

Parenting children with disabilities.
Some theoretical reflections and experimental data,
coded by the ICF, about the effect of child disability
on parental perception of their own offspring¹

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Abstract

Background: For many parents, making sense of “being together” with their disabled child is a very difficult undertaking, sometimes due to the objective complications in decoding the child signals, sometimes due to the parental phantasmization of the child. Consequently, the traumatic impact of disability on parents can generate a dissociation between the perception of the child and the (emotional and affective) meaning of the experience. The aim of this study is to corroborate a substantial amount of clinical observations with concrete evidence about the lack of accuracy, in some cases, for looking at interacting with, and representing their children with disability.

Method: In a sample of 44 children (0 to 17 y.o.) with disabilities, we compared the cognitive, motor, sensor, neuropsychological, communicative, emotional and relational functioning of children through

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an ICF-CY assessment with the parental perception of child's personal, domestic and community ability, evaluated by VABS (Vineland Adaptive Behavior Scales – Sparrow, Balla, & Cicchetti, 2003); and the social orientation and the emotional regulation, utilizing the QUIT (Questionari Italiani del Temperamento – Axia, 2000).

Results: In more than one third of parents in our sample, showing many difficulties in regarding his/her offspring, we found very significant differences in the inconsistencies between: the child's actual functioning and the level of his/her abilities as reported by the parents; the child's emotional evaluations coming from parents and professionals.

Conclusions: We can consider our results as an evidence of post-traumatic effects, with a significant narcissistic dimension, in some parents of children with disabilities, and in a percentage comparable to other evidence of trauma.

Keywords: Parenting; Perception; Disability; PTSD effect; ICF.

1. Introduction

The birth of a child with disability as well as with disability caused by an accident breaks the continuity between external reality and the internal world of parents, and between the different kinds and levels of parental representation. Thus, they can be considered as a major traumatic event in the life of parents (Grasso 1995; 2005a; 2005b; 2012).

The reported clinical and research evidence about parenting and disability reveal that, in order to continue living with and raising their child, parents are forced to carry out an intense psychic effort, with a significant narcissistic dimension.

1.1. Theoretical Assumption:

1.1.1. The relationship between perception and awareness

To explain the derangement in the representation of reality (i.e. expectations about the child and parenting) in parents of children with disabilities, we used as a theoretical framework J.J. Gibson's ecological perception model (1980; 1996). There is a mutual relationship of structural coupling and a pattern of perceptual anticipation between perceivers and the environment (Neisser, 1976). Three theoretical representative processes are observed in humans: a direct perceptual-motor representation of reality obtained through dual coding (both sensory and motor) mirroring mechanisms (Rizzolati & Sinigaglia 2006); a psychic representation, both symbolic and non-symbolic, arising from the subject's experience and from learning; and reflective and non-contextual psychic representations about self-personal experience.

These different forms of representation generate distinct psychological consciousness processes.

1. *Immediate Perception of Reality and Synchronic Primary Consciousness*: the ability to extract perceptual and conceptual invariants from the continuously-changing flow of sensory stimulation thanks to a mechanism of perceptual anticipation of reality due to sensory and category memories (Edelman, 1989). This complex ability, which perhaps responds to a specific and innate human motivational mechanisms, allows individuals to forecast the meaning and significance of immediate experience (Schank & Abelson 1975; Cole 1995).

2. *Diachronic Reflexive Consciousness of one's Experiences* that consists in working-through one's own experiences or learning processes at a later stage. It focuses on knowledge and accumulation of experience, as well as on making available, transforming, or excluding experience through what are essentially language-based processes of symbolization of reality.

1.1.2. Real and imaginary interaction with the child

A common denominator among the different conceptions of the psychic apparatus and the relationship between individuals and the outside world has to do with the multiplicity of human psychic representation processes. The psychic functioning, the intra-psychic dynamics, and consciousness result from the combination of several mental (brain) structures that operate based on a defined architecture.

1.1.3. Effects that result in "discontinuation" or discontinuity between perceived reality, intentionality, the processes of signification (the ability to symbolize and categorize), and consciousness.

In both the child and mother, the representation of (categorical) affects derived from the mother-child relation acquires a very powerful role when seen as a pattern of mutual anticipation of affective and mental states. The imitation and interactive games that the mother constantly puts in place to respond to her child's behavior, activate reciprocal extraction patterns of affective perceptual invariants – i.e. the vitality affects (Stern, 2010) – that guide interaction. In the context of appropriate interactions between adults and children, once the perceptual anticipation cycles of affective attunement have been activated, the former and the latter are already synced, or rather attuned (Stern, 1989). Information cross-flows, based on interactive physical relations in the early phases of the child's life, which permits common intersubjective meaning (form of sensation) and a very precise affective meaning (shared and acknowledged emotion) to the relationship between parent and child. Influence on the mother-child (or parent-child) interaction by different factors, post-partum depression, puerperal psychosis, risks to the child's life or child disability, leads to affective attunement to take atypical pathways as soon as the reciprocity of emotional exchanges is altered by physical or psychic elements that block or disrupt the normal flow of

sensations and perceptions, thus preventing the construction of a sense of mutual relation, which may also be totally dissociated from interaction.

1.1.4. The consequences (of child's disability) on parental narcissism and his retro-effect on parental perception of offspring

The disability of one's own children puts a heavy burden on the narcissism of parents, in the form of love for oneself and need to see themselves mirrored by others as recipient of love. Disability disrupts the project parents have to see children as a continuation of themselves (*His Majesty de Baby*; Freud, 1914). According to Luc Vanden Driessche (2009), the partial or total distortion of reality in fathers and mothers is the result of the gap that exists in the psychical representation of their own children and the adoption of an ideal image of the child (also known as the *Enfant Parallèle*).

1.2. The trauma of disability in parents as a failed process of psychic organization and source of conflict between the different levels of mental representation

What parents actually see is very different from what they expected (parental expectations) or experienced (actual interaction with a healthy baby). As a result, the attempt of primary consciousness to categorize the immediate experience (Edelman, 1989) and to create the expectations and mental representations normally used as a "perceptual" guide for the real child fails (setback), so for many parents, making sense of "being together" with their disabled child, is a very difficult undertaking, sometimes due to the objective complications in decoding the child signals.

When the much-unexpected external reality disrupts the expectations of the long expected for child and/or hinders the transfiguration between the real child as a damaged and uncanny entity and the idealized *Enfant Imaginaire* (Soulé, 1982), often symbolic and idealized representations of the child almost entirely replace the normal primary consciousness processes. The severe alterations in the personal background and signification of one's parenting experience (i.e. attribution and anticipation of meaning) force a lot of parents to adopt moment by moment strategies and make it difficult to imagine a long-term future for their child and to plan his/her life.

1.2.1. Trauma, Alteration of Basic Cognitive Processes (Perception/Signification of Reality) and Dissociation

At the beginning of a disabled child's life, the normal needs of a baby are complicated by his/her health problems, by the intensive care required, by rehabilitation and specialized education and by the great relational and social dedication he/she needs. The parents of children with disabilities, as well as traumatized people constantly exposed to the source of trauma, have a radically different conception of the world (Van der Kolk, 1996). Trauma causes survivors to "de-differentiate affects" (Krystal, 1978); i.e. they lose the ability to identify the specific emotions such as fear, anger, aggression that form the framework required to properly address a situation. Patients suffering from chronic PTSD have difficulties in neutralizing the environmental stimuli so as to participate in relevant tasks (Paige, Reid, Allen, & Newton; 1990; Mcfarlane, Weber, & Clark, 1993). In the long term, withdrawing into oneself serves as a compensatory effect to this response pattern. Janoff-Bullman (1992) used the expression "crushed representations" to describe the pairing process between individuals and the external world concerning traumatized subjects. Therefore, the trauma disaggregates (Janet 1892; 1904) the experience perceptually into split and isolated memory modes. Van der Kolk (1996) argues that internal schemes (memory/representations) based on trauma give rise to parallel patterns poorly integrated with each other. Other studies on PTSD-affected subjects show that the simultaneous separation of perceptual and perceptual-symbolic experience (a.k.a. perceptual non-integration) is probably the core around which revolves the whole process of disorganization and decay of one's own experience, of the sense of self, and of the world of those who have developed a chronic post-traumatic reaction.

Van der Hart, Nijenhuis & Steele, (2006) recall Janet's (1907) concept of "mental depression" found in hysterical subjects to state that the decreased efficiency in traumatized individuals who suffer from PTSD results in a structural dissociation which starts when mental efficiency and energy become too limited to allow full integration of events.

1.2.2. Degradation and Change in the Conception of (Traumatic) Experience in Parents

What scholars noted in patients with PTSD strongly resembles to what one can observe in many parents who experience the disability of their child.

Often for these parents, it is primarily or exclusively the contingency of the moment that gives meaning to things (a simple scratch can upturn their lives for days or months). The difficulty or inability to achieve integration among the characteristics of the parent's personality connected with the trauma of disability leads to exaggerated responsiveness to the surrounding environment, with no possibility to integrate the perceptual-symbolic personal experience without specific clinical support. The fragmentation of interaction with the child, the difficulties in understanding the signals the child sends, and sometimes the complete incapacity of the parents of disabled children to understand the words health professionals use to refer to their child are the evidence of a failed ability to *discriminate* and *select* stimuli. Very often, hatred and anger towards others as well as motor hyper-activation replace the feelings of incapacity, fatigue and despair in maintaining a harmonious relationship with one's own child (and with the surrounding environment), thus preventing any type of mentalization or reflection on the meaning of the relevant experiences. Last, but not least, the contamination of parenting processes is often extended to other children, thus compromising parenting efforts with respect to the brothers and sisters of children with disabilities and causing the progressive phasing out of the family (core) from the surrounding environment (suppression of relations with other relatives, friends or colleagues).

2. Aim of the study

The birth and the experience of a child with disability is always a major trauma in the parents' life that sometimes can lead to a subsequent disruption of their mental organization and behavior as post-traumatic symptoms. The aim of this study is to analyse the accuracy of parental assessment of the adaptive behavior of children – e.g. the execution of simple/complex tasks and daily routine, individual autonomy, and interaction with others – compared with his/her cognitive, motor, sensory, linguistic and communicational, and educational development. We have also studied the parental perception of affective-emotional functioning of the child in terms of temperament, emotional management, and control of behavior. To do so, we compared such a perception with that of the operators who follow the case. Furthermore, we analysed the consistency/inconsistency between the objective assessment of the level of development of the child and his/her functional social, relational and emotional-affective profiles based on what parents have subjectively reported.

2.1. Working hypothesis

We are expecting significant differences in our sample between:

1. the child functioning and the level of his/her abilities as reported by the parents;
2. the child's emotional evaluations coming from parents and professionals.

3. Methodology

- *Sample.* Our sample consists of 44 children with disabilities (29 males 15 females) with age between 11 and 214 months ($M = 74.2$ mo., $SD = 46.5$ mo.). Out of the 44 children, 20 had physical disability (structures: of the nervous system, s110; s1100; s1107; s11070; of the eye, ear and related structures, s2203; s230; involved in voice and speech, s3108; s3202; s3208; s330; of the cardiovascular, immunological and respiratory systems, s43010; related to the digestive, metabolic and endocrine systems, s598; related to movement s710; s7100; s7302; s7400; s7408; s750; s75000; s75001; s75002; s7502; s75011; s7600), of which 17 were clearly visible. The pathologies of the subjects are: Speech disorder ($n = 9$); Intellectual Disability ($n = 8$); Disorders of central motor control ($n = 8$); Pervasive developmental disorders ($n = 2$); Prematurity and fetal distress ($n = 4$); Retarded development/psychomotor retardation ($n = 11$); Degenerative genetic syndromes ($n = 2$).
- *Measures and evaluations.* The degree of development of the child was evaluated using separate instruments for the following development areas (Tab. 1).
- *Functioning of the child.* These assessments rely on the parents answers to specific concerns of the QUIT (Axia, 2000), such as temperament and ability to regulate emotions, and of the VABS (Sparrow *et al.*, 2003), such as autonomies and social functioning.

Table 1 - Tests and scales

COGNITIVE AND NEUROPSYCHOLOGICAL AREA:

WPPSI; WPPSI-III; WISC-R, WISC-III; WISC-IV; Brunet Lezine; Bayley's Scales; Griffith's Scales; Raven CPM; Stanford Binet Revised; BVN 5-11, TEMA Test; Piaget-Head Scale; TCR; TPV; Tower of London; Go-Stop Test; Attention and concentration Test; Bell Test; Stroop Test; CWT (Colour Word Test); Brown Attention Deficit Scale – Cluster 6; Stambak Tasks; Test des Deux Barrages; NEPSY-III.

MOTOR AREA:

Picq & Vayer Psychomotor Test for Early Age; Vayer Psychomotor Test; Brunet Lezine; Bunse Dev. Checklist; Self Control Rating Scale; KIWI Test for Motor Control; MRC Oxford; Dynamometric isokinetic evaluations; Ashworth Scale; Reflexes Examination; Walking Index; GARS; VAS Scale for Muscular Rigidity and Spasms; BAB Test; TGM Test.

SENSORY AND PERCEPTUAL AREA:

Eye Tracking; Saccadic Movements Clinical Tasks; Schnellen Scale; Lighthouse Near Visual Activity; Ophthalmic examination; Audiometric examination; Taste examination; Smell examination; Haptic function examination; Touch discrimination examination; Subjective pain examination; PRCR-2; Benton Test; VMI; Bender VMGT.

COMMUNICATION AND LANGUAGE AREA:

CMF Test; Peabody Test; TFL; TVL; TMF (Mean Phonation Time); Rossi Phonemic Inventory; Phono-lexical test; Omega Language Articulation Test; TPL; PCR; NEPSY-III.

EDUCATIONAL AREA:

Learning Batteries (reading, writing, calculating, text comprehension).

3.1. The application of ICF: coding and scoring issues

In order to make the analysis of feedback easier, we have: 1) assigned a code to the areas of our interest according to the categories established in the International Classification of Functioning – Children and Youth (ICF-CY) (WHO, 2007). We associated the ICF-CY categories and the indications of (psychometric and criteria) tests and scales based on a rigorous analysis of the correspondence among the definition, the inclusion/exclusion in selected categories, and the content and criteria for the validity of the assessment tools used; 2) translated the score of scales and standardised tests administered in the ICF qualifiers to obtain the developmental indexes of children.

With a view to monitoring the development of the child, we have taken into account the following ICF-CY categories distinct by areas (Tab. 2). The ICF-CY Code Set chosen to encode the development of the child has been validated (Grasso, 2015). The ICF categories measuring the child functioning – i.e. adaptation, social participation and interaction – have proven to be extremely sensitive to reveal the distortions of parental perception of the child, that is to say grossly over/underestimated assessments of behavior. All scores related to objective and subjective evaluations have been translated into ICF qualifiers. To convert them, we established the statutory equivalence between the ICF qualifiers (impairment/limitation percentage), on one side, and the gaps rounded down to the nearest figure of the normal distribution, the distribution in percentile ranks, the standard points, the “T” points, etc., on the other. The latter express the weighed score of the tests, scales, and standardised tests we have used (Fig.1).

Table 2 - *The ICF-CY Code Set*

Cognitive and Neuropsychological Area Index

BODY FUNCTIONS: *b1140 (Orientation to time); b1144 (Orientation to space); b117 Intellectual functions); b140 (Attention functions); b1440 (Short-term memory); b1441 (Long-term memory); b164 (Higher-level cognitive functions).*

ACTIVITIES & PARTICIPATION: *d160 (Focusing attention); d163 (Thinking); d175 (Solving problems).*

Neural and Psychomotor Area Index

BODY FUNCTIONS: *b1470 (Psychomotor control); b1471 (Quality of psychomotor functions); b1472 (Organization of psychomotor functions); b235 (Vestibular functions); b215 (Functions of structures adjoining the eye); b710 (Mobility of joint functions); b715 (Stability of joint functions); b730 (Muscle power functions); b735 (Muscle tone functions); b740 (Muscle endurance functions); b750 (Motor reflex functions); b760 (Control of voluntary movement functions); b765 (Involuntary movement functions); b770 (Gait pattern functions); b7800 (Sensation of muscle stiffness); b7801 (Sensation of muscle spasm).*

ACTIVITIES & PARTICIPATION: *d440 (Fine hand use).*

Sensory and Perceptual Area Index

BODY FUNCTIONS: *b1560 (Auditory perception); b1561 (Visual perception); b1564 (Tactile perception); b1565 (Visuo-spatial perception); b210 (Seeing functions); b230 (Hearing functions); b2304 (Speech discrimination); b250 (Taste function); b255 (Smell function); b265 (Touch function); b280 (Sensation of pain).*

ACTIVITIES & PARTICIPATION: *d110 (Watching); d115 (Listening); d120 (Other purposeful sensing).*

Communication and Language Area Index

BODY FUNCTIONS: *b1670 (Reception of language); b1671 (Reception of written language); b310 (Voice functions); b320 (Articulation functions); b330 (Fluency and rhythm of speech functions).*

ACTIVITIES & PARTICIPATION: *d133 (Acquiring language); d310 (Communicating with - receiving - spoken messages); d315 (Communicating with - receiving - nonverbal messages); d320 (Communicating with - receiving - formal sign language messages); d330 (Speaking); d331 (Pre-talking); d335 (Producing nonverbal messages); d340 (Producing messages in formal sign language); d360 (Using communication devices and techniques).*

Educational Area index

ACTIVITIES & PARTICIPATION: *d135 (Rehearsing); d140 (Learning to read); d145 (Learning to write); d150 (Learning to calculate); d1661 (Comprehending written language); d198 (Learning and applying knowledge, other specified).*

Adaptive functioning and relationship

Autonomous behavior

ACTIVITIES & PARTICIPATION: *d2102; d220 (Undertaking tasks); d230 (Carrying out daily routine); d710; d720; d730 (interactions with others).*

Personal autonomies

ACTIVITIES & PARTICIPATION: *d510; d520; d530; d 540; d550; d560.*

Affective-emotional functioning (temperament, emotion).

ACTIVITIES & PARTICIPATION: *b125 (social orientation); b1521 (Regulation of emotion); d250 (Managing one's own behavior)*

Figure 1 - *The rules to convert the standardized scores of tests and scales in ICF-CY qualifiers*

Universal qualifier (ICF-CY, p. 21)	0 No problem	1 Mild problem	2 Moderate problem	3 Severe problem	4 Complete problem
Percentage of problem (ICF-CY, p. 21)	0–4%	5–24%	25–49%	50–95%	96–100%
Quantifying words (ICF-CY, p. 21)	(none, absent, negligible)	(slight, low)	(medium, fair)	(high)	(total)
Descriptive terms for use in self-report, by key respondents, or in quantification of artifacts or common indices	average and above	slightly below average	moderately low	very low	extremely low
Clinical judgment	No difference or limitation for age, gender, or context	Slight difference or limitation	Moderate difference or limitation	Serious difference or limita- tion	Extreme difference or limita- tion
Standard Score example, where Mean = 100, SD = 15 SS points	86+	71–85	56–70	41–55	<40
Scaled Score example, where Mean = 10, SD = 3 scaled points	> 7	5–7	2–4	1	<1
T-Scores (mean = 50, SD = 10)	> 41	31–40	21–30	11–20	0–10
Percentile Ranks (may vary from test to test)	> 23	11–23	4–11	1–4	<1
Standard deviation units below the mean	0. +SDs	–1 to –2	–2 to –3	–3 to –4	>4

From Simeonsson, Sauer-Lee, Granlund, & Björck-Åkesson, 2010

3.2. Consistency and reliability of children profiles

3.2.1. Definitions match/mismatch of evaluations

A starting point is that inconsistent evaluations, which include perceptual distortion of both improvements and setbacks, are a constant feature of parental perception of their children – with or without diseases or illness (Achenbach, McConaughy, & Howell, 1987; Youngstrom, Findling, & Calabrese, 2003; De Los Reyes & Kazdin, 2005; Dozier, Aligne, & Schlabach, 2006; Faugli, Emblem, Veenstra, Bjørnland, & Diseth, 2008; Carlson & Blader, 2011; Carlson & Youngstrom, 2011). In order to specify what we mean for inconsistencies, we define match/mismatch of evaluations as the coincidence or positive/negative difference between the value of development indexes calculated on the basis of objective assessments and

the values of the functioning level of the child (see above) based on the subjective evaluations of his/her parents.

3.2.2. Unreliability/Reliability of a functioning profile (parents' perception).

We define a functioning or affective-emotional profile as “unreliable” whenever there is no agreement between the assessments of parents and those of operators who follow the child, as the latter detect macroscopic distortions in the parents' assessment. We also (improperly) define a functioning or affective-emotional profile as “reliable” whenever the evaluations of parents and operators who follow the subject are consistent with each other.

3.3. Data analysis

The data collected have undergone preliminary processing in order to establish the existence of and the degree of consistency/inconsistency between the level of development of the subjects in the sample and the assessment of (adaptive, autonomous, emotional, and affective) functioning reported by the parents of the children.

1. First, for each area (Tab. 2) we calculated both the mode and the average value of the qualifiers attributed to ICF categories included. In more than 90% of our cases, the mode and average of qualifiers are completely overlapping considering only the “open” categories, i.e. those with a qualifying value $\neq 0$. Therefore, we have identified the development indexes (cognitive; motor; sensorial; comm./lang. and educational) by using the medium values of qualifiers, since they are more consistent with the clinical assessment made by the operators who took care of the children in our sample. Finally, the global indicator of the level of development of the child (i.e., functioning) represents the average of the indexes of an area.
2. We have examined the consistency/inconsistency of (overall/by-area) development indexes through the qualifiers assigned to ICF-CY categories, with the latter relating to adaptive functioning, the child's personal autonomy; and interactions with others (the values attributed to these categories have been compared only with the indicators of the communication and language area and with the global indicator). We have calculated the reliability of assessments (see below) for the

categories related to social orientation, emotional regulation, and control of their own behavior used to measure the emotional and affective children's involvement.

3. Finally, for each subject, we measured the absolute and percentage value of match vs. mismatch (improvement/setback) between the indicators of development areas (objective assessments) and the categories of the child's functioning, which is the ratings based on the report of parents to VABS (Sparrow *et al.*, 2003).

3.3.1. Statistical analysis

Through the Chi Square test (Cochran, 1952), we have verified if the differences in the distribution of match/mismatch of evaluations (number and percentage) were a result of chance or were statistically significant. Then we compared match/mismatch of evaluations in the overall sample with those of the two subgroups – i.e., patients whose profiles were assessed as reliable or unreliable by operators – and match/mismatch of evaluations between the two subsamples. We have, in addition, verified the influence of the visibility of impairments.

In order to understand where the parental perception of the level of development of the child is more misaligned or distorted, we resorted to the Wilcoxon test for paired samples (1945). We therefore calculated the distribution of differences between the inconsistencies in the parental assessments of adaptive and relational functioning – i.e., performing simple and complex tasks, carrying out daily routine and autonomous decisions, interaction with others – and the indexes of global and area development.

4. Results

By studying the results we can see that 38 cases out of 43 show inconsistencies among the indexes of child development and the assessment of his/her functioning, while only out 5 of 43 are a match. The remaining two cases cannot be assessed due to the lack of some data. The percentage of inconsistencies (70%), for the better or worse, is much greater than match (30%) for the global development index.

We counted the cases with unreliable functioning profile (20 out of 45, i.e. 44%) and reliable functioning profile (25 out of 45, i.e. 56%). In the cases with unreliable profile, the percentage of inconsistencies for the better (33%) is lower than global sample; the percentage of inconsistencies for the

worse (21%) plus matches (46%) is significantly higher in this subgroup than in the others.

4.1. Comparisons of match/mismatch of evaluations between development (global; cognitive; motor; communication) indexes and adaptive functioning of subjects

As per the comparison among the subjects in general, subjects with reliable and unreliable functioning profiles, the results show that in the three groups the differences (frequencies and percentage) are significant (Tab. 3). The trends obtained by comparing these three groups are shown in table 4.

Table 3 - *Level of significance (Chi squared test) of the differences, in frequencies (f) and in percentage (%), of inconsistencies. Only significant differences are reported.*

Indexes		ALL		UNR		Differences Among All Subgroups	
		(f)	(%)	(f)	(%)	(f)	(%)
Global	ALL	-	-				
	UNR			-	-	$p < .001$	$p < .001$
	REL			$p < .01$	$p < .001$		
Cognitive	ALL	-	-		$p < .001$		
	UNR		$p < .001$	-	-	$p < .05$	$p < .01$
	REL			$p < .01$	$p < .001$		
Motor	ALL	-	-		$p < .001$		
	UNR		$p < .001$	-	-		$p < .001$
	REL			$p < .05$	$p < .001$		
Comm./Lang.	ALL	-	-				
	UNR			-	-		$p < .05$
	REL				$p < .01$		

Note: ALL (all cases); UNR (cases with unreliable profile); REL (cases with reliable profile).

Table 4 - Trends of inconsistencies (%)

Indexes	For the better	For the worse	Matches
Global	REL > ALL > UNR	UNR > ALL > REL	UNR > ALL > REL
Cognitive	REL > ALL > UNR	UNR > ALL > REL	UNR > ALL > REL
Motor	REL > ALL > UNR	UNR > ALL > REL	REL ≈ ALL > UNR
Comm/Lang.	some appreciable diff. UNR < RP	UNR > ALL > REL	REL > ALL > UNR

Note: ALL (all cases); UNR (cases with unreliable profile); REL (cases with reliable profile).

4.2. Analysis of the type of inconsistency based on the visibility of impairment

We have also analysed the distribution of inconsistencies between the index of motor development and the functioning profile with due consideration to the "visibility of impairments" as a factor. We have therefore grouped individuals with *visible/non-visible impairments* in subgroups (all cases; cases with reliable profiles; cases with unreliable profiles).

The comparison of inconsistencies in individuals with visible/non-visible impairments has shown significant percentage differences, whereas all cases ($p < .01$); cases with unreliable profiles ($p < .001$); cases with reliable profiles ($p < .05$). The trend observed in the three subgroups is as follows:

- inconsistencies for the better: subjects with visible impairments > subjects with all impairments > subjects with non-visible impairments;
- inconsistencies for the worse: subjects with invisible impairments > subjects with all impairments > subjects with visible impairments.
- matches: no differences

Considering all the cases in the sample, we note that inconsistencies for the better are much higher (61%) in subjects with visible disability than in those with non-visible disability (37%). Conversely, inconsistencies for the worse are much lower (15%) in the formers ($p < .01$). For persons with non-visible impairments there is an important decrease of inconsistencies for the better (37%) and an equally strong increase of inconsistencies for the worse (35%) with respect to all cases.

If we consider the *cases with unreliable profiles* (parental perception) and *non-visible impairments* the inconsistencies for the worse (47%) for these individuals are twice as much those for the better (24%) ($p < .05$).

Finally, if we consider only the subjects with visible impairments in the three subgroups, there is a strong majority of inconsistencies for the better ($\approx 60\%$).

4.3. Misalignment Between Development Indexes and Perceived Level of Functioning (Parental Perception)

We resorted to the Wilcoxon test for paired samples to conduct an analytical test of the differences among inconsistencies (Tab. 5). We found some significant differences between the level of functioning (especially in performing simple tasks (d2102); personal autonomy (d510; d520; d530; d540; d550; d560); interaction with others (d710; d720; d730), and the indexes of global and area development (cognitive; motor; communication).

If we consider all cases and those with reliable profiles, the trend of differences suggests a perception for the better of the functioning of the child. Based on the cognitive, motor, communicational, and global indexes, the inconsistencies for the better are significantly higher in number than those for the worse. Such effect, however, is not visible if we take the cases with *unreliable profile* alone. They show no statistically significant difference.

Table 5 - *Level of significance (Wilcoxon Test) of the differences among inconsistencies. Only significant differences are reported.*

Indexes	Undertaking a single task independently (d2102)			Undertaking multiple tasks (d220)			Carrying out daily routine (d230)			Personal autonomies (d510; d520; d530; d 540; d550; d560)			Interactions with others (d710; d720; d730)		
	ALL	UNR	REL	ALL	UNR	REL	ALL	UNR	REL	ALL	UNR	REL	ALL	UNR	REL
Global	$p < .01$		$p < .01$							$p < .01$		$p < .01$	$p < .01$		$p < .01$
Cognitive	$p < .01$		$p < .01$							$p < .01$	$p < .06$	$p < .01$	-	-	-
Motor	$p < .01$		$p < .05$							$p < .01$	$p < .06$	$p < .02$	-	-	-
Communicative	-	-	-	-	-	-	-	-	-	-	-	-	-	$p < .01$	$p < .01$
Sensorial														-	-

Note: ALL (all cases); UNR (cases with unreliable profile); REL (cases with reliable profile).

5. Discussion

The inconsistencies observed in cases with reliable profiles of adaptive functioning and emotional-affective functioning support the idea that the perception of own children is better than his/her real level of development. Anyway, if we compare the cases with an unreliable profile with those with a reliable profile (overall development index vs. functioning), we can observe 20% more inconsistencies for the better in favour of the latter.

This finding is consistent with reports in the literature about the distortions of parental judgment vis-à-vis other less emotionally involved people, e.g., operators, other relatives, etc. This reflects, also, the general tendency of parents to idealize their child and then report better performance for him/her (Vanden Driessche, 2009). This parental narcissistic projection (projective identification) can be frustrated, however, by various factors, not least the presence of impairment or disabilities in the children. This leads parents to underestimate the performance of their children.

According to operators who follow the cases, more than a third of our sample (20 out of 45) shows the adaptive and even more emotional-affective functioning profiles perceived about the child are unreliable. In all these cases, we detected a very significant different distribution of inconsistencies (for the better or the worse) and of the number of matches with respect to the total number of cases and the cases with reliable profiles:

1. the tendency to evaluate the development of the child for the better is maintained, although a lower if compared with the other two groups.
2. the number of inconsistencies for the worse and matches is significantly higher in this subgroup than in the others. This is true for both the comparison between the adaptive functioning and the global development index, and between the former and the indexes of the motor, cognitive and communicative-linguistic areas.
3. the perception of parents is not discriminative within the critical domains of adaptive functioning, i.e. autonomous behavior or interaction with others (Wilcoxon test). These parents (marked as unreliable) not only have difficulties in assessing the real characteristics of their children, but also a lack of sensitivity to invest their functional skills (un-differentiation).

In our opinion, this result is not only the consequence of the difficulty parents have in considering their children in an objective manner or to invest them in a narcissistic way. It can better explained as a loss of contact of some parents (i.e. one-third of the sample) with their children and the likely

result of the traumatic experience of their presence and disability. It is important to note that these parents have a vision of their child that is quite different from that of operators who follow them. In fact, the comments from the operators sound like: *"It is as if these fathers and mothers spoke of another child, not their own."* A comparison of the inconsistencies between the motor area development index and the assessments of adaptive functioning – i.e. executing simple and complex tasks; daily routine and autonomous behavior) reveals the widest gap.

1. The inconsistencies for the worse (in the cases with an unreliable profile) are four times higher in the cases with unreliable profile: 47% compared to 11% of cases with reliable profile. This can be explained by the fact that the motor impairments, even slight ones, are more visible than other forms of disability.
2. As far as inconsistencies for the better are considered, the opposite trend is observed in the cases with unreliable profile: 43% compared to 59% of cases with reliable profile. They seem to alter significantly the judgment of those parents who already show significant distortions in the way of being with and seeing their son.
3. In our sample, the visibility of disability causes a higher number of evaluations for the better in all subgroups. We can observe that on these children the influence of the parental narcissistic needs is very strong, and seems not to take into account the visibility of impairments to maintain an ideal image of the child. Non-visible disability, on the contrary, induce a smaller number of evaluations for the better, which are more than the number of evaluations for the worse anyway. An exception in this respect are the parents providing unreliable functioning profiles. In this subgroup the evaluation of the functioning in their children is dramatically different from the rest of the sample: the percentage of inconsistencies for the worse is twice that of inconsistencies for the better ($p < .05$). We can interpret this as a radical inhibition of the narcissistic projections of those parents who have obvious problems to get in touch with their child's non-visible impairments – which is perhaps most disturbing and confusing to them.

As per the inconsistencies noted in the relational functioning (interactions with others), we observed that in comparing cases with unreliable and reliable profiles, some significant changes emerge when the comparison is made with the total case set ($p < .05$). The cases with unreliable profiles show a slight increase in the number of inconsistencies for the worse (15%)

with respect to those with reliable profiles (4%). Anyway, the cases with unreliable profiles show a slight increase in the number of inconsistencies for the better (60%) with respect to those with reliable profiles (52%) and all cases (56%). In this area we detected inconsistencies only in 28 case out of 43. Given the low frequency, it is difficult to say that the perception of the child's ability to interact with others is untouched by the withdrawal of parental narcissistic investment when compared to other aspects of development (especially motor). In our sample, the perception of the child is altered mostly for the better. However, we can assume there is an effect of "assimilation" of the functioning of the child into the relations skills of the people the very child interacts with.

6. Conclusions

The data we have collected indicate that there are significant quantitative and qualitative alterations in the assessments made by the parents of children with disabilities. Some of these are in line with the usual distortions of parental evaluation that emerge when parents are asked to assess the skills or features of their child. However, in more than one third of the cases (unreliable profiles), these alterations of parental perception seem to be very different from those reported by other authors. They cannot be explained through the massive effect of parental narcissistic projection. In this subgroup, inconsistencies are in fact primarily for the worse. In addition, we should consider that the distortion of parental assessment of the functioning of their child is recognized as clinically relevant to the operators who follow the child. Studies on the long-term effects on trauma survivors demonstrate *that only a third of them develops a post-traumatic disorder over time*. Consequently, this can be considered a further indication of the post-traumatic effect that the disability of a child has on some parents, especially those who are more vulnerable than others are. We think that other studies on a larger sample, leading multivariate analysis focused on the weight of other dependent variables (about parents and children) can be useful in determining both the variance of the number and scope of inconsistencies in sample subjects and the variance of reliability/unreliability of the (adaptive functioning and emotional-affective) profiles.

If we can easily consider parenting disabled children and the related experiences as a major trauma in their lives, the severity of trauma alone cannot be used to predict the evolution of the response by a given individual, according to research results. It is influenced by a combination of factors: a

positive family history of psychiatric disorders; a neurotic personality; the role played by other events in life (especially other traumas) and by social mediators after the trauma; sustained exposure to stress; the energy level and mental efficiency of the subject exposed to a potentially traumatic event, and more recently the personal resilience to cope with the effects of traumas and to escape from the consequences (Cyrulnik, 1999). These are all factors to be taken into account to clearly define, in one way or another, the overall reaction of parents to trauma and the way they adapt to both the situation and its evolution.

6.1. The Disorganized Behavior of Parents: A New Clinical Explanation

Although there is not any linear effect of child's disability on the post traumatic responses of parents, in some cases, before the parents can reorganize their perceptual and signification system, the above framework remains extremely disturbing and in place for several years. This provides a plausible explanation of the severe impairment in the intersubjective and "emotional mirroring" ability of parents and it can perhaps better explain the sometimes-bizarre behavior of some parents, which translates in their difficulty to tune in with their child and send him/her adequate emotional signals. All that cannot be explained solely in terms of disease or illness of children, two aspects that are often not conclusive in this regard.

These observations to parenthood in disability exploit the possibility of integrating perceptions about how subjects with disabilities are "seen" by parents and professional caregivers and about very early and long-term psychotherapeutic support to parents. Continuity of psychological and social assistance, which goes hand in hand with medical treatment and rehabilitation, could facilitate the clinical evolution of the child and its inclusion in the family and social structures while ensuring, above all, greater solidity of the parents' mental health.

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