Inclusive Communities:
Pathways to Realizing the Vision

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Support Needs

Study on a Large Italian Population Comparing Supports Intensity Scale, Medical and Psychiatric Assessment, and A Regional Funds Allocation Tool

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General Aim

The aim was:

1. to implement a study on a large population of adults subjects with IDD, with a wide range of clinical and QOL indexes, examining different assessment systems for diagnosis and classification of psychopathology, functioning and needs of supports
2. to examine data within the different assessment tools, aligning them with a comprehensive QOL frame, and work out suggestion to help professionals working with IDD to select the more useful methodologies

Northern Italy

- Data comes from Lombardy
- Population: 10mil (like Georgia, double of Minnesota)
- Highest GDP (Gross Domestic Product) of all European Regions (35 billions of Euros); like Belgium
- Budget of 16 billions of Euros; 1,5 bils for social-medical care for disability;150 millions for social care for disability; Private funding (including families with co-partecipate)

Introduction: practices...

- Old models: most of facilities (at least in Italy) have assessment procedures based just on IQ tests or limitations/pathologies scales (reinforcing a "deficit model of IDD") (Corti, 2008)
- Old processes: limitations in assessment are related to problems in Personal Planning; if we reckon that most of the studies suggest that well being is linked to adaptation to the environment (Schalock, 2007), when we use modification planning which are not based on QOL assessment it is unlikely to have positive outcomes on QOL factors

Introduction: mental disorders and needs…

- The field of psychiatric epidemiology has yielded several large and important studies of the prevalence of **psychiatric disorders**. These surveys have been enhanced by the inclusion of methodologies that reflect the **NEEDS** of the population in question. Clinical studies of psychiatric disorders and unmet needs have focussed on identifying needs and correlating them with service evaluation and satisfaction measures. The association between prevalence, service use and unmet need requires review in order to establish whether there are trends and consistent findings.

(Joska J, Flisher AJ, 2005)

Key questions

The field of Intellectual Disabilities probably has one of the most strong need of consistency, in term of processes ("what we do"): we have hundreds of models, theories, interventions, etc...but we are far away from a common agreement both in scientific and clinical community...

1. Can we improve general knowledge about persons with IDD, exploring a wide range of variables in large and complex sample?
2. Can we give some suggestion to further research in order to implement some consistency in processes (i.e. the alignment between assessment and intervention)?

Study structure

- The study was divided into 4 main objectives:

1. To assess the all sample on multiple levels (descriptive an., functioning, needs, pathology, etc.)
2. To compare *pathology* with *needs*
3. To compare a regional *system of resources allocation* with *pathology* and *needs*
4. To compare all *assessment* measures to *intervention* processes

Methodology

- 406 subjects, living in a residential setting in Italy (Fondazione Sospiro), have been assessed on 6 instruments:
  1. SIS
  2. SIDI
  3. CIRS
  4. DASH-II
  5. ABC
  6. Farmacological intervention analysis tool
  7. Educational intervention analysis tool
- Statistical (SPSS) analysis have been performed on data

Assessment tools

Aberrant Behavior Checklist - ABC (Aman MG, Borrow WH, Wolford PL., 1995):

this scale was used to examine CBs; the scale has 58 items, rated on a Likert scale to assess problem behavior on 4 main domains

Comorbidity Index Rating Scale – CIRS (Parmalee PA, Thuras PD, Katz IR, Lawton MP, 1995; Chiodelli et al., 2010):

this scale was used to analyze specific categories of diseases into 14 subscales: 1) Heart, 2) Hypertension, 3) Vascular, 4) Respiratory, 5) ENT (ear, nose and throat), 6) GI superior, 7) GI inferior, 8) Liver, 9) Kidney, 10) Genitourinary, 11) Muscle, skeletal, skin, 12) SNC, 13) Endocrine metabolic; 14) Psychiatric and behavioral

And 2 composite scores: SEVERITY and COMORBIDITY. The rating is made on a 5 points Likert Scale: 1: absent; 2: mild; 3: moderate; 4: severe; 5: profound. We used a version adapted for IDD population.

Assessment tools

The Diagnostic Assessment for the Severely Handicapped-II – DASH-II (Matson, J.L., 1991, 1994, 1998; Guaraldi et al., 2002):

The DASH-II is an 84-item psychopathology screening instrument; this scale was used to analyze specific categories of diseases into 13 subscales: (1) autism and PDD, (2) organic syndromes, (3) anxiety, (4) mood d., (5) mania, (6) schizophrenia, (7) stereotypies and tics, (8) self-injurious behavior, (9) elimination d., (10) eating d., (11) sleep d., (12) sexual d., and (13) impulse control and other miscellaneous behaviors.

Items are scored on three dimensions: frequency, duration and severity.

Supports Intensity Scale - SIS (Thompson et al., 2005; It. trans. 2007-2008):

this scale was used to examine the needs of supports, assessed in a QOL perspective; the scale has 1 section with 49 items rated on 3 factors which produce a standardized measure of needs, plus a section dedicated to rights and 2 section dedicated to exceptional needs on medical and behavioral condition

SIDI (Lombardy Region): this scale is an Italian regional system used to allocate funds (in terms of resources) to persons with IDD. Is was built collecting items from various instruments and models; it produces a classification divided into 5 categories directly related to resources (minutes of paid work)

OBJECTIVE 1: To assess the all sample on multiple levels

- Age
- Sex
- Years lived in residential setting
- ABC
- CIRS revised
- DASH-II
- SIS
- Pharmacological treatment (AD, BDZ, AP, AP off label, AED, other medications)
- Educational interventions (coded using QOL domains and Supports activities)

- N. 406 subjects
- Mean age = 55,992
- DS =11,996; range 18-90 years
- Sex: 297 male, 109 female
- Years of life in residential service:
  - mean 32 years
  - range 1-70 years

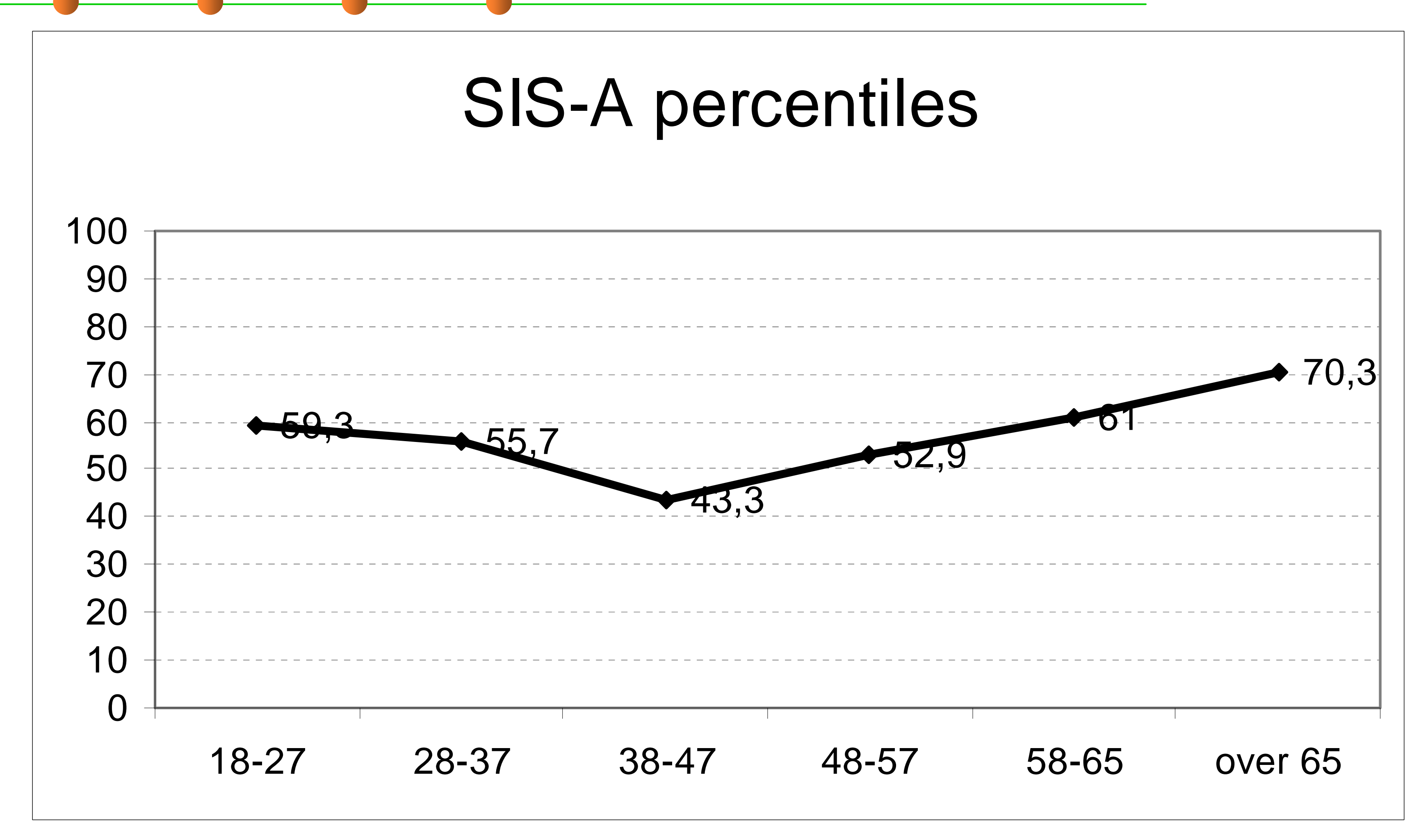
100
90
80
70
60
50
40
30
20
10
0

A B C D E F

PERCENTILE SD

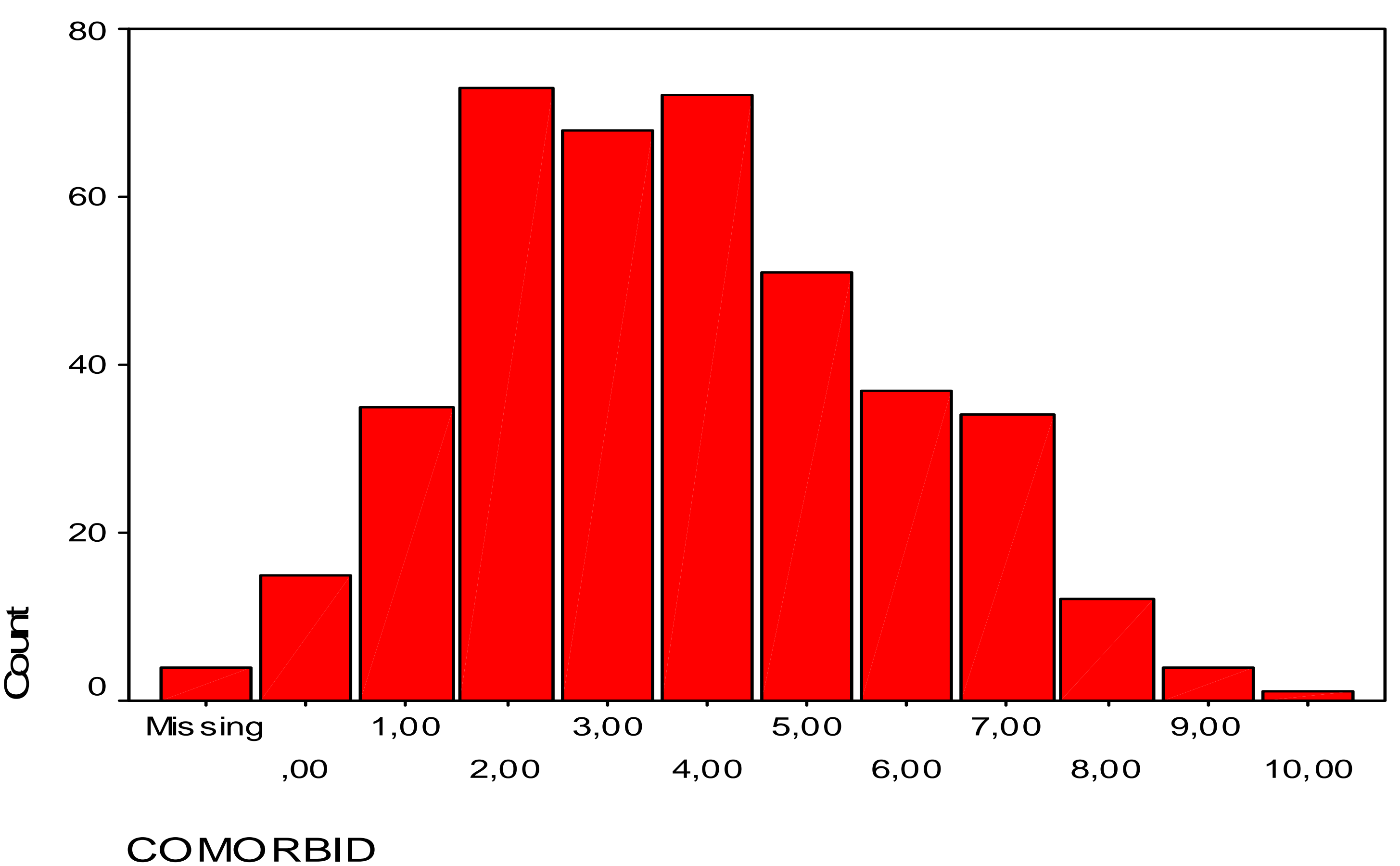
A. Home Living, **B.** Community Living, **C.** Lifelong Learning, **D.** Employment, **E.** Health and Safety, and **F.** Social

An example: Home living activities per age



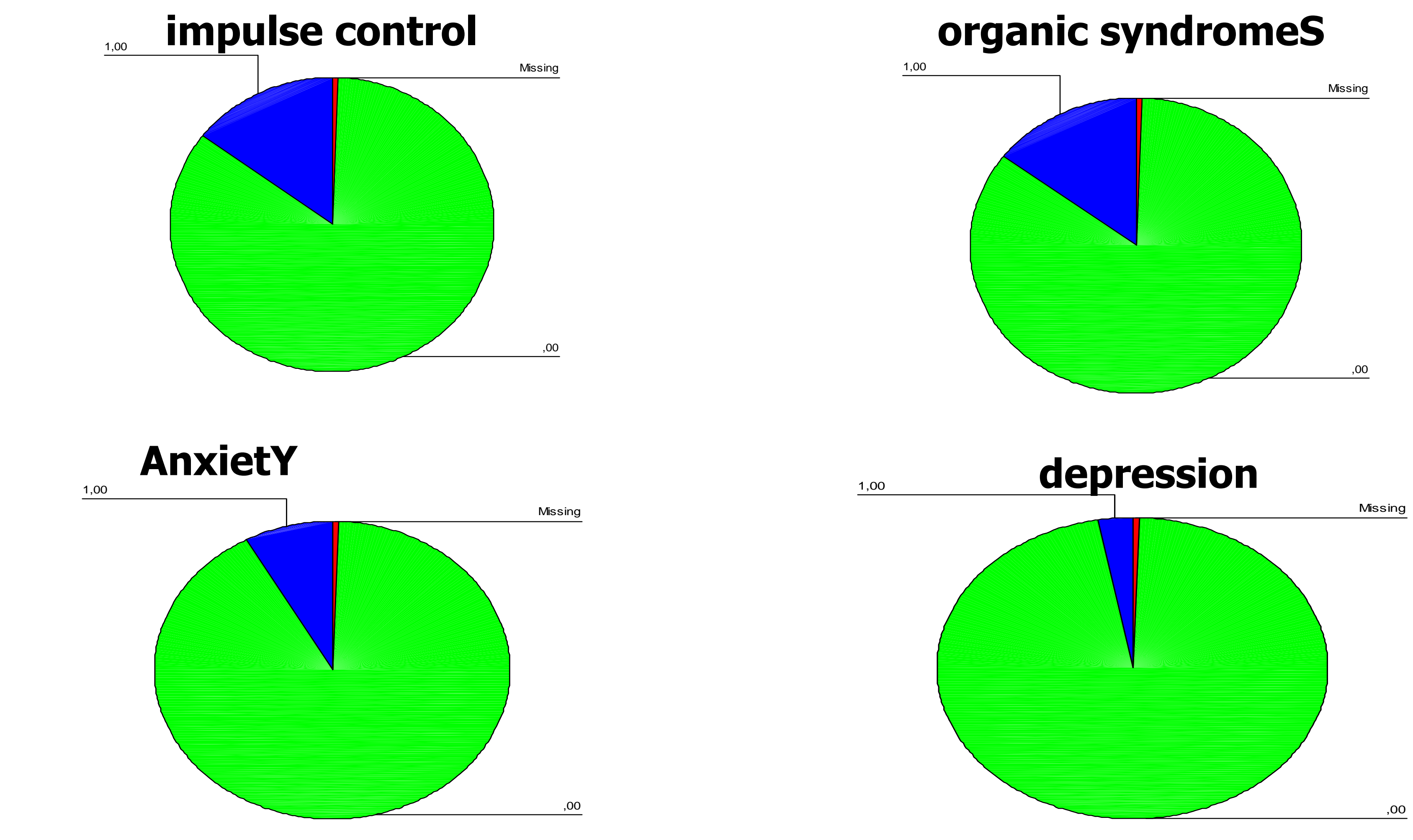
CIRS:

M=1,898; SD=0,442 (n= 406)

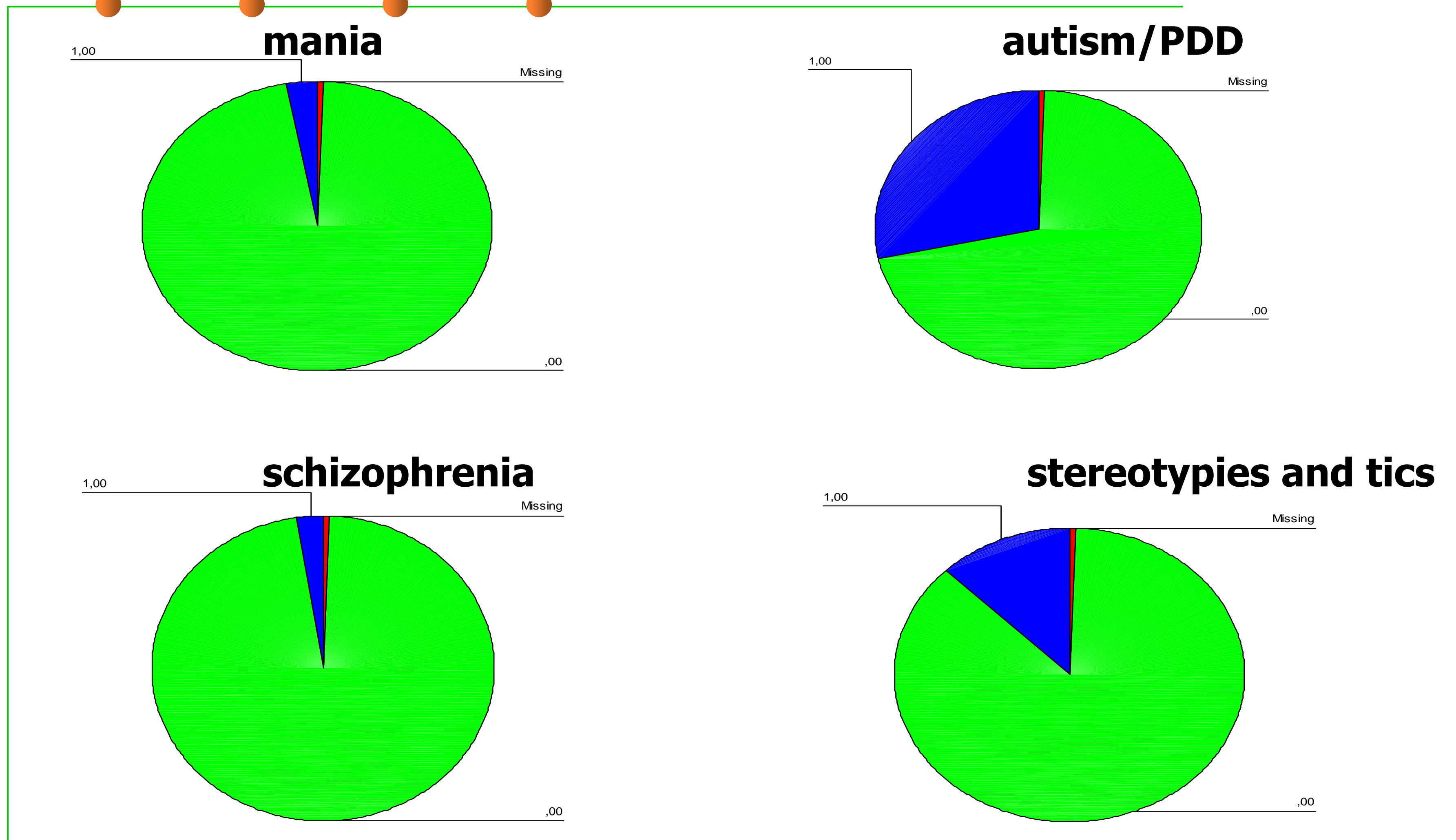


1) Heart, 2) Hypertension, 3) Vascular, 4) Respiratory, 5) ENT (ear, nose and throat), 6) GI superior, 7) GI inferior, 8) Liver, 9) Kidney, 10) Genitourinary, 11) Muscle, skeletal, skin, 12) SNC, 13) Endocrine metabolic

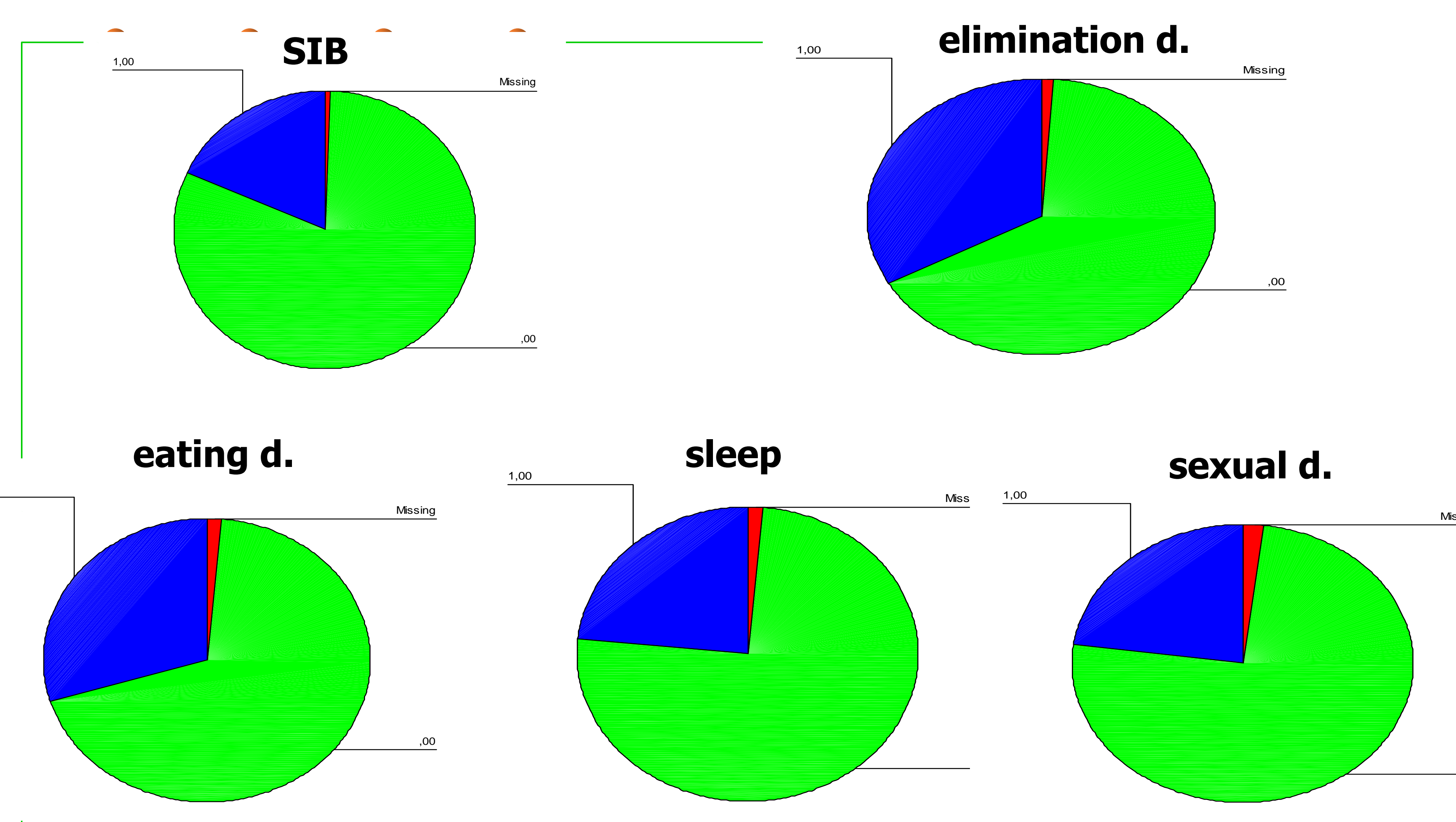
DASH (N=406)



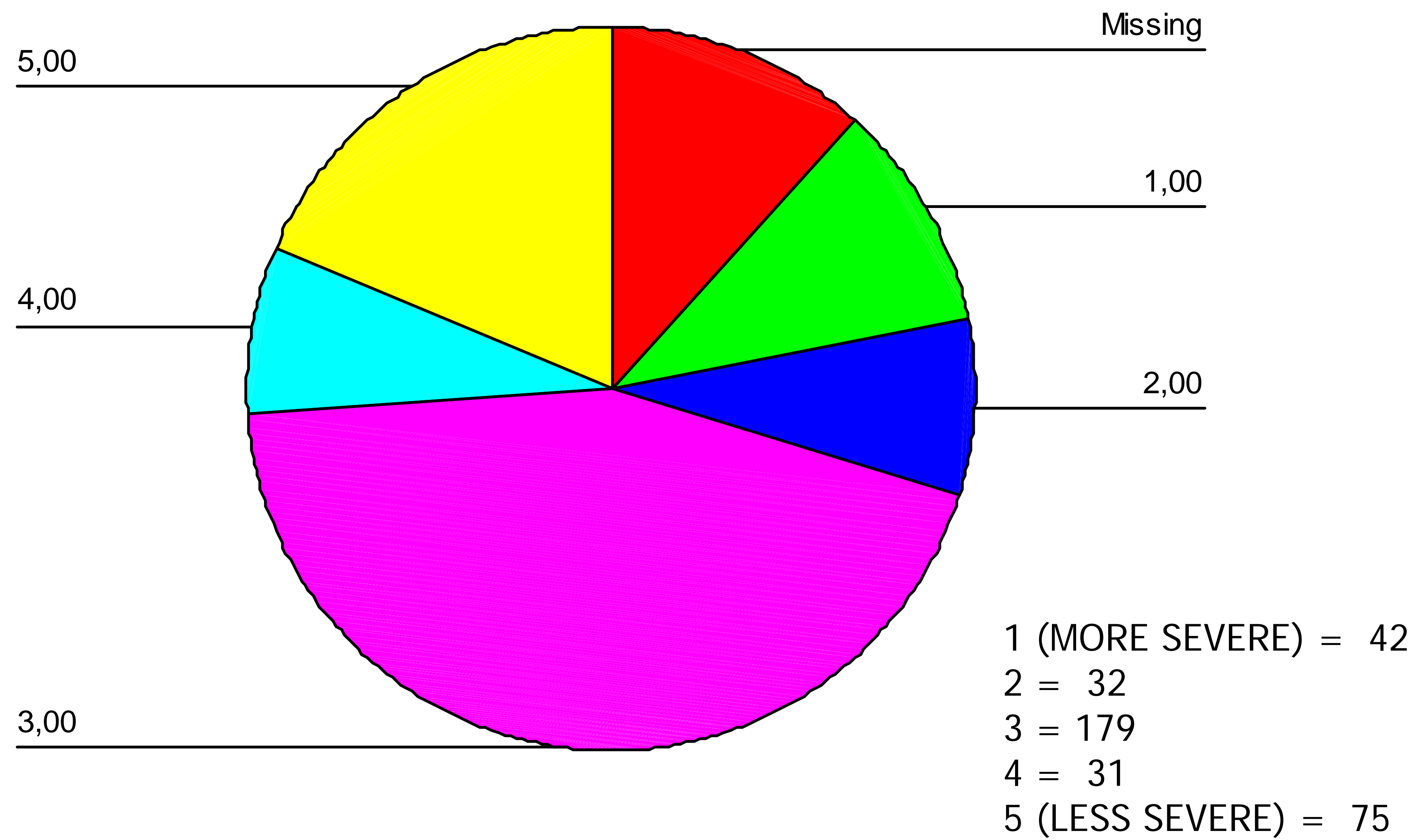
DASH cont



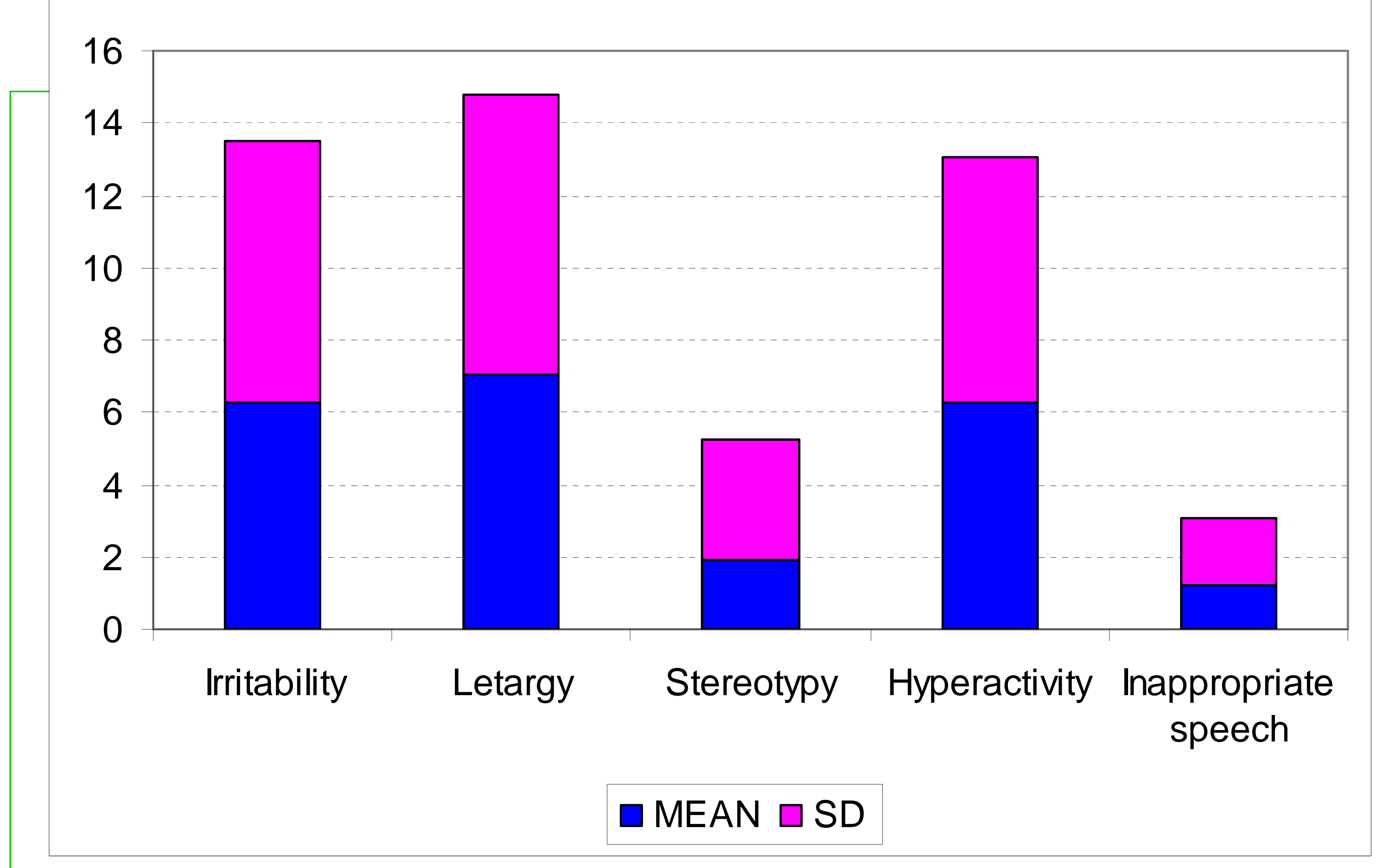
DASH cont



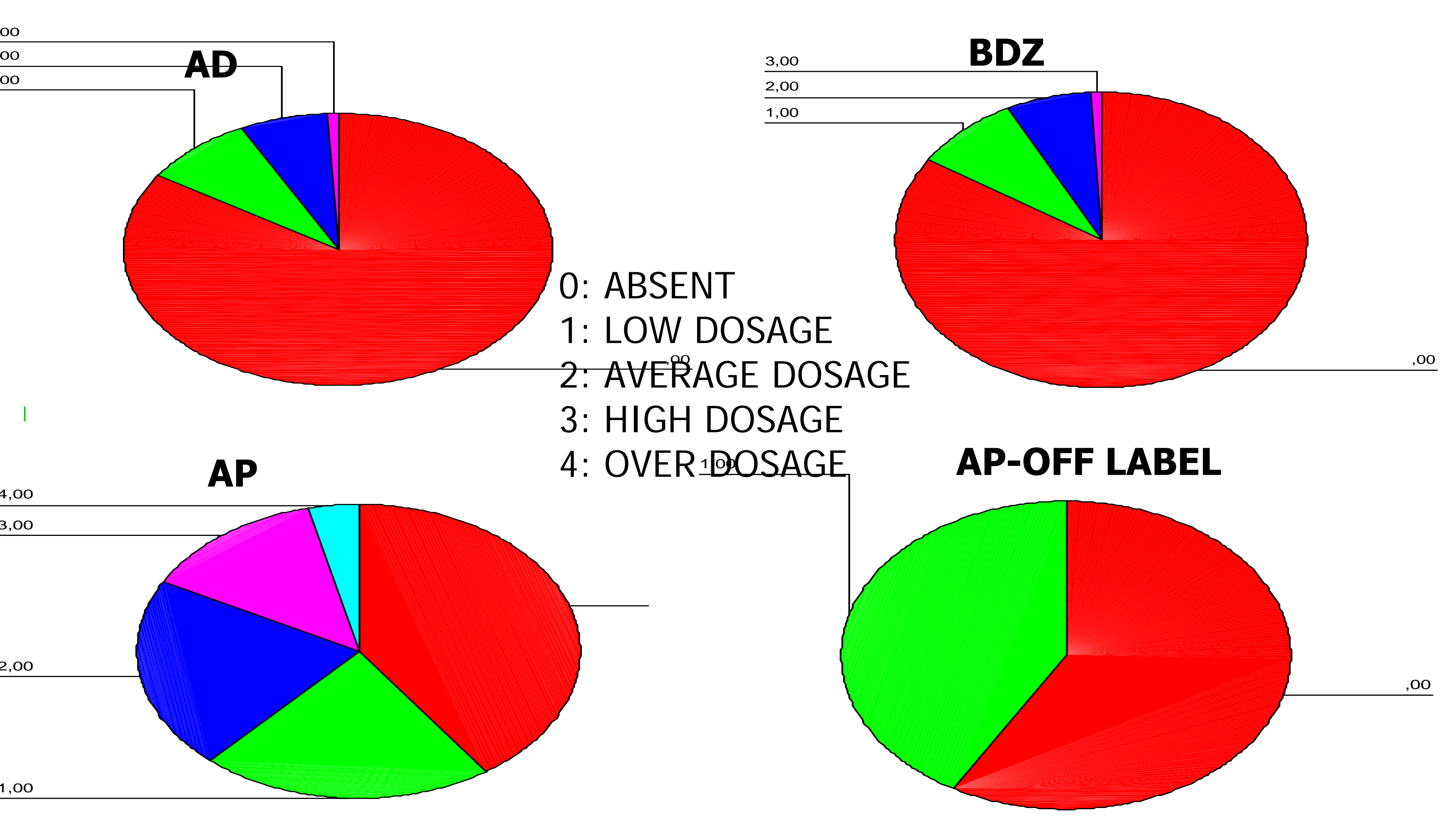
SIDI (n=406)

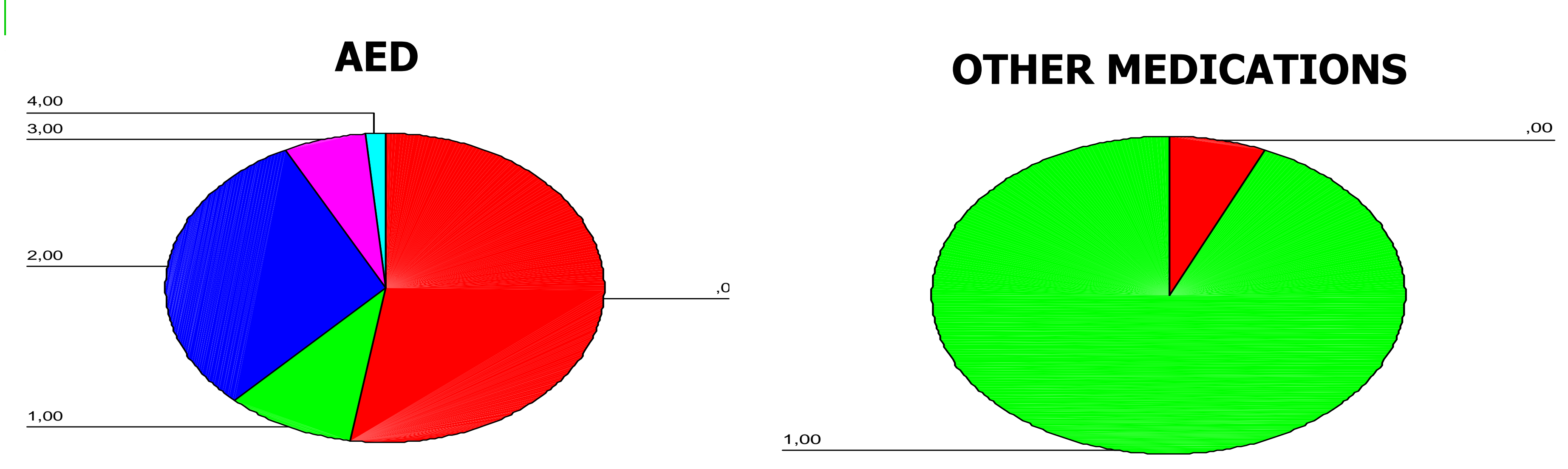


ABC (n=406)

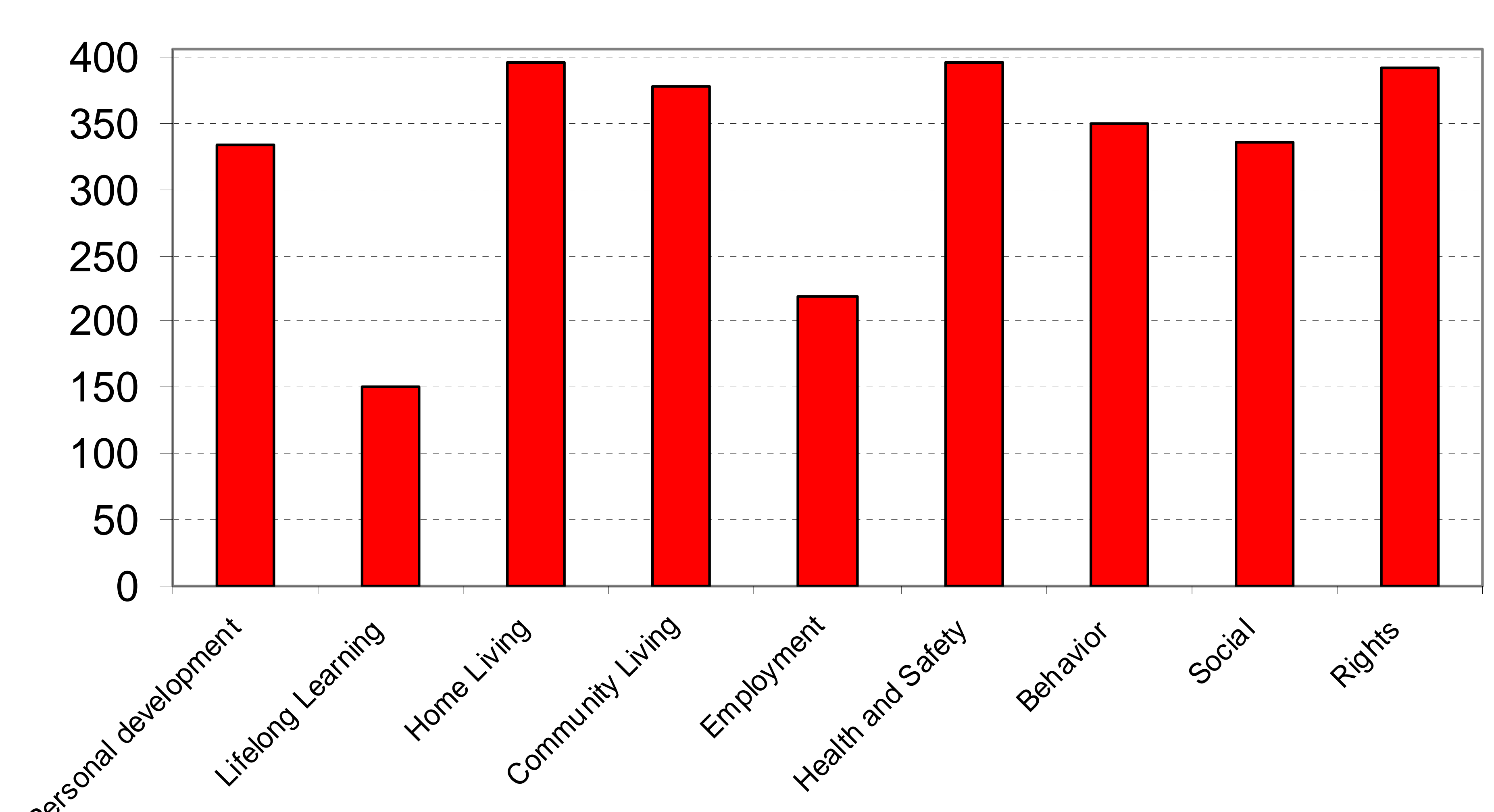


PSYCHOACTIVE MEDICATIONS





0: ABSENT
1: LOW DOSAGE
2: AVERAGE DOSAGE
3: HIGH DOSAGE
4: OVER DOSAGE


ISP areas with intervention in QOL perspective
(n of subjects with 1 or more modification objective)
400
350
300
250
200
150
100
50
0
Personal development
Lifelong Learning
Home Living
Community Living
Employment
Health and Safety
Behavior
Social
Rights

Age factor analysis

- **AGE vs SIS, ANOVA**: non significant, veen if we note a decrese of needs with the increase of age, we reckon this data are referred to systematic bias like a **lower expectation perspective towards older people with IDD**
- **AGE vs CIRS, ANOVA**: significant, **when age increase increase organic syndromes as well**; this data reinforce the hypothesis that SIS and CIRS (adapted for IDD pop.) measere different factors, meaning that supports needs and physical diseases are different and NOT related
- **AGE vs ABC, ANOVA**: apparently significant, but with deeper analysis emerges that it is NOT significant; therefore types and patterns of CBs are NOT related to age
- **AGE vs DASH, CHI SQUARE**: non significant

OBJECTIVE 2: To compare *pathology* with *needs*

- **SIS vs DASH-II (ANOVA)**

SIS vs impulse control: people with this diagnosis has highr needs of support
SIS vs organic s.: too low nr of subjects with this diagnosis
SIS vs anxiety: anxiety doen NOT affect needs of support
SIS vs depression: too low nr of subjects with this diagnosis
SIS vs mania: too low nr of subjects with this diagnosis
SIS vs autismo/PDD: highly significant
SIS vs schizophrenia: too low nr of subjects with this diagnosis
SIS vs stereotypies/tic: significant
SIS vs SIB: highly significant
SIS vs elimination d.: highly significant
SIS vs eating: highly significant
SIS vs sleep: significant
SIS vs sexual d.: highly significant

We can conclude that **the need of supports (SIS) is generally consistent with the level of different psychopathological diseases (DASH)** (when it doen't emerge this is due to a too low nr of subjects with diagnosis)

OBJECTIVE 2: To compare *pathology* with *needs*

- **SIS vs CIRS (ANOVA)**

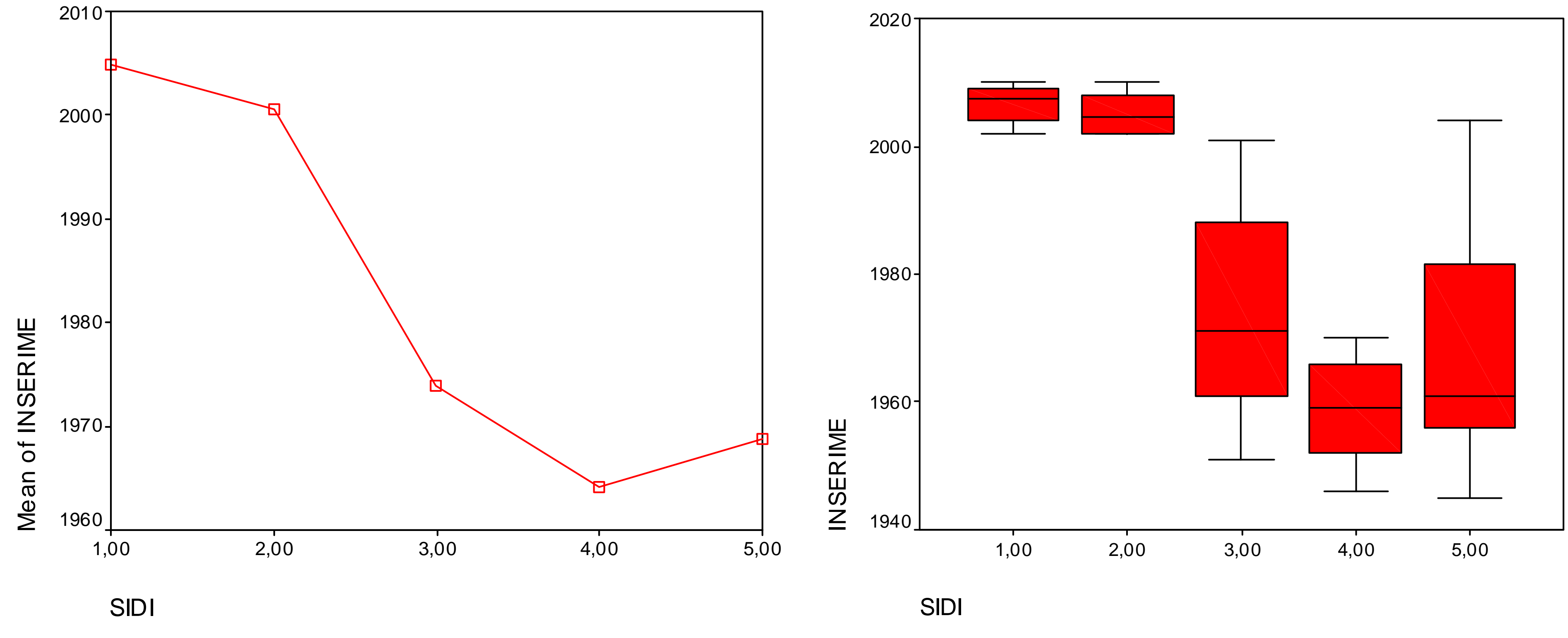
- Highly significant
- We can conclude that the **need of supports (SIS) is consistent with the level of different medical disease (CIRS** adapted for IDD pop.)

- SIS vs ABC (r)

- Highly significant
- We can conclude that **the need of supports (SIS) is consistent with the level of different CBs (ABC)**

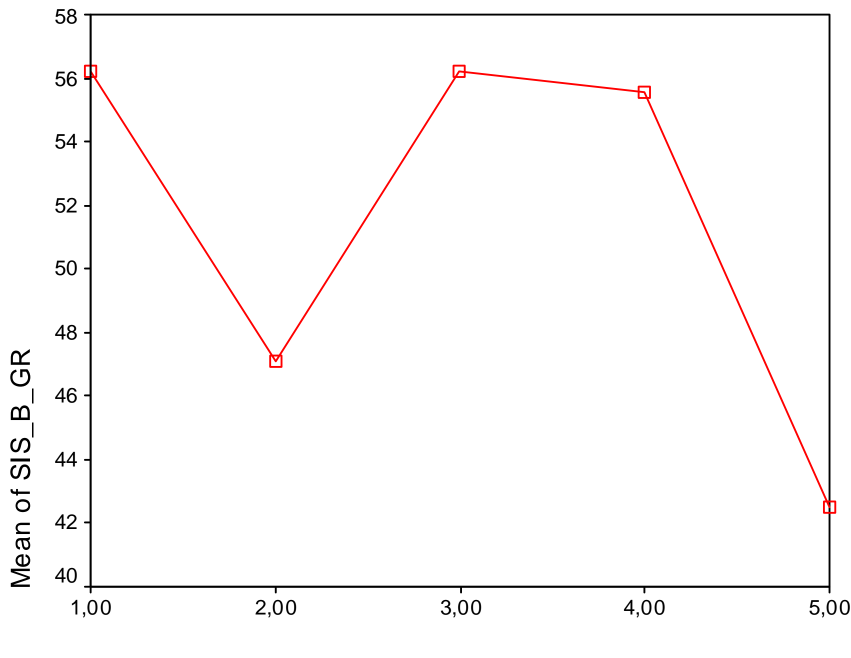
OBJECTIVE 3: To compare a regional *system of resources allocation* with *pathology* and *needs*

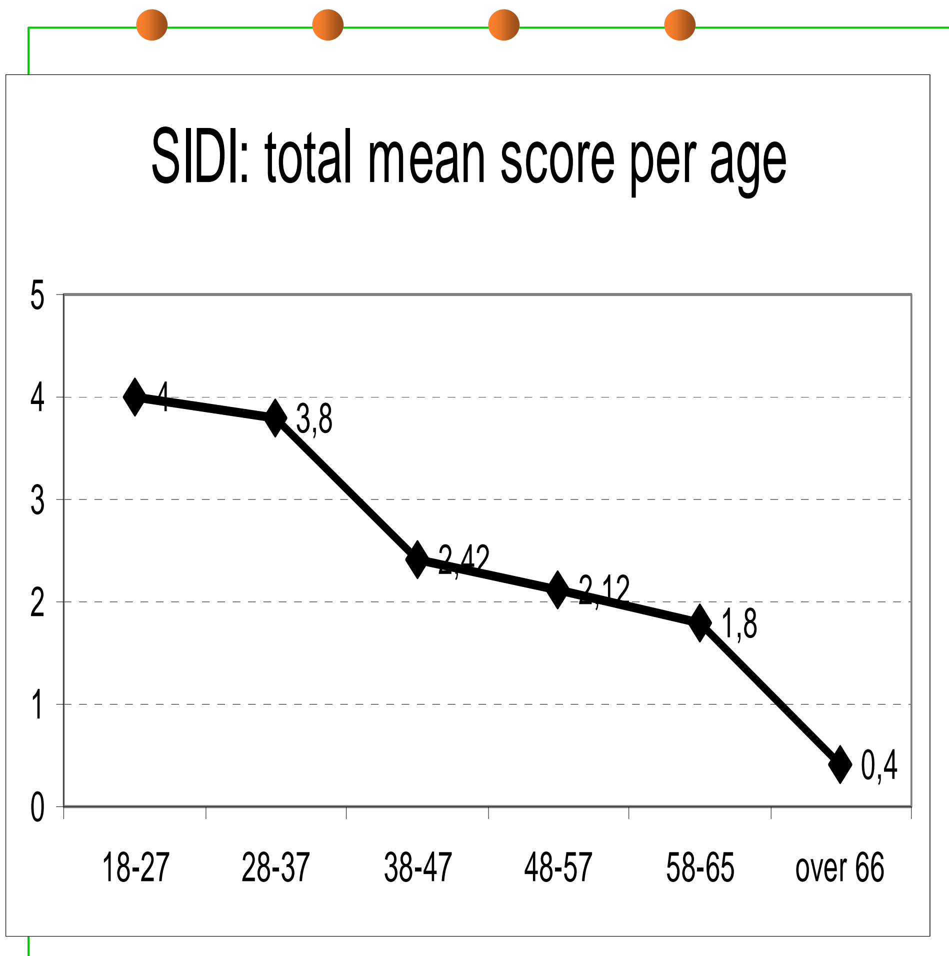
- **SIDI vs years of residential service**
- This variable, plus age, are those which determine the class of SIDI

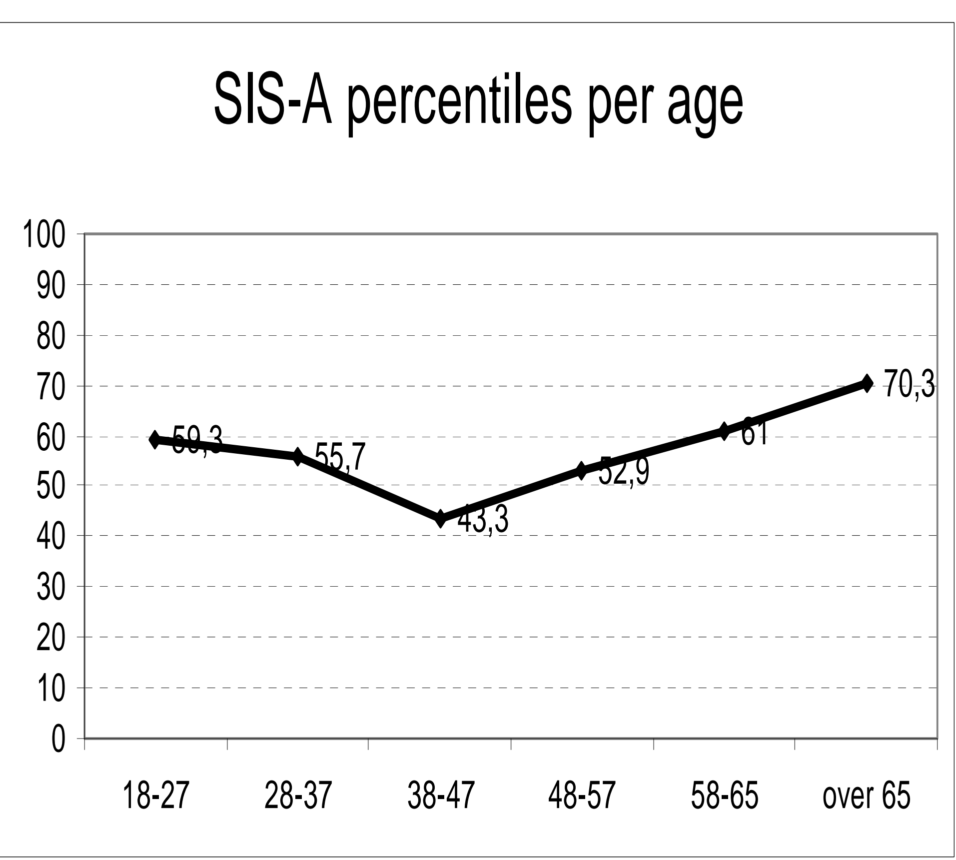


OBJECTIVE 3: To <u>compare</u> a regional *system of resources allocation* with *pathology* and *needs*

- **SIDI vs SIS (ANOVA; r)**
- The differencies are **NOT significant and makes NO sense**: subjects have higher classes of SIDI (i.e. more severe, more money) without having more needs
- Age is the main factor to determine SID classes scores




SIDI: total mean score per age
5
4
3
2
1
0
4
3,8
2,42
2,12
1,8
0,4
18-27
28-37
38-47
48-57
58-65
over 66

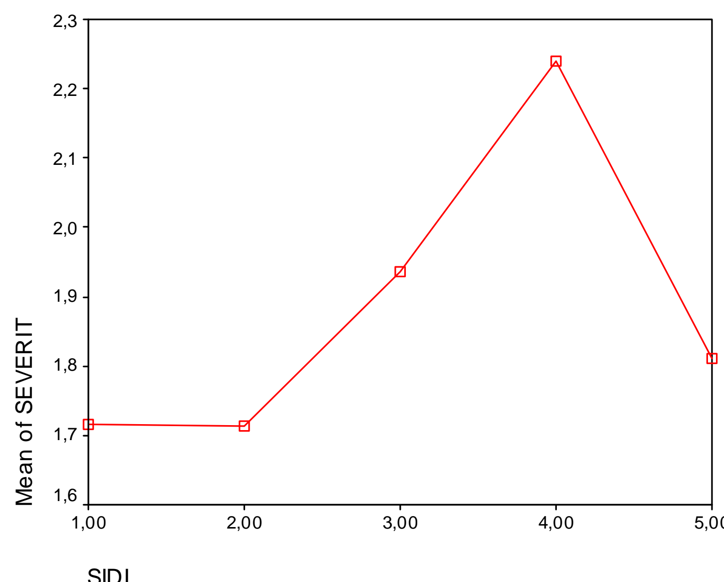

SIS-A percentiles per age
100
90
80
70
60
50
40
30
20
10
0
59,3
55,7
43,3
52,9
61
70,3
18-27
28-37
38-47
48-57
58-65
over 65

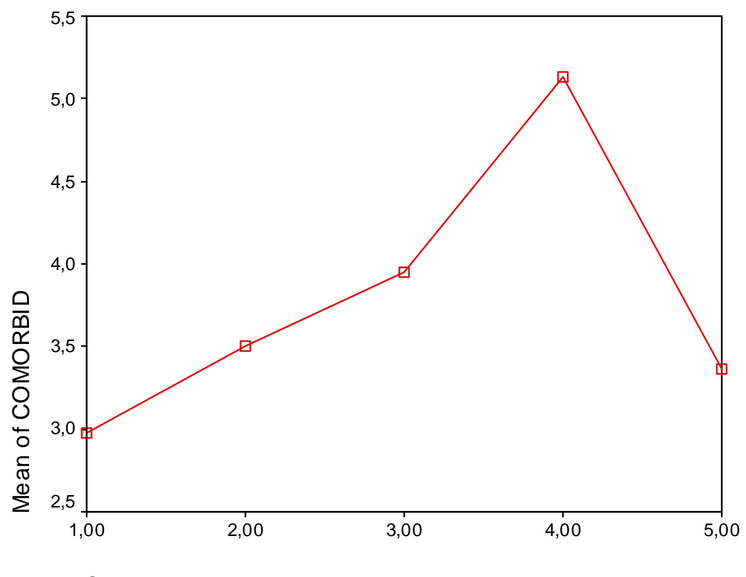
OBJECTIVE 3: To compare a regional *system of resources allocation* with *pathology* and *needs*

- **SIDI vs DASH ($\chi 2$)**
- Non significant

OBJECTIVE 3: To compare a regional *system of resources allocation* with *pathology* and *needs*

- **SIDI vs CIRS (ANOVA; r)**
- The differences are **NOT significant and makes NO sense**: subjects have higher classes of SIDI (i.e. more severe and more money) without having more physical diseases
- Data confirm that SIDI is just determined by age and years of residential living

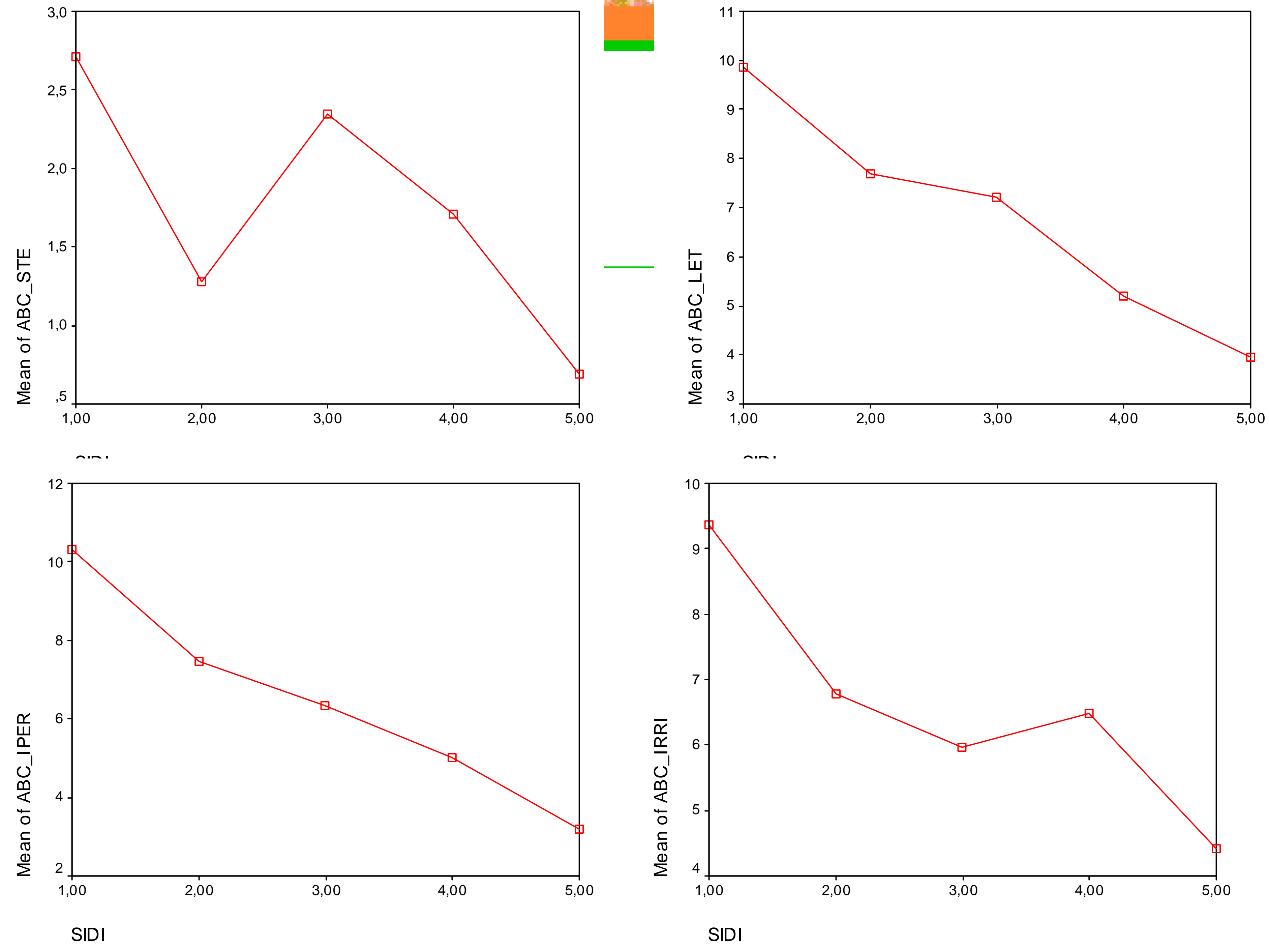




OBJECTIVE 3: To compare a regional *system of resources allocation* with *pathology* and *needs*

- **SIDI vs ABC (ANOVA)**

Data confirm the same conclusion as for SIS and CIRS, except subs. lethargy and hyperactivity



Mean of ABC_STE
3,0
2,5
2,0
1,5
1,0
,5
1,00
2,00
3,00
4,00
5,00
Mean of ABC_LET
11
10
9
8
7
6
5
4
3
1,00
2,00
3,00
4,00
5,00
Mean of ABC_IPER
12
10
8
6
4
2
1,00
2,00
3,00
4,00
5,00
SIDI
Mean of ABC_IRRI
10
9
8
7
6
5
4
1,00
2,00
3,00
4,00
5,00
SIDI

OBJECTIVE 4: To compare all *assessment* measures to *intervention* processes

- **ISP areas with intervention in QOL perspectives SIS**

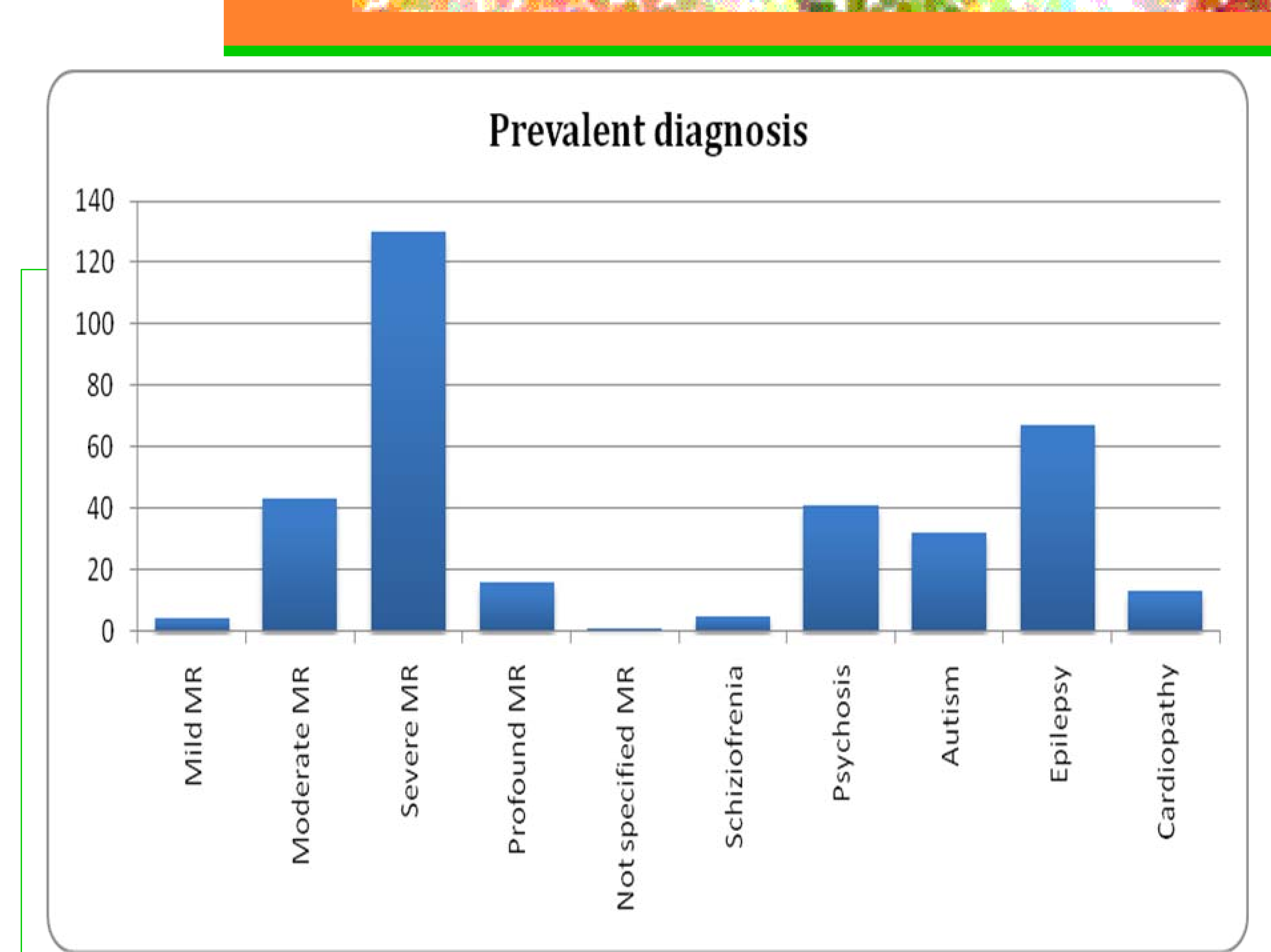
Generally data show that a lower level of needs is related to a higher nr of intervention. We reckon this could be due to:

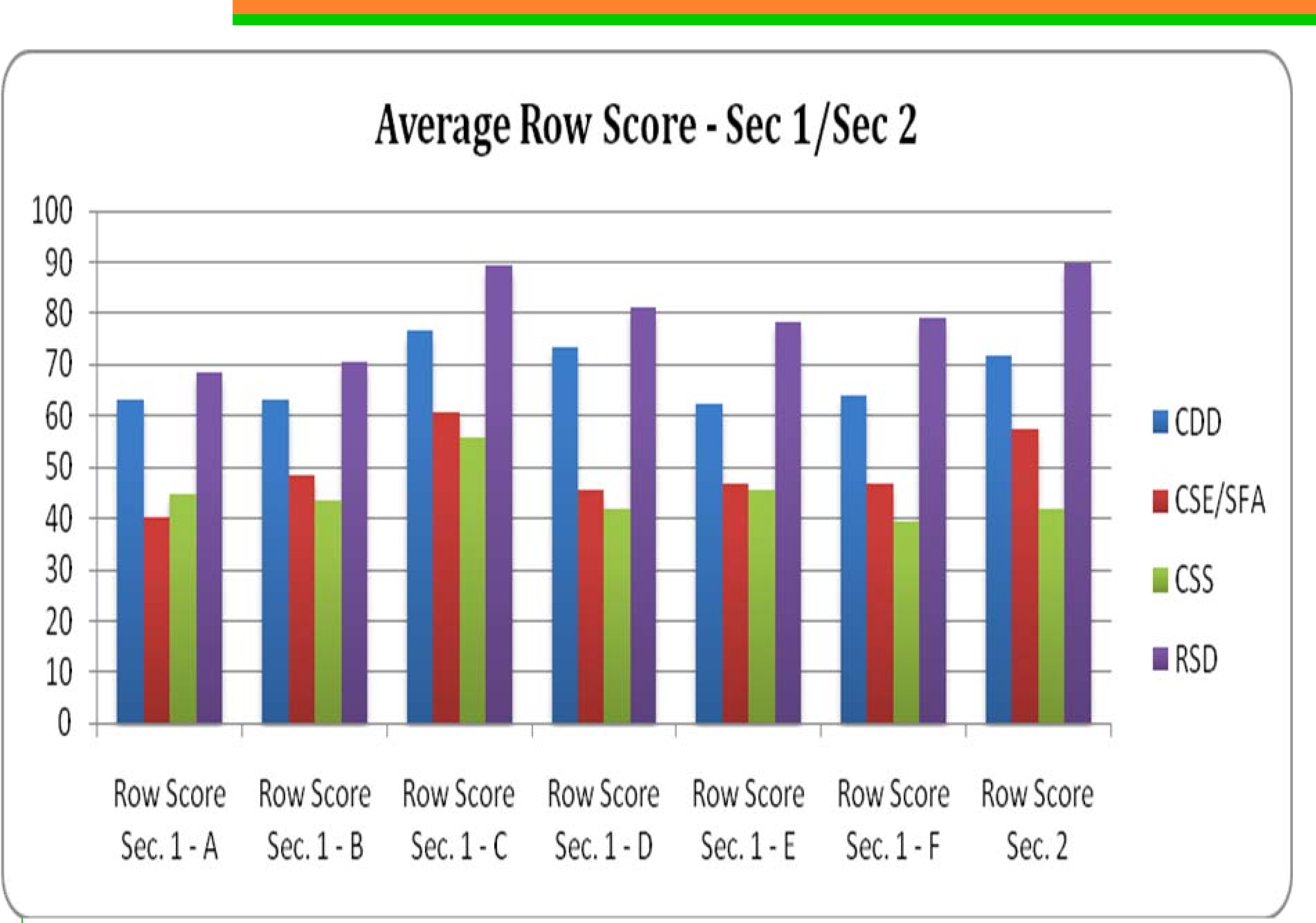
- A bias: staff members tend to do easier things
- A bias: staff members tend to do what they have been trained for, despite people have different needs of support
- A motivational strategy: promote activities with higher success can increase motivation towards more difficult task

Other surveys in Italy

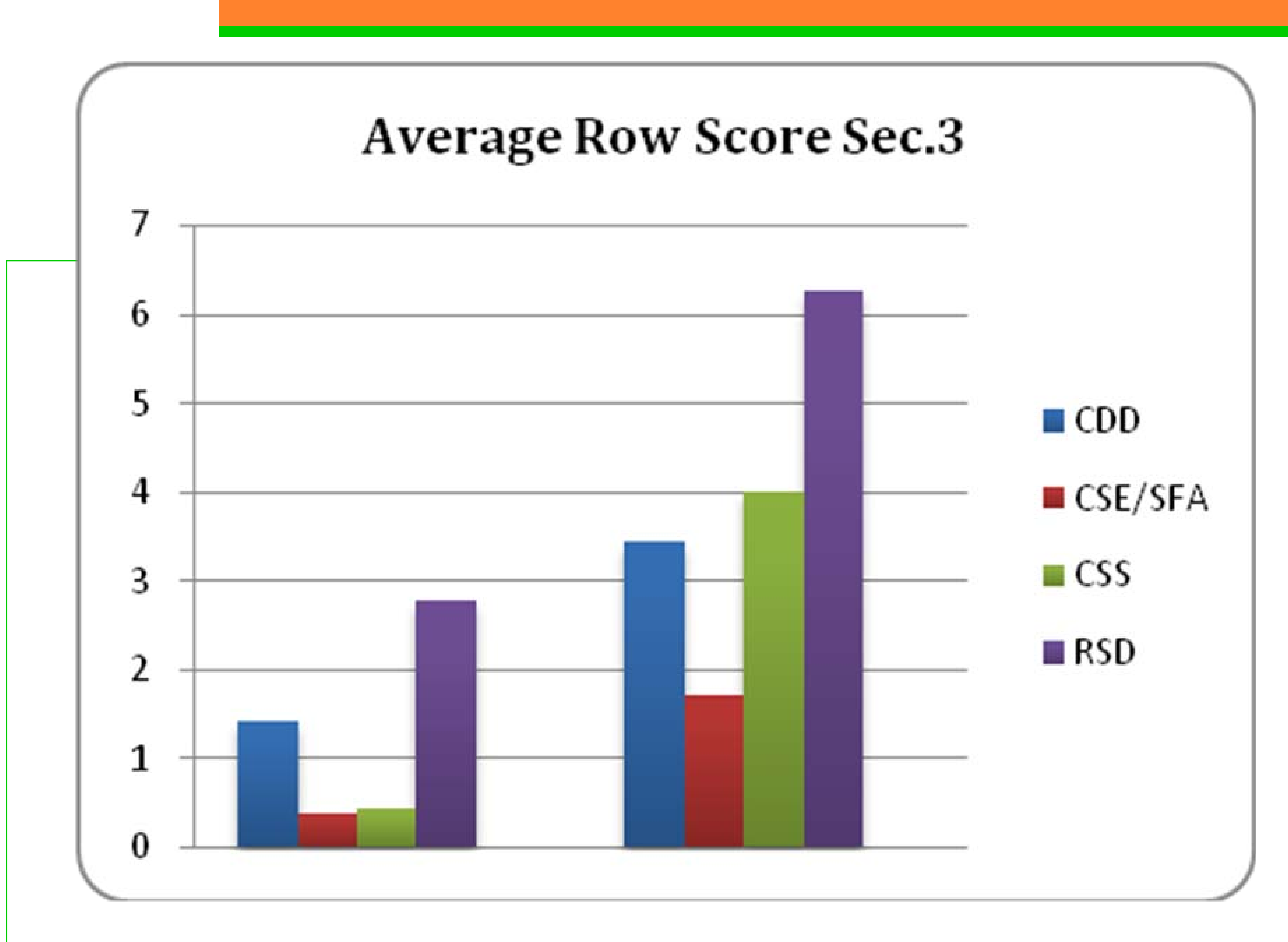
(Croce, L., Cavagnola, L., Lombardi, M., Nolani, M.)

- **AIM**: (**a**) to describe the **SIS profiles** related to other clinical and functional variables, socio demographic parameters and activity settings; (**b**) promoting the understanding of people on the organizational level, on the benefits of the extensive use of SIS within a comprehensive model (AAIDD; AIRIM) to improve QOL.
- The **SAMPLE** is composed by **363 users** from **16 centers** divided in 4 types of services from day-centers to residential facilities for people with IDD (Lombardy and Sardinia)


Prevalent diagnosis
140
120
100
80
60
40
20
0
Mild MR
Moderate MR
Severe MR
Profound MR
Not specified MR
Schiziofrenia
Psychosis
Autism
Epilepsy
Cardiopathy



Average Row Score - Sec 1/Sec 2
100
90
80
70
60
50
40
30
20
10
0
Row Score Sec. 1 - A
Row Score Sec. 1 - B
Row Score Sec. 1 - C
Row Score Sec. 1 - D
Row Score Sec. 1 - E
Row Score Sec. 1 - F
Row Score Sec. 2
CDD
CSE/SFA
CSS
RSD



Average Row Score Sec.3
7
6
5
4
3
2
1
0
CDD
CSE/SFA
CSS
RSD

Some ongoing results from this second survey

1. SIS is an extremely necessary tool because data point out specific set of functional information which cannot be predicted by other variables like diagnosis
2. When SIS is somehow related to specific functional/clinical variables (e.g. in Positive Behavior Support analysis) it becomes a good predictor of a higher efficacy of ISP which includes these variables

Discussion: a new paradigm

1. There is a robust suggestion for using integrated medical and psychoeducational approach
   - Evidences on non-pharmacological cognitive-behavioral efficacy on CBs (Wieseler, 1999; Emerson, 2002)
   - Evidences on Biopsychosocial Model efficacy for a better understanding of CBs and Psychiatric problems (Ellis, 1980; Dosen, 2005)
   - Evidences on necessity of Behavioral Ecological Model to implement a Quality process (Hovell et al., 2002)

2. There is a strong need to implement a clinical management which is soundly data-driven and Evidence Based

   (Heyness 2001; AAMR, 2000; Deb, 2006)

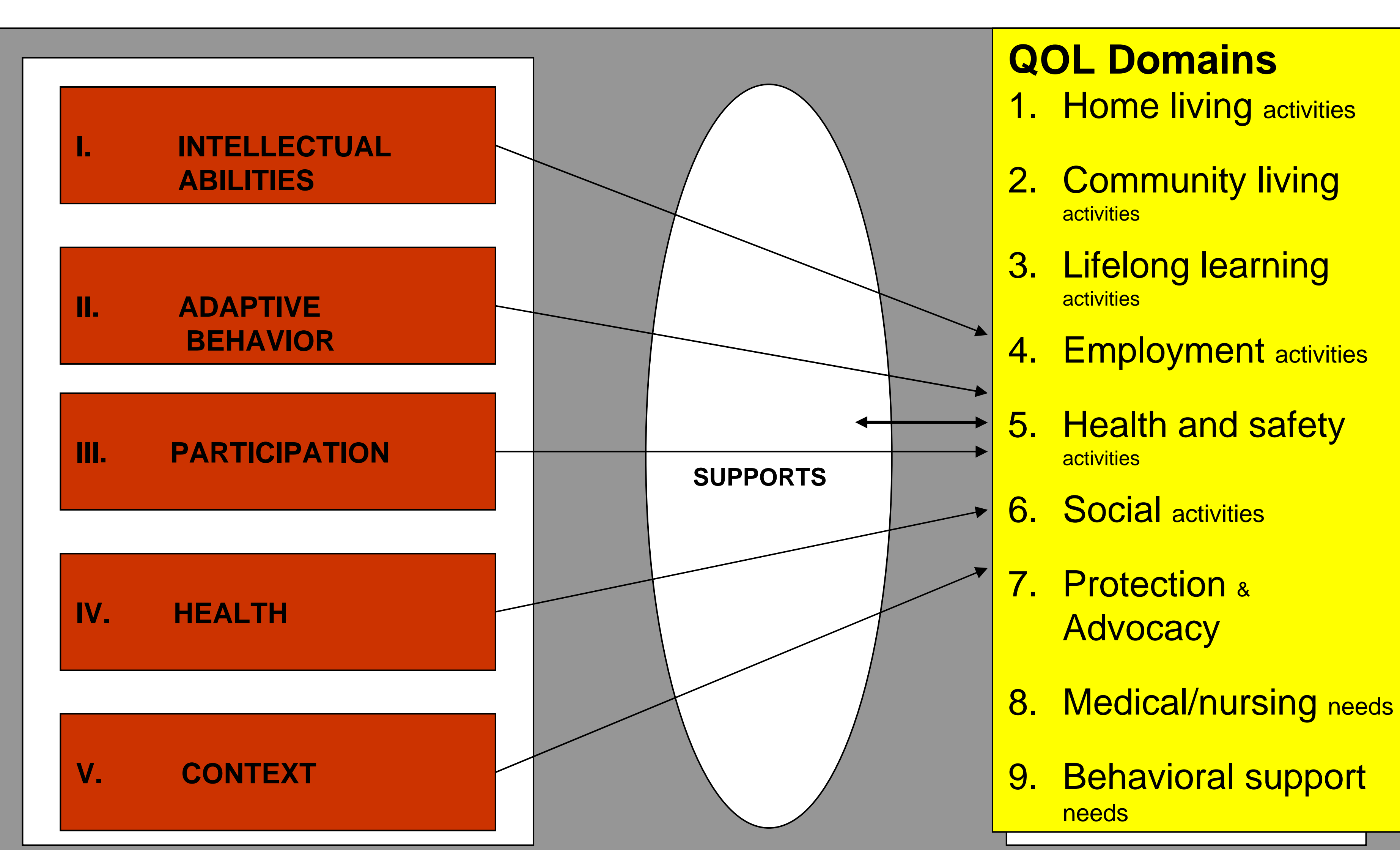
Discussion

- From a measurement perspective the use of the **QOL construct** is changing. Initially it was used as a sensitizing notion, social construct, and unifying theme. Increasingly, it is being used as **conceptual framework** for **assessing quality outcomes**, a social construct that guides quality enhancement strategies, and a criterion for assessing the effectiveness of those strategies. This new role places additional emphasis on the valid assessment of one's QOL

(Verdugo MA, Schalock RL, Keith KD, Stancliffe RJ, 2005)

Shift from Clinical to QoL Approach

(AAIDD, 2005, 2010)



Conclusion

- Results support the idea that in order to have better results in the implementation of positive outcomes in interventions for IDD population, we do need a **QOL perspective** which starts from *assessment* and STUDY the **alignment** of diagnosis procedures to *processes/intervention* and *outcome* measurement

The Italian experience

- The group is related to **AIRIM (the Italian Association on IDD)**
- Group leaders, **Luigi Croce** and **Mauro Leoni**, with more than 20 Professionals Head of Facilities (managing more than 1400 direct care staff professionals)
- **DATABASE**:
  - Direct daily contact with more than **1500 clients**
  - Extensive use of the **AAIDD 10th ed. USERS BOOK (3000 forms collected)**
  - Extensive use of **SIS (4300 forms collected)**
  - Experimental trials of **MODELS for THE ALIGNMENT in QOL** processes (INPUT-THOUGHPUT-OUTPUT)

Promoting QOL issues in Italy

- Associazione Italiana per lo Studio delle Disabilità Intellettive ed Evolutive (AIRIM) (2010). LINEE GUIDA per la definizione degli Standard di Qualità nei servizi per le disabilità in Italia - Assessment, interventi, outcomes. Genova: Autore.
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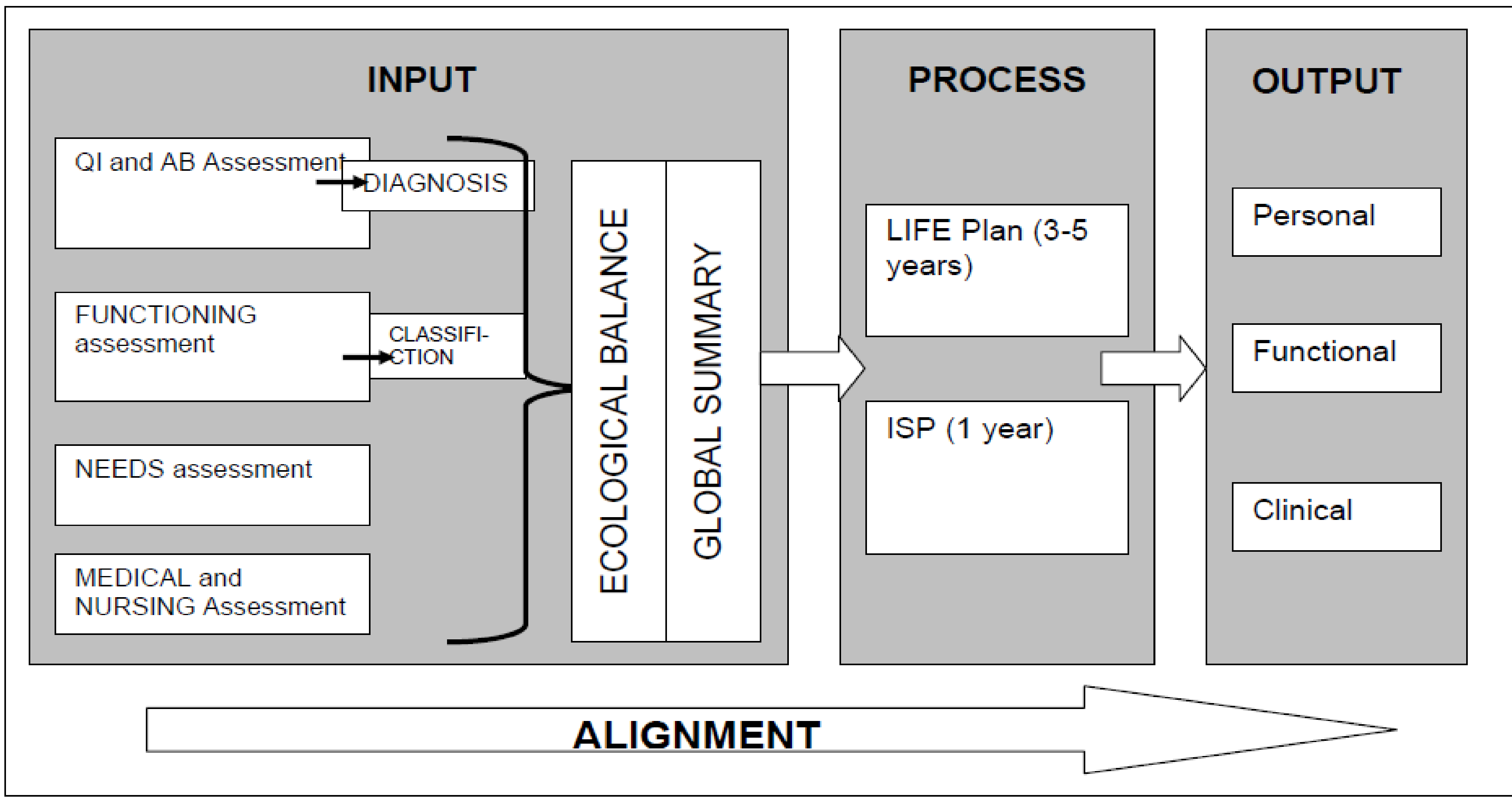
QUALITY STANDARDS FOR DISABILITY PROGRAMS
Guidelines for Assessment, Support and Outcomes



the Italian Association for the study of Intellectual and Developmental Disabilities (AIRIM)

Conclusion

- The samples seems to be extremely interesting if studied from a multidisciplinary perspective with attention to QOL
- **SIDI** doesn't show any power to discriminate needs and disease, therefore we wander if research can help to find better instruments to allocate funds
- **SIS** gives data different from other tools, indicating that needs require to studied as an **independent source of information**
- Data generally indicate the high importance related to **methodological attention**, and..
- The need to increase research in this area in order to improve understanding of **needs**, **medical features**, and **CBs** in ID population, and the alignment of strategies needed to reach better outcomes

- We hope this study is the prompt to link all research of the **comparison of SIS with other funds-allocation systems**

- Please contact JIM THOMPSON as a refernce for the research project

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