

LA VULNERABILITÀ PSICOPATOLOGICA DELLA PERSONA CON DSA

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VULNERABILITÀ PSICHIATRICA DEI DSI

Le Persone con Disturbi dello Sviluppo Intellettivo presentano una vulnerabilità allo sviluppo di disturbi psichiatrici significativamente superiore a quella della popolazione generale.

Le cause sono molteplici e di natura potenzialmente diversa, come ovvio in un raggruppamento meta-sindromico.

Evidenze di:

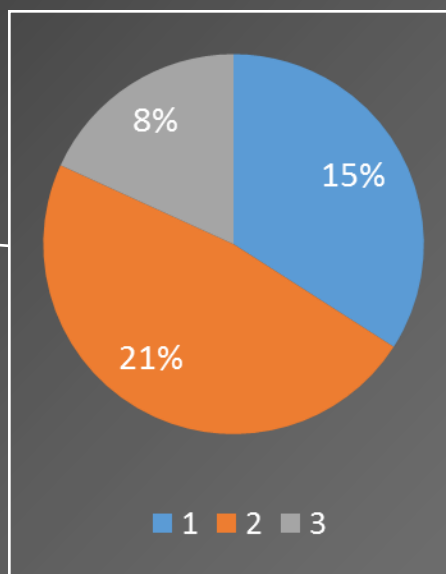
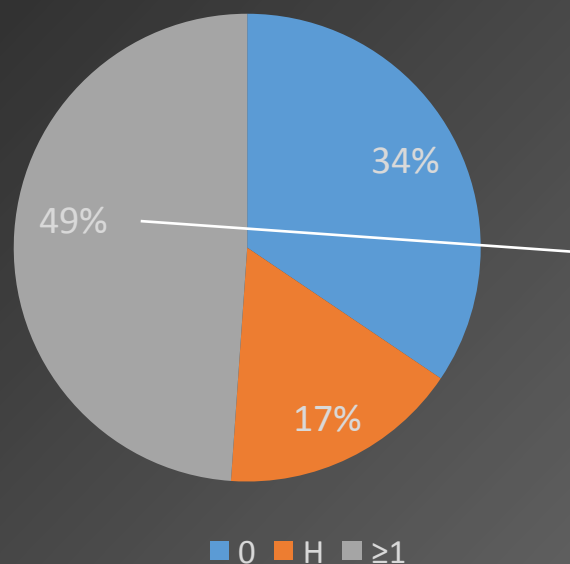
- maggiore prevalenza (fino a 4 volte),
- soglia psicopatogena più bassa
- più bassa età d'esordio

DNS E DISTURBI PSICHIATRICI

Ospedale psichiatrico popolazione generale (Olanda)
N=208 ricoverati
screening per DI e FIL 208

- 43,8% positivo allo screening
- positività associata a:
 - specifica diagnosi (-)
 - numero di ricoveri (+ + +)
 - interventi obbligatori (+ + +)
 - prognosi negativa (+)
 - problematiche gestionali (+ + +)

TASSO DI PREVALENZA DEI DP NELLA DI



0 = nessun disturbo
 ≥1 = almeno 1 disturbo
 H = morbidità nascosta
 1 = 1 disturbo
 2 = 2 disturbi compresenti
 3 = 3 disturbi compresenti

1. Borthwick-Duffy SA. Epidemiology and prevalence of psychopathology in people with mental retardation. *J Cons Clin Psy*, 1994; 62: 17-27
2. Cooper SA., Smiley E., Morrison J., et al. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British J Psy* 2007; 190: 27-35.
3. Deb S., Thomas M., and Bright C. Mental disorder in adults with intellectual disability. I: prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *J Intell Dis Res*, 2001; 6: 495-505
4. Cooper, S.-A. Psychiatry of elderly compared to younger adults with intellectual disability. *J of Appl Res in Intellectual Disability* 1997, 10 (4): 303-311.
5. Meltzer, H., Gill, B., Petticrew, M. & Hinds, K. (1995) The prevalence of psychiatric morbidity among adults living in private households: OPCS survey of psychiatric morbidity in Great Britain, report 1. London: HMSO.
6. Borthwick-Duffy, S. A. & Eyman, R. K. (1990) Who are the dually diagnosed? *American Journal of Mental Retardation* 94 586-595.
7. Reiss, S. Prevalence of dual diagnosis in community-based day programs in the Chicago metropolitan area. *Am J Mental Ret* 1990, 94: 578-585.
8. Lund, J. The prevalence of psychiatric morbidity in mentally retarded adults. *Acta Psychiatrica Scandinavica* 1985, 72: 563-570.
9. Corbett, J. A. (1979) Psychiatric morbidity and mental retardation. In: F. E. James and R. P. Snaith (Eds) *Psychiatric Illness and Mental Handicap* pp11-25. London: Gaskell Press.

WIDTH OF PREVALENCE RATES (%) OF SPECIFIC PSYCHIATRIC DISORDERS IN ID

	Cooper 2007 ¹	Deb 2001 ²	Cooper & Bailey 2001 ³	Lund 1985 ⁴	Corbett 1979 ⁵
Psychotic Disorder	4,4	5,6	2,7	1,3	6,2
Affective Disorder	6,6	2,2 (5,5 PAS-ADD)	6,0	1,7	6,0
Anxiety Disorder	4,5	6,6 (8,9 PAS-ADD)	7,2	2,0	combined
Autistic-spectrum	7,5	-	6,8	3,6	8,2

1. Cooper SA., Smiley E., Morrison J., et al. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British J Psy* 2007; 190: 27-35.
2. Deb S., Thomas M., and Bright C. Mental disorder in adults with intellectual disability. I: prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *J Intell Dis Res*, 2001; 6: 495-505
3. Cooper SA., Bailey NM. Psychiatric disorders amongst adults with intellectual disability: prevalence and relationship to ability level. *Irish J Psych Med*, 2001; 18: 45-53
4. Lund, J. The prevalence of psychiatric morbidity in mentally retarded adults. *Acta Psychiatrica Scandinavica*, 1985; 72: 563-570.
5. Corbett, J. A. (1979) Psychiatric morbidity and mental retardation. In: F. E. James and R. P. Snaith (Eds) *Psychiatric Illness and Mental Handicap* pp11-25. London: Gaskell Press.

COMORBIDITY, HEALTHCARE UTILIZATION, AND EXPENDITURES OF MEDICAID ENROLLED ADULTS WITH ASD

A retrospective data analysis using 2000-2008 three state Medicaid Analytic extract Adults (22-64 years) with (n = 1772) and without autism spectrum disorders (ICD-9).

Adults with autism spectrum disorders had significantly higher rates of:

- psychiatric comorbidity (81%)
- epilepsy (22%)
- infections (22%)
- skin disorders (21%)
- hearing impairments (18%)

- mean annual outpatient office visits (32ASD vs 8noASD)
- prescription drug use claims (51ASD vs 24noASD)
- mean annual outpatient office visits (US\$4375ASD vs US\$824noASD)
- emergency room (US\$15,929ASD vs US\$2598noASD)
- prescription drug use (US\$6067ASD vs US\$3144noASD)
- total expenditures (US\$13,700ASD vs US\$8560noASD)

The presence of a psychiatric comorbidity among adults with ASD increased the annual total expenditures by US\$4952.

Table 1. Psychiatric co-morbidity in individuals assessed for possible ASD in adulthood.

	ASD group, N (%)	Non-ASD group, N (%)	χ^2 (d.f.), p**	UK Adult Psychiatric Morbidity Survey 2007 ¹¹	ASD Group and UK Survey ¹¹ χ^2 (d.f. = 1), p**	Non-ASD group and UK Survey χ^2 (d.f. = 1), p**
ADHD	46 (9.7)	39 (10.1)	ns	2.3%	ns	Ns
Specific phobia	2 (0.4)	2 (0.5)	ns	All phobias: 1.4%	581.68 ***	333.26***
Agoraphobia	19 (4)	7 (1.8)	ns			
Social phobia	59 (12.4)	47 (12.2)	ns			
Panic disorder	1	0	ns	1.1%	ns	
Generalised anxiety disorder	56 (11.8)	46 (11.9)	ns	4.4%	52.04***	45.08***
OCD	85 (17.9)	51 (13.2)	*3.50(1)	1.1%	603.77***	330.21***
Any anxiety disorder	186 (39.2)	127 (32.9)	*3.58(1)			
PTSD/acute stress reaction	2	0	ns	3%	10.73***	
Depressive episode	75 (15.8)	49 (12.7)	ns	2.3%	259.44***	141.17***
BPAD	4 (0.8)	5 (1.2)	5.760 (2)			
Any mood disorder	95 (20)	86 (22.3)	ns			
Specific personality disorder	4 (0.8)	8 (2.0)	ns	0.7% (antisocial, borderline personality disorders)	ns	8.82**
Psychotic disorder	10 (2.1)	16 (4.1)	ns	0.4%	24.12***	82.22***
Schizophrenia	6 (1.2)	9 (3.2)	ns			
Schizotypal disorder	4 (0.8)	7 (1.8)	ns			
Alcohol dependence	3 (0.6)	10 (2.5)	5.686 (2)	5.9%	23.44***	7.37**
Drug dependence	1	5 (1.2)	ns	3.4%	14.61***	5.07*
Eating disorder	1	0	ns	1.6%	5.72*	
Tic disorder	7 (1.4)	1	ns			
Genetic condition	6 (1.2)	6 (1.5)	ns			

ASD: autism spectrum disorder; d.f.: degree of freedom; ADHD: attention deficit hyperactivity disorder; ns: not significant; OCD: obsessive compulsive disorder; PTSD: post-traumatic stress disorder; BPAD: bi-polar affective disorder.

*p < 0.05; **p < 0.01; ***p < 0.001.

BORDERLINE INTELLIGENCE AND PSYCHIATRIC VULNERABILITY

N = 8450 adults

- around 1/8 of the population has borderline intelligence (12,3% of the sample)
- this people present higher rate of:
 - neurotic disorders
 - substance abuse
 - personality disorders
 - social disability
 - psycho-pharmacological therapies, but not speech therapies
 - health service use, including emergency services

FATTORI DI VULNERABILITÀ PER LA PERSONA CON DI

- danno cerebrale
- disabilità fisica cronica
- perdite ripetute
- problemi di comunicazione
- mancanza di relazioni soddisfacenti
- mancanza di occupazioni e ambiti ricreativi soddisfacenti
- fallimenti ripetuti e rifiuti
- eventi di vita negativi
- difficoltà di controllo su circostanze personali e situazioni di vita

COMPLESSITÀ DELLA FENOMENOLOGIA DEI DISTURBI PSICHIATRICI NELLA DI

- **distorsione intellettiva¹**
livello di funzionamento cognitivo, comunicativo, fisico e sociale
- **appropriatezza evolutiva²**
livello di sviluppo individuale
- **mascheramento psicosociale³**
influenze interpersonali, culturali e ambientali
- **sovrapposizione diagnostica⁴**
differenziare fra sintomi psichiatrici e segni e sintomi del disfunzionamento cognitivo di base
- **presentazione atipica o mascherata²**
aggressività, urla, comportamenti disadattivi, ecc.
- **vulnerabilità neurovegetativa**
sintomi somatici, cambiamenti del ritmo circadiano, distonie NV
- **disintegrazione cognitiva³**
compromissione dei meccanismi di coping e soglia più bassa

1. Sovner R, DesNoyers Hurley A. Four factors affecting the diagnosis of psychiatric disorders in mentally retarded persons. *Psychiatric Aspects of Mental Retardation Reviews* 1986; 5: 45–48.

2. Cooper SA., Salvador-Carulla L. (2009) Intellectual Disabilities. in I.M. Salloum and J.E. Mezzich Eds. *Psychiatric Diagnosis: Challenges and Prospects*. John Wiley & Sons, Ltd

3. Sovner R. Limiting factors in the use of DSM-III criteria with mentally ill/ mentally retarded persons. *Psychopharmacol Bull* 1986; 24:1055–1059.

4. Reiss S, Syszko J. Diagnostic overshadowing and professional experience with mentally retarded persons. *Am J Ment Deficiency* 1993;87:396–402.

FENOMENOLOGIA DEI SINTOMI PSICHIATRICI NEI DSI:

EPIODIO DEPRESSIVO MAGGIORE (DM-ID II) - 1

DSM-5	DM-ID II (adattamento da lieve a gravissimo)
<p>A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.</p> <p>Note: Do not include symptoms that are clearly attributable to another medical condition.</p> <p>1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). (Note: In children and adolescents, can be irritable mood.</p>	<p>A. Four (or more) symptoms have been present during the same 2-week period and represent a change from previous functioning: At least one of the symptoms is either (1) depressed mood, (2) loss of interest or pleasure, or (3) irritable mood.</p> <p>Note: Do not include symptoms that are clearly attributable to another medical condition.</p> <p>1. Depressed or irritable mood most of the day, nearly every day, as indicated by either subjective report or observation made by others.</p> <p>Note: In people with ID, depressed mood may be described by others in one or more of the following ways, that constitutes a change from what is usually observed in this individual: sad facial expression, flat affect or absence of emotional expression, rarely smiles or laughs, cries or appears tearful.</p> <p>Note: Observers may describe individuals with ID who are irritable as: appearing grouchy or having an angry facial expression, having the onset of (or increase in) agitated behaviors (assaults, self-injurious behavior, spitting, yelling, swearing, disruptive or destructive behaviors) accompanied by angry affect.</p>

FENOMENOLOGIA DEI SINTOMI PSICHIATRICI NEI DSI:

EPIODIO DEPRESSIVO MAGGIORE (DM-ID II) - 2

DSM-5	DM-ID II (adattamento da lieve a gravissimo)
<p>2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation).</p>	<p>2. No adaptation.</p> <p>Note: Observers may report the individual with ID: refuses preferred activities, appears withdrawn, spends excessive time alone (more time than before), participates but shows no signs of enjoyment, becomes aggressive in response to request to participate in activities he or she used to like, has lost response to reinforcers, finds previously motivating events or objects no longer motivating, avoids social activities, aggresses or becomes agitated when prompted to attend social activities once enjoyed.</p>

FENOMENOLOGIA DEI SINTOMI PSICHIATRICI NEI DSI

SINTOMI DI SCHIZOFRENIA - 1

- fissare con lo sguardo una zona dell'ambiente, in cui non sembra esserci nulla di particolarmente interessante da vedere (allucinazioni visive)
- fare cenni col capo (allucinazioni uditive o visive)
- fare gesti con le mani con apparente valore reattivo o comunicativo (allucinazioni uditive o visive)
- girarsi improvvisamente come verso una fonte sonora (allucinazioni uditive)
- muoversi come se stesse difendendosi o combattendo (allucinazioni visive)
- muoversi come se stesse amoreggiando (allucinazioni visive e tattili)
- fare gesti come se volesse togliersi qualcosa dalla pelle o dal corpo (allucinazioni tattili)

FENOMENOLOGIA DEI SINTOMI PSICHIATRICI NEI DSI

SINTOMI DI SCHIZOFRENIA - 2

- indossare indumenti pesanti, aderenti o vestiti con molti strati di indumenti (allucinazioni propriocettive, gli abiti vengono interpretati come contenitori per impedire la fuoriuscita di parti del corpo percepite come instabili)
- coprirsi gli occhi o le orecchie con le mani o le dita (allucinazioni uditive o visive)
- coprirsi gli occhi o tapparsi le orecchie con materiali vari (allucinazioni visive, uditive o cenestesiche)
- fasciarsi le caviglie o i polsi con materiali vari (allucinazioni propriocettive)
- guardare male o addirittura con rabbia persone prima apprezzate o persone estranee (allucinazioni visive)
- evita o si nasconde da persone familiari o con le quali ha un buon rapporto (allucinazioni visive)

FENOMENOLOGIA DEI SINTOMI PSICHIATRICI NEI DSI

SINTOMI DI SCHIZOFRENIA - 3

- indossare copricapi, bandane o foulard in modo inadeguato al resto dell'abbigliamento e al contesto (allucinazioni uditive o cenestesiche)
- ispezionare oggetti, cibo o bevande con intensità esagerata e inusuale (allucinazioni visive o olfattive)
- fa smorfie o si allontana come se percepisse odori insopportabili (allucinazioni olfattive)
- emette suoni col naso come se sniffasse o odorasse l'aria per verificare la presenza di gas (allucinazioni olfattive)
- ha difficoltà a concludere sequenze di azioni, mostra comportamento disorganizzato o si esprime in modo disorganizzato o incoerente
- mostra atteggiamenti di diffidenza nei confronti degli altri e/o comportamenti sostenuti da ostilità ingiustificata

FENOMENOLOGIA DEI SINTOMI PSICHIATRICI NEI DSI: SINTOMI DI SCHIZOFRENIA

- resta in posizione di ascolto e/o risponde a suoni o voci non udibili
- indirizza lo sguardo verso zone dove non ci sono oggetti da vedere e/o fissa ripetutamente lo sguardo
- mostra una tendenza eccessiva ad identificarsi con persone o oggetti
- attribuisce arbitrariamente nessi di causa-effetto con autoreferenzialità
- ha difficoltà a concludere sequenze di azioni, mostra comportamento disorganizzato o si esprime in modo disorganizzato o incoerente
- mostra atteggiamenti di diffidenza nei confronti degli altri e/o comportamenti sostenuti da ostilità ingiustificata

MANUALI DIAGNOSTICI PER I DSI/DSA

Diagnostic Criteria for Learning Disability (DC-LD; 2001) adattamento dell'ICD-10 del Royal College of Psychiatrists (UK)



Diagnostic Manual – Intellectual Disability (DM-ID; 2016) adattamento del DSM-5 da parte della National Association for Dual Diagnosis (USA)



SPAIDD

(Systematic Psychopathological Assessment
for people with Intellectual and Developmental Disabilities)

The SPAIDD project was started in response to the scientific need of a deeper understanding of the issues related to psychiatric comorbidity in IDD, especially in terms of clinical and epidemiological features, and to provide the various professionals working in this field with a tool for psychopathological evaluation able to elaborate a more refined assessment method.

Is the first Italian toolpackage for carrying out psychiatric diagnosis in PwIDD.

It includes: a general version (SPAIDD-G) for the preliminary identification of the most important psychopathologic diagnostic areas for general diagnostic orientation, and area-specific modules (**SPAID-P; SPAID-ASD; SPAID-A; SPAID-M**).

All tools involved in SPAID system were constructed considering the possibility of identifying psychiatric symptoms starting from the **observation of behaviors**, which is the only survey method applicable to all IDD cases.

IMPLICAZIONI DELLE EVIDENZE SUI SERVIZI E SULLE PRATICHE DI SALUTE MENTALE PER I DNS

- vulnerabilità multi-sistemica sequenziale
- multi-disciplinarietà
- trasversalità nosologica
- considerazione dell'intero arco della vita
- Neuro-caratterizzazione
- pianificazione degli interventi e valutazione degli esiti centrata-sulla-persona (differenziazione delle opportunità e integrazione dei servizi)



QUALITÀ DI VITA

Normalizzazione

restituire l'integrità strutturale e funzionale

Incremento della Qualità di Vita

aiutare a essere soddisfatti della propria vita

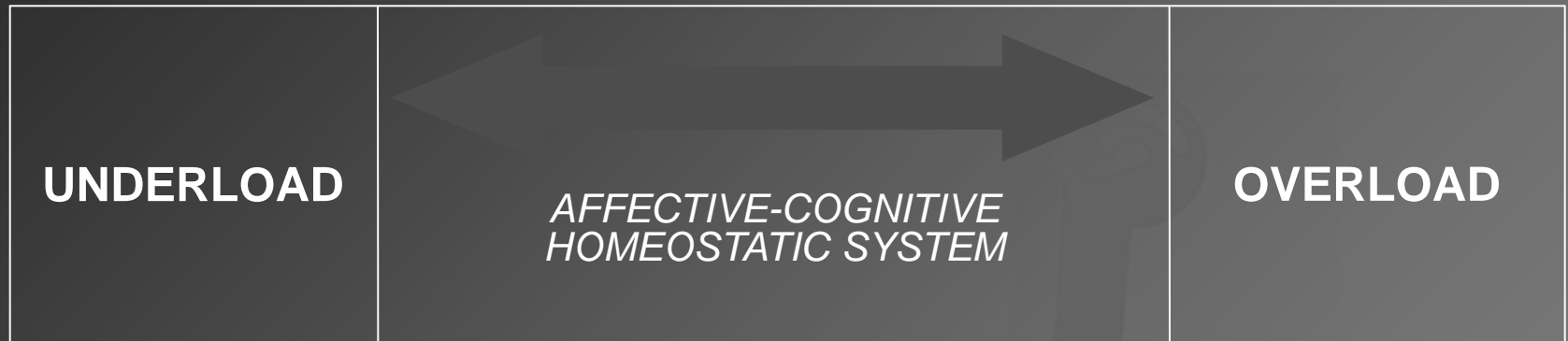
QoL vs SUBJECTIVE WELL-BEING

- Subjective well-being concerns itself primarily with affective states, positive or negative¹
- QOL implies a broader assessment and although affect-laden, it represents a subjective evaluation of oneself and one's social and material world¹.
The exploration refers to those areas and dimensions of life that are applicable to anybody's life²

1. Orley J., Saxena S., Herrman H. Quality of life and mental illness. Reflections from the perspective of the WHOQOL. BJP, 1998

2. Bertelli M. e Brown I. Quality of Life for PWID. Current Opinion in Psychiatry, 2006; 19:508-513

THE BALANCE OF SWB



Variables indicator of Subjective Well-Being should be considered as the least sensitive subjective measures

GENERIC QOL VS HR QOL

Generic: subjective modulation in those areas of life that are applicable to anybody's life

Health-Related: mixture of clinical or dysfunctioning aspects, compared to normality

SELF AND PROXY RELIABILITY FOR PWIDD

614 adults with IDD from 6 international centres

874 proxies (professional carers and relatives)

WHOQOL-BREF-DIS

RESULTS

- significant moderate association between self and proxy assessment in all QoL domains
- mean scores of people with disabilities tend to be higher
- factors which seems to most significantly contribute to these differences:
 - proxy knowledge of the person
 - WHODAS-disability score
 - cultural level doesn't seem to significantly impact on concordance

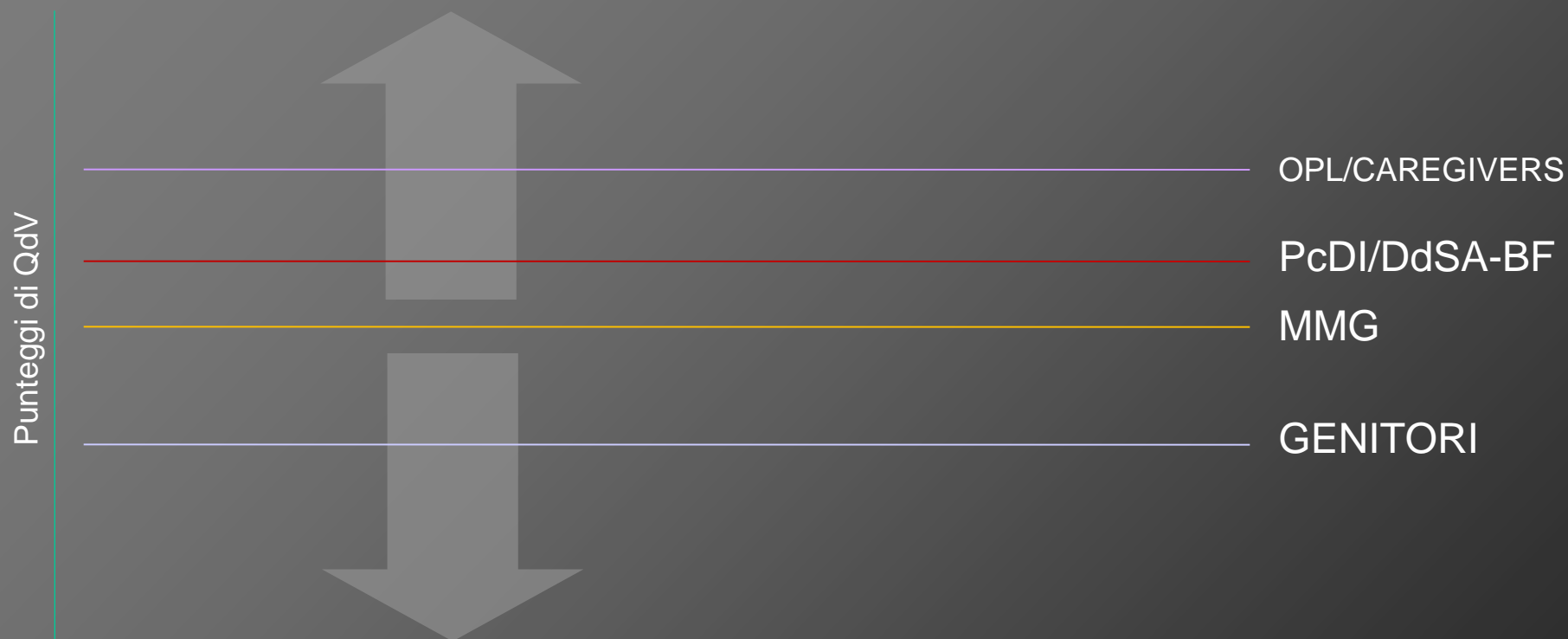
RELIABILITY OF SELF REPORT IN ASD

39 adolescents with ASDs (IQ >70) and their parents completed a QoL (Pediatric Quality of Life Inventory) instrument and brief measures of psychosocial distress and self-esteem.

RESULTS

- Adolescent self-reports of QoL demonstrated internal reliability and concurrent validity
- Self-reports demonstrated moderate to large positive correlations with a measure of self-esteem and moderate to large negative correlations with measures of anxiety and mood
- Concurrent validity with parent proxy reports fell within the range of expected values based on past studies of inter-rater reliability for QoL (reporting lower QoL when compared with adolescent reports)
- Adolescents reported QoL below the population mean for all domains.

QdV: differenze nella valutazione



LEGENDA

OPL= Operatori di Prima Linea

PcDI/DdSA= Persona con Disabilità Intellettiva/Disturbo dello Spettro Autistico

MMG = Medico di Medicina Generale

LIMITS OF QoL INSTRUMENTAL ASSESSMENT

- Validity
- Time of administration / completion
- Extension / Number of item
- Intelligibility
- Reliability

THE QOL-Q DOMAINS

QoL Factor	QoL Domain ²	QoL indicators
Independence	Personal Development	personal Skills (e.g. adaptive behaviour)
	Self-Determination	choices/decisions autonomy/control
Social Participation	Interpersonal Relations	social networks friendships social activities
	Social Inclusion	involvement in community community role
	Rights	equal opportunities legal access
Well-Being	Emotional Well-Being	safety and security protection from abuse positive experiences
	Physical Well-Being	health status nutritional status physical exertion
	Material Well-Being	income possessions

THE 9 AREAS OF LIFE OF THE QOL-IP

BEING (who the patient is as a person)

- **PHYSICAL BEING**
- **PSYCHOLOGICAL BEING**
- **SPIRITUAL BEING**

BELONGING (relates to connections with one's environments)

- **PHYSICAL BELONGING**
- **SOCIAL BELONGING**
- **COMMUNITY BELONGING**

BECOMING (relates to achieving personal goals, hopes and aspirations)

- **PRACTICAL BECOMING**
- **LEISURE BECOMING**
- **GROWTH BECOMING**

QdV: Caratteristiche

- Importanza attribuita dall'individuo
- Soddisfazione percepita dall'individuo
- Opportunità disponibili
- Scelte fatte dall'individuo

SIQF

STRUMENTO DI INDAGINE DELLA
QUALITÀ DI VITA DELLA FAMIGLIA

Per i fornitori di assistenza e cura più vicini alla persona con disabilità intellettiva
Firenze - 2006

'Family Quality of Life Survey' di
Ivan Brown
Roy I. Brown
Nehama T. Baum
Barry J. Isaacs
Ted Myerscough
Shimshon Neikrug
Dana Roth
Jo Shearer
and Mian Wang

Adattamento italiano a cura di

Marco Bertelli
Annamaria Bianco
Francesca Gheri

SECTIONS

Instructions for Completing the SIQF

About your Family

1. FAMILY HEALTH
2. FINANCIAL WELLBEING
3. FAMILY RELATIONSHIPS
4. SUPPORT FROM OTHER PEOPLE
5. SUPPORT FROM D-R SERVICES
6. INFLUENCE OF VALUES
7. CAREERS AND PREPARING FOR CAREERS
8. LEISURE AND RECREATION
9. COMMUNITY INTERACTION
10. OVERALL FAMILY QoL

FAMILY QOL: DIMENSIONS

- Importance
- Satisfaction
- Attainment
- Initiative
- Stability
- Opportunity



UN NUOVO MODELLO DI INTERVENTO PER I DISTURBI DEL NEUROSVILUPPO

PSICO-CARATTERIZZAZIONE

-
- ```
graph TD; A[PSICO-CARATTERIZZAZIONE] --> B[OFFERTA DI UN'AMPIA GAMMA DI OPPORTUNITÀ E SUPPORTI]; B --> C[MIGLIORAMENTO DEL RAPPORTO IMPORTANZA/SODDISFAZIONE]; C --> D[MIGLIORAMENTO DELLA QdV]; D --> B;
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- FUNZIONI COGNITIVE SPECIFICHE
  - ABILITÀ INDIVIDUALI
  - ATTRIBUZIONE INDIVIDUALE DI IMPORTANZA
  - VULNERABILITÀ PSICO-FISICA
  - PRESENTAZIONE DEI SINTOMI
  - COMPORTAMENTI PROBLEMA

OFFERTA DI UN'AMPIA GAMMA DI  
OPPORTUNITÀ E SUPPORTI

MIGLIORAMENTO DEL RAPPORTO IMPORTANZA/SODDISFAZIONE  
MIGLIORAMENTO DELLA QdV

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