



May 27th, Washington, DC



SIS Leadership Forum

Quality of Life paradigm applied

AAIDD and SIS experience in Italy

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American Association
on Intellectual and
Developmental Disabilities



Vannini Editrice

colonna psicologia apprendimento di abilità
MANUALE



SupportsIntensityScale

Valutazione dell'intensità dei bisogni di sostegno

Standardizzazione
italiana

Italian Edition

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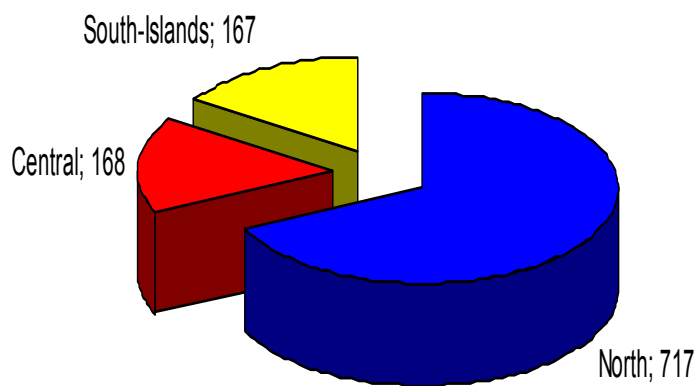


American Association
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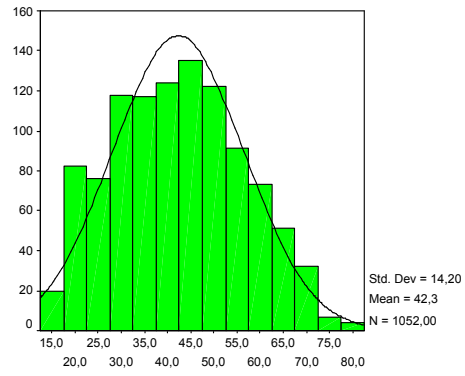
The Italian Standardization Study

A research project funded by the Italian Ministry of Equal Opportunity and ANFFAS (2007-2008)

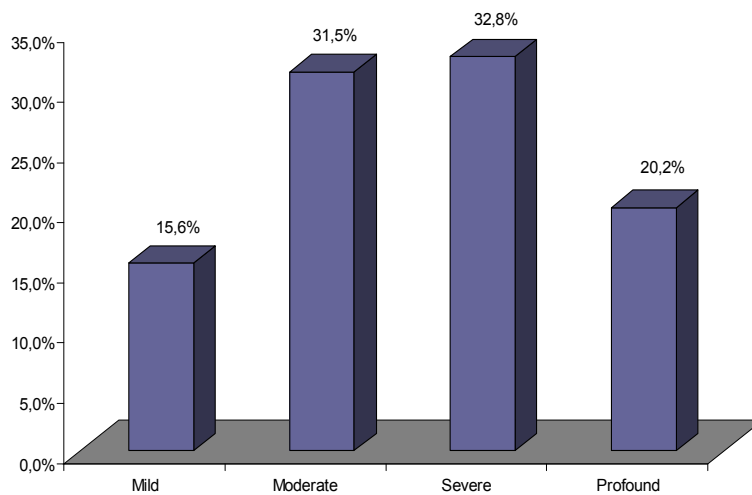
Subjects sample (N=1052) *per geographical areas*



Subject sample (N=1052) Age



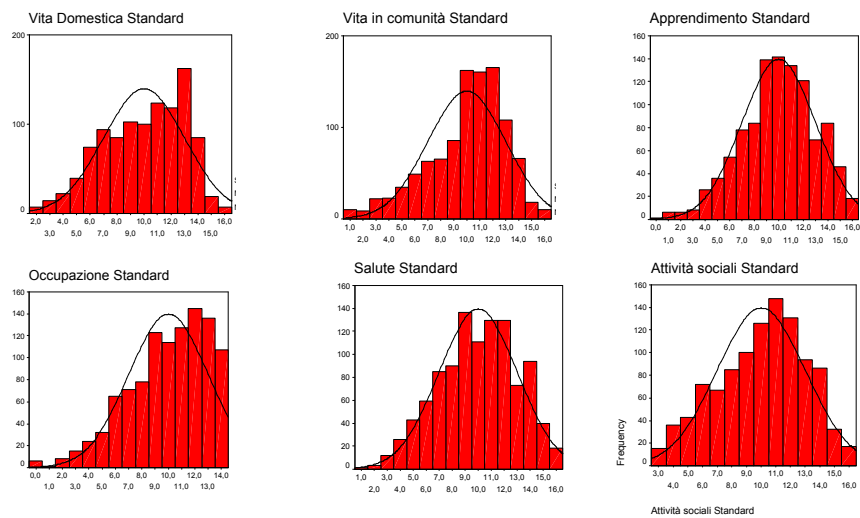
Subject sample (N=1052) ID levels



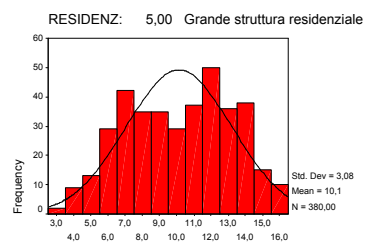
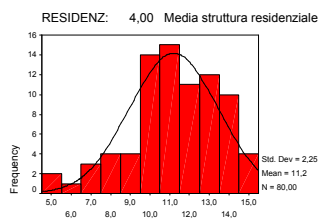
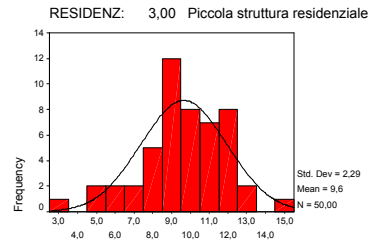
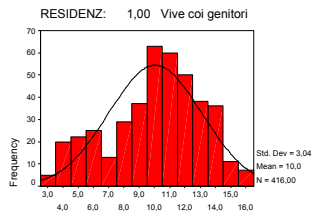
Adaptation data: SECTION1

Punteggi standard	A. Vita nell'ambiente domestico	B. Vita nella comunità	C. Apprendimento nel corso della vita	D. Occupazione	E. Salute e sicurezza	F. Sociale	Ranghi percentili
20							> 99
19							> 99
18							> 99
17							99
16	> 85	> 88	104		> 87	> 90	98
15	80-85	83-88	97-103		82-87	84-90	95
14	74-79	76-81	90-96	> 82	76-81	77-83	91
13	68-73	70-75	84-89	76-82	70-75	70-76	84
12	62-67	64-69	77-83	70-75	64-69	63-69	75
11	55-61	58-63	71-76	64-69	58-63	56-62	63
10	49-54	51-57	64-70	58-63	52-57	49-55	50
9	43-48	45-50	57-63	51-57	45-51	42-48	37
8	37-42	39-44	51-56	45-50	39-44	35-41	25
7	31-36	33-38	44-50	39-44	33-38	28-34	16
6	24-30	26-32	37-43	32-38	27-32	20-27	9
5	18-23	20-25	31-36	26-31	21-26	13-19	5
4	12-17	14-19	24-30	20-25	15-20	6-12	2
3	6-11	8-13	18-23	14-19	9-14	< 6	1
2	< 6	1-7	11-17	7-13	3-8		< 1
1		0	4-8	2	< 3		< 1
0			< 4	< 2			< 1

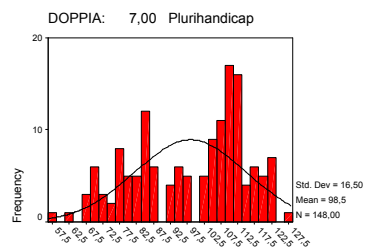
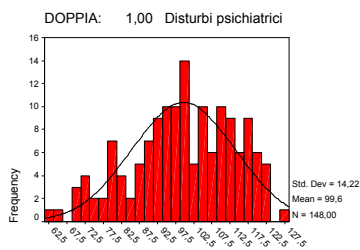
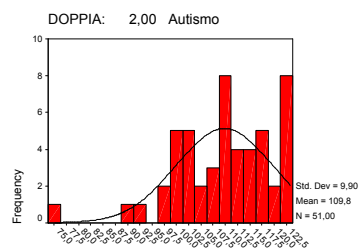
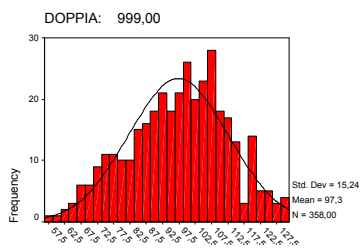
Adaptation data: SECTION1 SUBSCALES



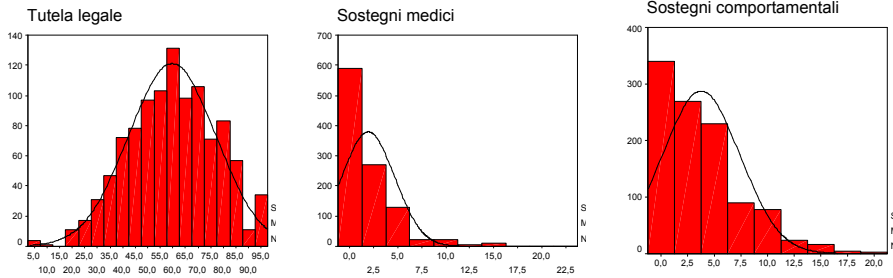
Adaptation data: SECTION1 SOCIAL ACTIVITIES



Adaptation data: SECTION1 TYPE OF DISABILITY

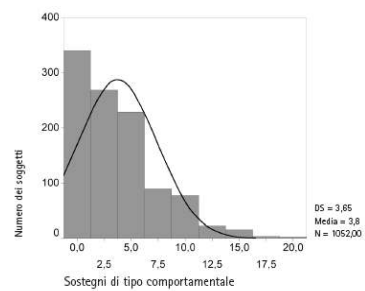
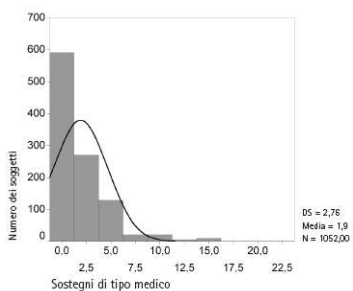


Adaptation data: SECTION 2 and 3



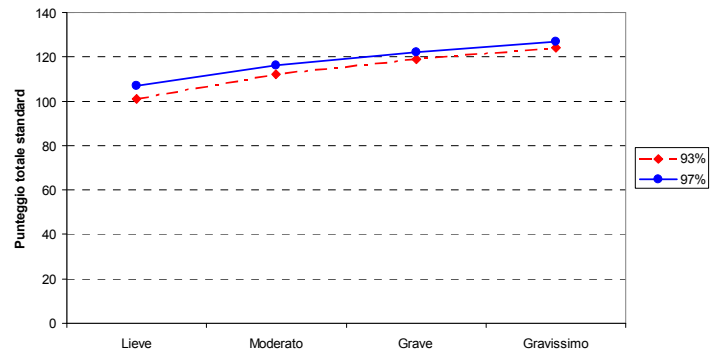
Section 2 and 3 data

Scala	Media	Deviazione standard	Min/Max
Sezione 2. Scala supplementare di protezione e tutela legale	59,7	17,3	3/94
Sezione 3A. Bisogni di sostegno di tipo medico	1,9	2,8	0/22
Sezione 3B. Bisogni di sostegno di tipo comportamentale	3,8	3,6	0/20



Construct validity: ID level

Confronto percentili x livello di ritardo mentale



Construct validity: age

Confronto percentili x fasce d'età



Subscale	Correlazione	Livello di probabilità
Vita nell'ambiente domestico	0,070	$p > 0,05$
Vita nella comunità	-0,028	$p > 0,05$
Apprendimento nel corso della vita	0,012	$p > 0,05$
Occupazione	-0,035	$p > 0,05$
Salute e sicurezza	0,025	$p > 0,05$
Sociale	0,005	$p > 0,05$
Totale	0,013	$p > 0,05$

SIS supports needs index (composite standard score)



Italian experiences:

**a residential service aligned to
AAIDD and QOL Models**

Fondazione Sospiro
(Cremona, northern Italy, 2005-2008)

Introduction

- **Fondazione Sospiro** (Cr, Northern Italy) is a big residential facility for 408 adults with IDD from mild to profound
- Since it was created in **1896** until May **2006**, it used a merely **medical management system**

Population features

- 408 adult subjects with Intellectual Disabilities from mild to profound
- Male : Female = 2.7 : 1
- Age (average): 53.1 ± 10.5 (DS) years
- Long standing (average): 34.2 ± 14.8 (DS) years

Comorbidity

- Epilepsy: 33%
- Medical diseases (ICD-10): 83%
- Mental disorders (DSM-IV): 62%
- Behaviour disorders: 48.8%

Objectives

1. To implement a data-driven (evidence-based) QOL system
2. To implement an economic budget-driven management

Shift in paradigm

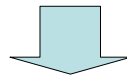
- ⌚ 1896-1980: Religious Model care
- ⌚ 1980-May 2006: Medical Model care
- ⌚ June 2006 to present:

AAIDD 10° System (Luckasson et al., 2002) plus
QOL (Schalock, 1999) Models

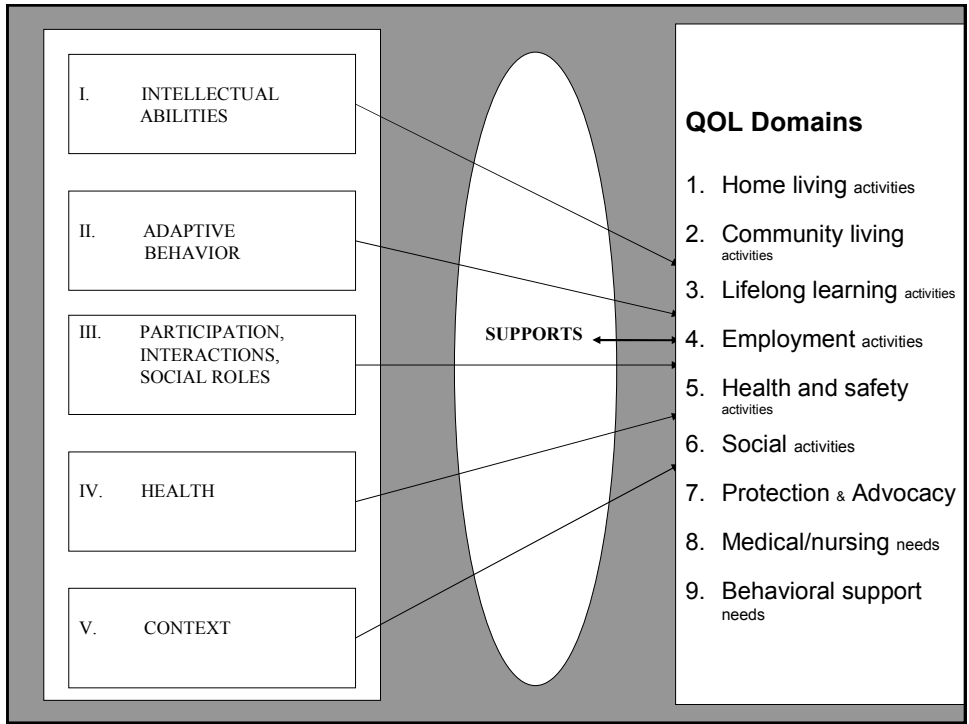
May 2006: “Day zero”

How to care people with IDD as
individuals?

(Nirje, 1969; Cummings, 2000; Felce & Perry, 1997; Schalock, 1999)



We started and implemented
a structural and functional
re-management based on...



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From hospital to residential model





Change process methodology

- A. Analysis of population needs and features
- B. Planning of new groups
- C. Models implementation: towards an outcomes evidence-based system

Quality of Life Assessment Framework

<u>QOL Factor</u>	<u>QOL Domain</u>	<u>Exemplary QOL Indicators</u>
Independence	Personal Development	Personal Skills (e.g. Adaptive Behavior) ADLs / IADLs
	Material Well-Being	Income Professions
	Self-Determination	Choices/Decisions Autonomy/Control
Social Inclusion/ Civic Participation	Interpersonal Relations	Social Networks Friendships Social Activities
	Social Inclusion	Involvement in Community Community Roles (e.g. Volunteer)
Well-Being	Emotional Well-Being	Safety and Security Protection from Abuse Positive Experiences/Success
	Physical Well-Being	Health Status Nutritional Status Recreation/Physical Exertion
	Rights	Equal Opportunities Respectful Treatment

Quality Improvement Strategies

Persons with Disabilities and Their Families

- Participant Involvement
- Individualized Supports

Source Providers

- Quality of Life as a Change Agent
- Quality of Life Assessment and Feedback
- Organizations Redefining Their Roles
- New Management Strategies
- Quality Improvement as a Continuous Process

Policy Makers

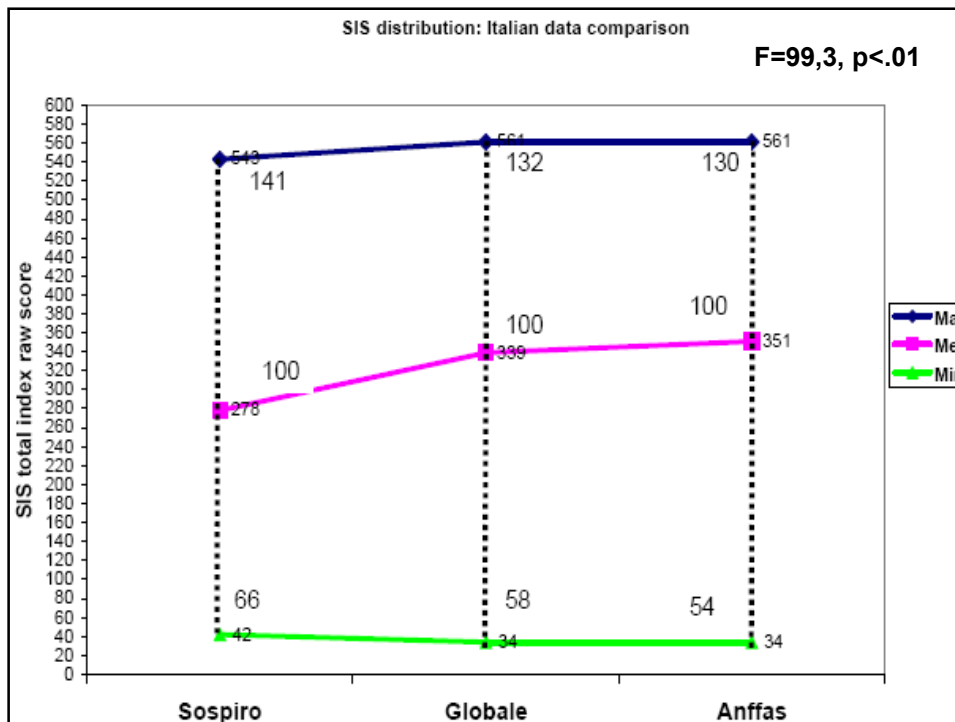
- Consensus Building
- Supports Provision (Technical, Legislative, Regulatory)
- Fostering an Attitude of Change

First results: improvement in QOL indirect indexes

As a first step emerging from new sanitary approach integrated with Psychoeducational CBT strategies

- Significant reduction in drugs administration
- Drastic decline in physical restraint for challenging behaviors
- Quick drop of sedative intervention for acute behavioural problems
- Decrease of emergency medical interventions
- *Preventive care vs Emergency care*

SIS profiles: group perspectives...



Future challenges

1. Promote and diffuse **SIS adoption** (e.g. state guidelines)
2. Develop **e-based platform** to give updated data from all region and services (transparency and EST)
3. Implement an **assessment-to-planning toolpack** which shows :
 1. How to read what they do (supports offered to date) in QOL prospective
 2. How to become AWARE of choices (how to use resources)
 3. ALIGN goals to practices using AAIDD and QOL Models to individual level
4. **Peculiar aspects**: extreme needs population (e.g. challenging behaviors, autism, etc.)

We ask for...

1. Define the SIS TASK FORCE in order to collect all SIS data, experiences, and researches, and TRANSLATE them into PRACTICAL ready-to-use data-pack, to present and elicit people and services to join
2. Facilitate the SIS NET, to share ongoing knowledge and expertise

The future has already happened,
and what we need to do is to use
the changes as opportunities

Peter Drunker