



## Origins & Meanings of the Supports Intensity Scale (SIS) and the AAIDD 10th ed. Model in a Quality of Life Framework

**Anffas Onlus Seminar on the Italian Standardization Version Supports Intensity Scale (SIS)**

**February 22, 2008**

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## Presentation Schedule

- **AAIDD 10th ed. model for understanding Intellectual Disability**
- **How the SIS was developed in response to this model**
- **How the SIS can be used in a Supports Needs Assessment and Planning Process**
- **How the SIS relates to the Quality of Life construct: A case study**

## AAIDD 10th ed. & understanding Intellectual Disability

- It is evidenced by significant limitations in personal competency (adaptive behavior and intelligence) in comparison to typically developing people
- It results in experiencing great difficulty in one's attempts to successfully function/participate in school and society, because there is a mismatch between what the person can do, and what the environment demands
- It can be addressed effectively if the right types of support are provided

In typically functioning people, the demands of the environment are relatively equal to personal competence - no mismatch exists

Demands of the Environment

=

Personal Competence

With people with intellectual disability, the demands of the environment are not aligned with personal competence - a mismatch exists which can be addressed by providing individualized supports

**Demands of the Environment**

Need  
For  
Individualized  
Supports

Personal Competence

People with intellectual disabilities (ID) need individualized supports over and above those typical for people without ID. Support needs will vary from person to person both Quantitatively & Qualitatively.

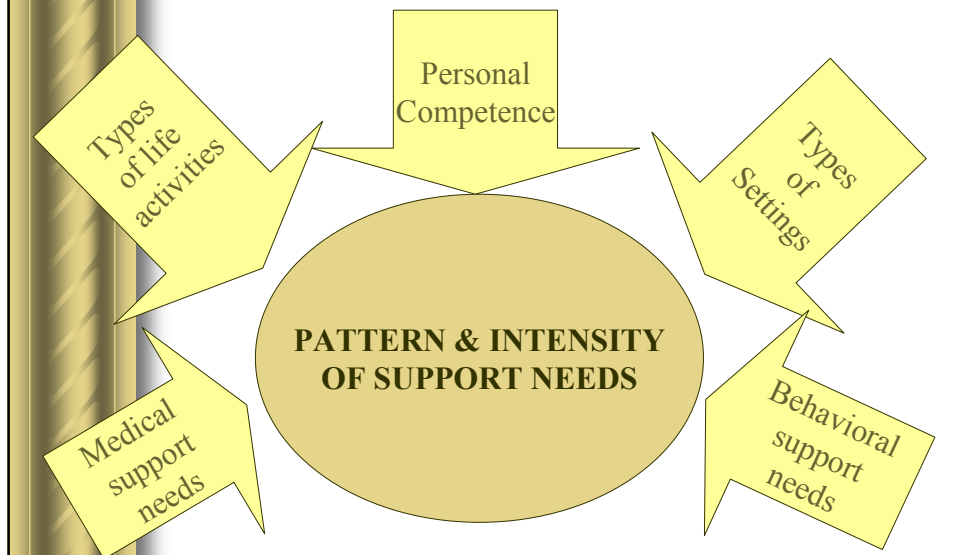
## Why was the SIS developed?

- **Intellectual Disability (ID) is associated with *needs for supports* over and above those that are typical for people without ID.**
- **The SIS was developed to assess support needs fairly (reliably and validly; employ a uniform procedure).**

Other assessment instruments do not measure support needs

- **IQ tests and AB scales measure aspects of personal competence, but do not measure support needs**

## Inferring Support Needs from Measures of Personal Competence can be Misleading



The SIS attempts to measure the relative intensity of an individual's support needs directly – other assessment instruments provide indirect measures

## How the SIS was developed

- **Literature Review – 12 initial support areas**
- **A Pool of 130 indicators across the 12 areas was developed Q-Sort was used to reduced and validate the initial item pool**
- **An initial SIS requiring ratings of frequency, daily support time, and type was developed**
- **5 Field Tests involving 1,700 consumers were used to expand and refine the instrument**

## Reliability of the SIS

- **Reliability**
  - **Internal Consistency Statistics Extremely High**
  - **Standard Error of Measurement Very Low**
  - **Test-Retest Reliability was Good**
  - **Inter-rater reliability was Acceptable with the first study, with the second study it was Excellent**

## Inter-rater Reliability

### First Study

- Interviewers with no training nor familiarity with SIS, provided with verbal instructions; there was no manual available
- Different interviewers interviewed different respondents

### Second Study

- Interviewers completed training or were “very familiar” with SIS
- 3 Conditions
- Different interviewers & same respondent
  - Same interviewer & different respondents
  - Different interviewers & different respondents

Thompson, J. R., Tassé, M. J., McLaughlin, C. A. (in press). The inter-rater reliability of the *Supports Intensity Scale*. *American Journal on Intellectual Disability*.

SUBSCALE	Same Interview with Different Respondents	Different Interviewers with Same Respondent	Different Interviewers with Different Respondents	Average r Across All 3 conditions	First Study (2004)
Home Living	.83	.89	.86	.86	.79
Community Living	.85	.85	.83	.84	.56
Life-long Learning	.60	.73	.51	.61	.35
Employment	.74	.54	.47	.58	.36
Health & Safety	.84	.92	.81	.86	.58
Social	.65	.51	.70	.62	.36
SIS Support Needs Index (TOTAL)	.87	.90	.85	.87	.54
Thompson et al. (in press)					

## Validity of the SIS

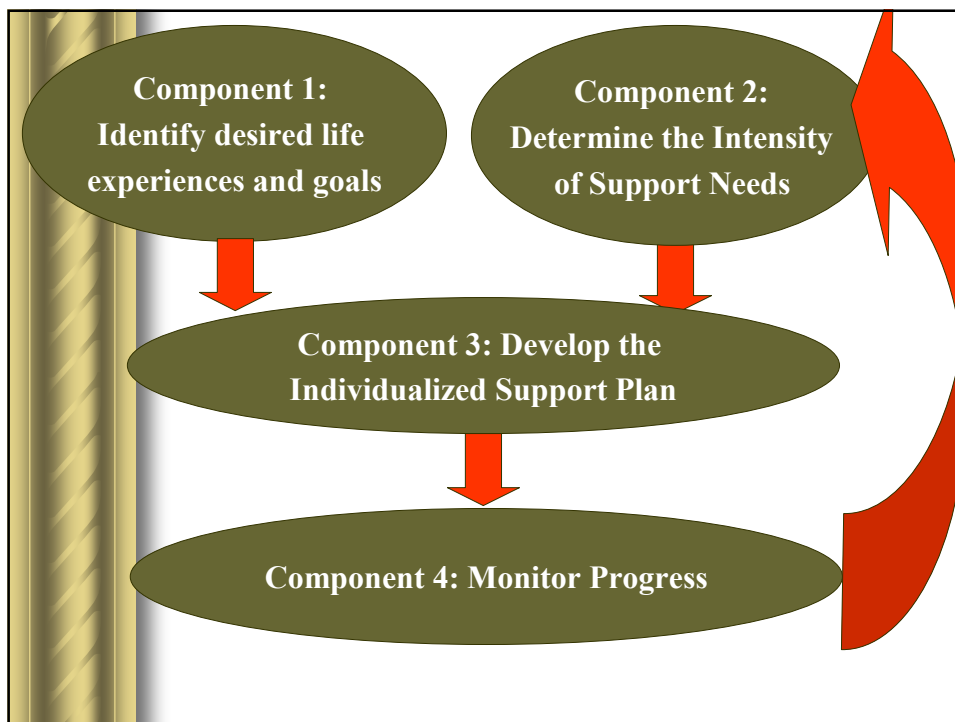
- **Validity**
  - **Content Validity** established through literature review and Q-Sort
  - **Content Validity** verified through analyses of interrelationships among items within and among SIS domains
  - **Criterion Validity** confirmed through strong correlations with raters measures of overall support needs
  - **Construct validity** was ascertained by relating SIS scores with AB and IQ measures, as well as levels of funding

## What information does the SIS provide?

- **Section 1** lists an array of life activities against which an individual's support needs are rated in regard to frequency, duration, and type.
- **Section 2** promotes consideration of support needs related to protection and advocacy activities
- **Section 3** identifies exceptional support needs related to medical and behavioral concerns

# The Support Needs Profile - Sample

%tile	Home Living	Community Living	Life Long Learning	Employment	Health & Safety	Social	SIS Support Needs Index	%tile
99	17-20	17-20	17-20	17-20	17-20	17-20	>131	99
	15-16	15-16	15-16	15-16	15-16	15-16	124-131	
90	14	14	13	14	14	14	120-123	90
	13	13	13	13	13	13	116-119	
80							113-115	80
	12	12	12	12	12	12	110-112	
70		11		12	12		111	70
	11						105	
60	10		11	11	11	11	102-104	60
	10						100-101	
50		10	10	10	10	10	98-99	50
	9	9	9	9	9	9	97	
40							94-96	40
	8	8	8	8	8	8	92-93	
30							90-92	30
	7	7	7	7	7	7	88-89	
20							85-87	20
	6	6	6	6	6	6	82-84	
10							75-81	10
	5	5	5	5	5	5	<74	
1	1-4	1-4	1-4	1-4	1-4	1-4		1





How the SIS relates to the  
Quality of Life construct:  
A case study

### Individualized Support Planning for Mel - Background

**36 year old male; IQ between mild/moderate range; AB in mod range; Some bizarre “autistic like” behavior (self-stimulation, strange vocalizations; usually compliant with others requests – takes an “I don’t see why not” attitude toward life; great family support; parents are old, has been living with 4 other men in a neighborhood home for past 3 years**

## Individualized Support Planning for Mel - Background

- Works at a “sheltered workshop” type of program during the daytime
- Likes routines; comes home and rests, eats dinner, watches TV but likes to go out to mall, etc., ready for bed at 9:00
- Enjoys going to see family; visits brother’s house quite a bit; stays there overnight
- Enjoys eating; eats everything and doesn’t gain weight
- A bit indifferent to others; always pleasant, but doesn’t get real excited to see anyone

## Individualized Support Planning for Mel – Person Centered Planning

- Used MAPS for PCP
- Priorities to change were for Mel to begin to work in the community in a supported employment situation and to start gardening/ external home decorating as a hobby; also begin exploring other hobbies
- Priorities to maintain were to maintain living arrangements, sense of privacy & comradery with housemates were positive; also maintain contact with family

## Mel's Support Needs Profile

%tile	Home Living	Community Living	Life Long Learning	Employment	Health & Safety	Social	SIS Support Needs Index	%tile
99	17-20	17-20	17-20	17-20	17-20	17-20	>131	99
	15-16	15-16	15-16	15-16	15-16	15-16	124-131	
90	14	14	13	14	14	14	120-123	90
	13	13	13	13	13	13	116-119	
80							113-115	80
	12	12	12	12	12	12	110-112	
70		11					111	70
	11		11	11	11	11	105	
60	10						102-104	60
	10	10	10	10	10	10	100-101	
50							98-99	50
	9	9	9	9	9	9	97	
40							94-96	40
	8	8	8	8	8	8	92-93	
30							90-92	30
	7	7	7	7	7	7	88-89	
20							85-87	20
	6	6	6	6	6	6	82-84	
10							75-81	10
	5	5	5	5	5	5	<74	
1	1-4	1-4	1-4	1-4	1-4	1-4		1

## Individualized Support Planning for Mel – SIS insights

- **Mel is going to need more support than most other individuals with ID & related DD in employment**
  - Completing work with acceptable speed and quality
  - Changes in job routines and assignments
  - Seeking information/assistance from employer
- **Job coach will be needed for a long time; very close assistance**

## Individualized Support Planning for Mel – More SIS insights

- **Mel's gardening and exploration of hobbies is going to require thoughtful support based on support needs identified in the community living, life-long learning, and social subscales**
  - He is going to need 1:1 assistance if he participates in a community education or recreation class
  - Small group (2 to 4 people) probably better situations than large groups; need so much support in large groups that activity may be less meaningful
  - Communication skills are major barrier to participating in social activities (Part F #5)
- **Needs to try some things, and try them more than once to determine what he likes to do.**

## Individualized Support Planning for Mel – The ISP

- **Maintain home life and connections with extended family; respect desire for routines**
- **Start with part-time job in community; hotel needed maintenance help; use picture prompting to help with communication**
- **Identify gardening/home decorating opportunities each week and involve with a support person; explore different community leisure activities – try a least 2 new ones per month**
- **Meet in 60 days to evaluate**

## Individualized Support Planning for Mel – The ISP

- **Meeting in 60 days indicated he enjoyed the home decoration/gardening opportunities – Holiday lights, dressing up goose on the doorstep**
- **Began working at a group of hotels that share maintenance staff; “independence” has been slow, but seems to enjoy the new opportunities**

## Schalock’s 1997 QOL Indicators

- **Emotional Well-Being**
- **Interpersonal Relations**
- **Material Well-Being**
- **Personal Development**
- **Physical Well Being**
- **Self-Determination**
- **Social Inclusion**
- **Rights**

## Quality of Life Indicators and Mel's Support Plan

↑ Emotional Well Being - greater happiness due to expanded array of things he enjoys doing

↑ Interpersonal Relations - more interactions because of work opportunities

↔ Material Well Being - no meaningful change in wealth

↑ Personal Development - increase in purposeful activity

## Quality of Life Indicators and Mel's Support Plan

↑ Physical Well Being - increased leisure skills

↑ Self-Determination - Involvement in planning process provided more choices and autonomy

↑ Social Inclusion - increased interaction with neighbors due to gardening and decorating

↔ Rights - no change in his exercise of right

## In closing .....

People with ID experience a mismatch between their personal competency and environmental demands



With support needs assessment and person centered planning meaningful life goals can be identified and prioritized, and supports can be arranged to address the person-environment mismatch



Thoughtful planning and application of individualized supports can lead to a more meaningful Quality of Life



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