an individual profile – A&P

Figure 6 Jessica: Functioning and disability continuum in an individual profile - A&P



b) Disaggregated data by ICF Component

			ASSESSMENT/INTERVENTION DIMENSIONS								
Sylvia, 94 years **OBJECTIVES OF THE INDIVIDUAL CUSTOMIZED CARE PLAN**			Mental functions	Sensory functions and pain	Voice and speech functions	Functions of the cardiovascular, haematological, immunological and respiratory systems	Functions of the digestive, metabolic and endocrine systems	Genitourinary and reproductive functions	Neuromusculoskeletal and movement-related functions	Functions of the skin and related structures	
			b1	**b2**	**b3**	**b4**	**b5**	**b6**	**b7**	**b8**	
UNBALANCED interaction	**A**	**Design facilitators**							b730.2 b735.2 b740.2		**Value of the first qualifier 2-4**
	B	**Remodulate facilitatos and/or eliminate barriers**		b280.2				b620.3	b770.2		
BALANCED interaction	**C**	**Monitor**		b230.0		b450.1 b4500.1	b525.1 b530.1		b710.1		**Value of the first qualifier 0-1**
	D	**Assure sustainability of facilitators**	b134.1	b210.1		b420.1				b810.1	

			ASSESSMENT/INTERVENTION DIMENSIONS								
Sylvia, 94 years **OBJECTIVES OF THE CUSTOMIZED INDIVIDUAL CARE PLAN**			Structures of the nervous system	The eye, ear and related structures	Structures involved in voice and speech	Structures of the cardiovascular, immunological and respiratory systems	Structures related to the digestive, metabolic and endocrine systems	Structures related to the genitourinary and reproductive systems	Structures related to movement	Skin and related structures	
			s1	**s2**	**s3**	**s4**	**s5**	**s6**	**s7**	**s8**	
UNBALANCED interaction	**A**	**Design facilitators**						s630.220			**Value of the first qualifier 2,3,4**
	B	**Remodulate facilitators and/or eliminate barriers**									
BALANCED interaction	**C**	**Monitor**								s810.170	**Value of the first qualifier 0, 1**
	D	**Assure sustainability of facilitators**							s750.173		

			ASSESSMENT/INTERVENTION AREAS									
Sylvia, 94 years **61 items** **OBJECTIVES OF THE CUSTOMIZED INDIVIDUAL CARE PLAN**			Learning and applying knowledge **d1**	General tasks and demands **d2**	Communication **d3**	Mobility **d4**	Self-care **d5**	Domestic life **d6**	Interpersonal interactions and relationships **d7**	Major life areas **d8**	Community, social and civic life **d9**	
UNBALANCED interactions	**A**	**Design facilitators**				d415.222 d455.333 d475.333		d660.222				**Performance 2, 3, 4**
	B	**Eliminate barriers**								d880.303	d920.303	
	C	**Remodulate facilitators and/or eliminate barriers**								d870.220		
BALANCED interactions	**D**	**Monitor**	d115.000 d132.000 d137.000 d160.000 d161.000 d172.000	d230.000 d240.000 d250.000	d310.000 d315.000 d330.000 d335.000 d350.000 d355.000 d360.000	d435.111 d440.111 d445.111 d470.000	d560.000		d730.000 d740.000 d750.000 d770.000	d820.000 d825.000 d830.000 d840.000 d845.000 d850.000 d860.000	d940.000 d950.000	**Performance 0, 1**
	E	**Monitor and verify sustainability of facilitators**	d110.010 d166.010 d170.010		d325.010 d345.010	d465.000	d550.011		d760.100			
	F	**Verify sustainability of facilitators**				d410.122 d420.122 d450.121 d460.121	d510.022 d520.122 d530.121 d540.022 d570.122	d620.133 d630.022 d640.033				

			ASSESSMENT/INTERVENTION DIMENSIONS								
Jessica, 12 years **OBJECTIVES OF THE INDIVIDUAL CUSTOMIZED CARE PLAN**			Mental functions **b1**	Sensory functions and pain **b2**	Voice and speech functions **b3**	Functions of the cardiovascular, haematological, immunological and respiratory systems **b4**	Functions of the digestive, metabolic and endocrine systems **b5**	Genitourinary and reproductive functions **b6**	Neuromusculoskeletal and movement-related functions **b7**	Functions of the skin and related structures **b8**	
UNBALANCED interaction	**A**	**Design facilitators**	b125.2 b152.2 b164.2								**Value of the first qualifier 2, 3, 4**
	B	**Remodulate facilitators and/or eliminate barriers**									
BALANCED interaction	**C**	**Monitor**	b117.1 b122.1 b140.1 b144.1 b147.1 b156.1 b160.1 b176.1 b180.1								**Value of the first qualifier 0, 1**
	D	**Assure sustainability of facilitators**	b163.1 b167.1 b172.1								

			ASSESSMENT/INTERVENTION DIMENSIONS							
Jessica, 12 years **OBJECTIVES OF THE CUSTOMIZED INDIVIDUAL CARE PLAN**			Structures of the nervous system **s1**	The eye, ear and related structures **s2**	Structures involved in voice and speech **s3**	Structures of the cardiovascular, immunological and respiratory systems **s4**	Structures related to the digestive, metabolic and endocrine systems **s5**	Structures related to the genitourinary and reproductive systems **s6**	Structures related to movement **s7**	Skin and related structures **s8**	
UNBALANCED interaction	**A**	**Design facilitators**									**Value of the first qualifier 2, 3, 4**
	B	**Remodulate facilitators and/or eliminate barriers**									

BALANCED interaction	**C**	**Monitor**									**Value of the first qualifier 0, 1**
	D	**Assure sustainability of facilitators**									

			ASSESSMENT/INTERVENTION AREAS									
Jessica 12 years **60 items** **OPERATIONAL OBJECTIVES OF THE CUSTOMIZED PROJECT**			Learning and applying knowledge **d1**	General tasks and demands **d2**	Communication **d3**	Mobility **d4**	Self-care **d5**	Domestic life **d6**	Interpersonal interactions and relationships **d7**	Major life areas **d8**	Community, social and civic life **d9**	
UNBALANCED interaction	**A**	**Design facilitators**						d660.222	d770.222			**Performance = 2, 3, 4**
	B	**Eliminate barriers**										
	C	**Remodulate facilitators and/or eliminate barriers**	d166.222									
BALANCED interaction	**D**	**Monitor**	d110.000 d115.000	d230.000 d240.000 d250.000	d310.111 d315.111 d330.111 d335.111 d360.000	d410.000 d415.000 d420.000 d435.000 d440.111 d445.000 d450.000 d455.000 d460.000 d470.000 d475.000	d510.000 d530.000 d540.000 d550.000 d560.000		d740.111 d760.000	d820.000 d825.000 d830.000 d840.000 d845.000 d850.000	d940.000 d950.000	**Performance = 0, 1**
	E	**Monitor and verify sustainability of facilitators**	d132.011 d160.011 d172.011				d520.100			d860.011 d880.111		
	F	**Verify sustainability of facilitators**	d137.122 d161.122 d170.122		d325.122 d345.122 d350.122 d355.122		d570.022	d620.022 d630.022 d640.022	d730.122 d750.122	d870.033	d920.122	

Sylvia – Neutral List of Environmental Factors (ICF code, second level + descriptive label) recognized at the referral, that were qualified and related to each A&P categories quantified in the functioning assessment.

e110 Medication - EN

e110 Medication - FUROSEMIDE

e110 Medication - CO-EFFERALGAN

e110 Medication - COTAREG

e115 ISO 09 30 Urine absorbing and defecation aids - NAPPIES

e120 ISO 12 06 Walking aids manipulated by both arms – WALKING FRAMES

e125 ISO 21 03 Optical aids - GLASSES

e165 Extra indemnity (law 118/1971)

e165 Pension

e165 Owned accomodation

e310 Immediate Family

e310 Son, Mario, 50 ys, unemployed

e340 Personal assistant

e340 Paid help

e355 General practitioner, Aldo Rossi, M.D.

e570 100% loss of work capacity and with persisting incapacity to perform basic activities of daily living (L.18/80)

e575 Home care provided by general social support services

e580 Home care provided by local health authorities

e580 Medication provision by local health authorities

e580 General practice