

# **Paradigma dei Sostegni e Qualità della Vita: risultati del progetto di ricerca sul Modello del 10° Sistema dell' *American Association on Intellectual and Developmental Disabilities* e la Supports Intensity Scale (SIS)**

**Roma, 22 Febbraio 2008**

## **ABSTRACTS**

### **Magisterial presentation - Origins & Meanings of the Supports Intensity Scale (SIS) and the AAIDD 10th ed. model in a Quality of Life Framework**

Jim Thompson, Illinois State University (USA)

Jim Thompson, *Illinois State University (USA)*, Origins & Meanings of the Supports Intensity Scale (SIS) and the AAIDD 10th ed. model in a Quality of Life Framework.

In this presentation the major tenants of AAIDD 10th ed. model for understanding Intellectual Disability will be reviewed. Distinctions between the operational definition explicitly presented and the constitutive definition implicitly suggested in the AAIDD's 10<sup>th</sup> ed. manual will be highlighted, particularly in regard to the importance of understanding intellectual disability in relation to human functioning and support needs. The history of how the Supports Intensity Scale (SIS) was developed in response to the constitutive definition will be presented. A case study will be presented which illustrates ways in which information from a SIS assessment can be used in a Supports Needs Assessment and Planning Process. This case study will also be used to illustrate how providing individualized supports can enhance the Quality of Life (QOL) of individuals with intellectual disability, based on Schalock's (2007) QOL domains.

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### **La standardizzazione italiana della SIS - *Aspetti metodologici e psicometrici***

Lucio Cottini, Università degli studi di Udine

Daniele Fedeli, Università degli studi di Udine

Nella presente relazione verranno descritte le procedure psicometriche usate per la standardizzazione della Supports Intensity Scale (SIS). In particolare ci si soffermerà sulle caratteristiche del campione coinvolto e sulle modalità di selezione dello stesso, sui dati normativi ottenuti, sulla validità e affidabilità dello strumento. La standardizzazione italiana della SIS è stata effettuata attraverso la somministrazione della stessa ad un campione di 1052 persone con ritardo mentale di varia gravità, distribuite sul territorio nazionale. Le variabili considerate per la stratificazione del campione normativo sono state: (1) il sesso, (2) l'età cronologica al momento della somministrazione, (3) il livello di ritardo mentale, (4) la tipologia residenziale, (5) l'occupazione, (6) il quoziente intellettivo, (7) il grado di comportamento adattivo e (8) l'eventuale presenza di diagnosi aggiuntive.

I punteggi normativi, così come previsto nella versione americana originale, si riferiscono alle sei subscale della SEZIONE 1. SCALA DEI SOSTEGNI NECESSARI. In riferimento al punteggio grezzo totale di ogni subscale sono stati calcolati i *punti standard* su una scala con *media 10* e *deviazione standard 3*. È stata quindi costruita la tavola di conversione, tramite la quale trasformare il punteggio ottenuto da ciascun soggetto in punti standard e posizione percentile. Oltre al punteggio standard e ai ranghi percentili riferiti ad ogni singola subscale, è possibile anche calcolare il punteggio standard totale (complessivo delle sei subscale) espresso in una scala con *media 100* e *deviazione standard 15*.

Successivamente alla standardizzazione dei dati, sono state condotte alcune verifiche sull'attendibilità e la validità dei dati raccolti. In particolare, sono stati calcolati i seguenti indici di affidabilità: 1) la *consistenza interna*; 2) l'*errore standard di misurazione*. In entrambi i casi, i risultati sono soddisfacenti. Per quanto riguarda la validità, in considerazione del fatto che le SIS sono già state oggetto di valutazione della validità di contenuto e della validità convergente nella versione originale e che non sono state apportate modifiche agli item dello strumento, non è risultato necessario ripetere un controllo della validità. Viceversa, è stato condotto uno specifico approfondimento sul grado di *correlazione* tra punteggi SIS e variabili sociodemografiche.

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## Catalan version of the *support intensity scale* (sis): translation and standardization process

Climent Giné Giné, Blanquerna Universitat Ramon Llull (Catalunia)

The reasons for the Research Group<sup>1</sup> on *Disability and Quality of Life: Educational Aspects* (Ramon Llull University; Faculty of Psychology and Educational and Sports Sciences Blanquerna) to translate and adapt SIS into Catalan are the same as those that encouraged authors to elaborate it: To have an instrument that measures support intensities needed by a person so that professionals and organizations can develop individual support plans, resource provision and result assessment systems, and also that administrations have a solid basis to decide funding issues.

Catalonia is an Autonomous Community in Spain, with seven million inhabitants with their own language, Catalan; the region also has its own Government with a wide scope of competences. The cultural tradition and linguistic differences made it essential to have the Catalan version of SIS, which was possible thanks to funding from the *Federació Catalana Pro Persones amb Retard Mental – APPS*.

To this end, the first initiative of the research group was to plan a training workshop with Professor Robert Schalock; then, we followed the next necessary steps. The Faculty's Language Service was asked to translate the original SIS Manual, questionnaire, expanded items, and FAQ; the translation was submitted to expert judgement, and appropriate corrections were made. Finally, and after having introduced the peculiarities of the Catalan adaptation into the Manual, two professionals, who may use the materials in the future, were asked to revise all the materials in order to ensure their comprehension.

Regarding the standardization, SIS was applied to a sample of 352 people from all of Catalonia. To obtain data, a group of centres and institutions representing a wide variety of services for people with intellectual disability and developmental disorders (homes, residential homes, special work centres, etc.) were selected.

Prior to application, all the professionals that would act as interviewers attended to an intensive training course given by members of the Research Group responsible for adapting SIS. The centres selected users for the SIS application and they had at most three months to apply the scale and give back the documentation (answer sheets, and signed consent forms) to the research group. During this period, assessors had support by phone, email, or in person by the research group members.

In order to know the reliability of the Catalan SIS, the index of internal consistency, which indicates the degree of homogeneity among the items of a measurement instrument, was obtained. But, previously, Pearson correlation coefficients were calculated between every SIS subscale and the age and gender of sample users. The coefficients obtained were very low (the highest correlation reaches only 0.16). Therefore, neither age nor gender was included in further analysis. To determine the degree of homogeneity, Cronbach's (1951) alpha coefficients were calculated for every SIS subscale and overall score. In all cases, alpha coefficients were higher than 0.90. Standard Errors of measurement for every SIS subscale and for SIS overall score were calculated. Criterion-related validity and content validity was also obtained, as well as the normative scores. The normative scores include the six subscales and composite standard scores and percentiles.

Nevertheless, only the use of this instrument by professionals and researchers will allow us to know its possibilities more accurately, supplementing initially obtained basic information. For this reason, besides encouraging professionals to use SIS in their daily practice, they should be also encouraged to continue studying the Catalan SIS (for instance, applying it to different samples, relating it with other measurement and assessment instruments, etc.), and to disseminate their findings among all the academic and professional community.

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## European experiences in group and social policies management

Wil Buntinx, University of Maastricht

The SIS has recently be used in various contexts of organizational and national policy. We will show examples of SIS application within specific organizations to monitor supports need intensities over different regions or divisions and the relation with allocation of resources. We will also demonstrate briefly how the SIS can be used to study management issues that are related to the distribution of resources. Next we will show the application of

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<sup>1</sup> The Research Group on Disability and Quality of Life: Educational Aspects is made up, besides the authors, by Elisabeth Alomar, Anna Balcells, Pilar Carasa, Maria Carbó, Marga García, Marina González, Joana Maria Mas, Pere Rueda, and Xavier Vidal.

nation wide standardized norms. We will also discuss critically the scientific and professional conditions for using the SIS as an instrument for resource allocation.

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## **The Spanish version of sis: adaptation process and main psychometric characteristics**

Miguel-Angel Vedugo, University of Salamanca

Research on Spanish adaptation of Support Intensity Scale consisted of two parts: the translation of SIS into Spanish, and the analyses of its main psychometric characteristics.

After a first translation into Spanish carried out by two Psychology professionals, a synthesis of both translations was made, followed by an inverse translation Spanish-English in order to guarantee that translated items' contents accurately reflected the original one. A team composed by 9 experts assured semantic, idiomatic, experience and conceptual equivalence of both translations.

All 85 items were randomly arranged and submitted to 8 experts, who estimated the dimension (i.e., home living, community living, lifelong learning, employment, health & safety, social activities, protection & advocacy, medical needs, or behavioral needs) each item belonged to. All of the concordance coefficients (e.g., Scott's Pi, Fleiss-Cohen kappa, Krippendorff's alpha...) showed a high congruence among judges' ratings, and strongly supported content validity of the scale. Specifically, global Krippendorff's alpha was .684.

SIS was applied to a sample of 885 people with various levels of intellectual disability in 20 provinces nationwide. Main characteristics of sample were as follows: Age ranged from 15 to 76 years ( $M=34.60$ ,  $SD=11.77$ ); Gender (61.5% male, 38.5% female); Type of disability (each participant had 1.90 disabilities on average); most of participants lived at family home with parents, worked at special work centers and lived in urban areas.

Finally, a series of reliability and validity analyses were carried out. Reliability analyses showed that both internal consistency, OMEGA and ZETA coefficients (based on factorial structure of scale), test-retest and inter-rater coefficients were all very high, and thus demonstrated that

Spanish adaptation of SIS is a very consistent, stable and, in one word, reliable instrument. Content validity was analyzed by means of Bangdiwala, Krippendorff, and Fleiss-Cohen coefficients on agreement matrix of the Support Needs Scale (Section 1 of SIS). Results ( $BN=.679$ ;  $a=.787$ ;  $k=.787$ ) gave away that the Support Needs Scale exhibits a high content validity, especially in the domains of employment, lifelong learning, and home living activities. Construct validity was determined by means of contrasting these hypotheses: (a) absence of relationship between age and SIS scores; (b) high inter-scale correlations; (c) significant relationship between SIS scores and both intellectual disability and adaptive behaviour level; (d) significant relationship between support needs assessed and perceived; (e) high correlations between individual items and total score; and (f) a clear factorial structure. All of these forms of validity were, in general, strongly supported by empirical data. Noteworthy, four items (i.e., 'Interacting with others in learning activities', 'Obtaining health-care services', 'Engaging in loving and intimate relationships', and 'Engaging in volunteer work' showed cross-loadings, perhaps indicating some degree of confusion in their wording. Discriminant validity was also quite satisfactory: SIS scores discriminated fairly well between both intellectual disability and adaptive behaviour levels. Finally, factorial structure of SIS has been tentatively confirmed by means of CFA made on item parcels using robust maximum likelihood method of estimation from asymptotic covariance matrix. A complete baremation of SIS was also made (i.e., standard scores and percentiles for the six support intensity scale domains, plus Support Needs Index and corresponding percentiles were calculated).

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## **Resource allocation based on Supports - Two studies with the Supports Intensity Scale**

Dr. Jos van Loon, Arduin Foundation / Department of Special Education, University of Ghent

Prof.dr. Geert Van Hove, University of Ghent

Prof.dr. Robert Schalock

### Aim

Two studies on resource allocation: The development of a formula to translate scores on the Supports Intensity Scale to financial means and a study into the possibilities of the Supports Intensity Scale in the Dutch system of financing service delivery for people with intellectual disabilities.

### Method

1. It can be presupposed that the supports clients get from the service provider Arduin make a good quality of life possible (Van Loon, 2005). The available finances are considered enough to do what is done. In the budget of Arduin

one can distinguish stable costs, and client-dependent costs. The stable costs (material costs, housing, transport, and overhead costs) were totalised, and the remaining money is the budget for the supports-dependent costs. This budget was divided per client according to the SIS scores, with a formula based on the several sections of the SIS. This was validated on a sample of 27 clients, living in 11 houses, by comparing the financial outcomes of the formula with the actual supports-dependent costs per person.

2. In Arduin the Supports Intensity Scale (SIS) is used in an electronic version, next to an electronic format for an interview about a persons's perspectives and goals. The clients of Arduin are also classified according the new Dutch funding system based on seven care weights, which define functions and amount of time needed per client for living, daily activities and treatment (Ministerie van VWS, 2006). The scores on the SIS were compared with this classification in care weights.

#### Results

1. The correlation between the support-dependent costs and the financial outcomes of the formula based on the SIS, is a strong .885 ( $p < 0.01$ ).

2. There are high correlations between the care weights and the SIS-Index plus the score on Exceptional Medical Support Needs ( $r = 0,729$ ,  $p < .001$ ) and between the care weights and the score on Exceptional Behavioral Support Needs ( $r = 0,540$ ,  $p < .001$ ).

#### Conclusions

The SIS can be used in resource allocation. It can be used for calculating support-dependent costs. However, in deciding on a budget, one should also take into account the environment needed to give the support to the person (Thompson et al., 2004). The SIS can also be used to get a classification in seven care weights, but it first produces information on supports needs of people along a continuum. The advantage of the SIS is that it emphasizes support needs instead of system offers. Connecting financial means to SIS-scores directly, means more directly attributing finances to well-described individualised support needs.

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## In dept study of 3 SIS Analysis Levels Presentations

Jim Thompson, Illinois State University (USA)

Jim Thompson, *Illinois State University (USA)*, Creating a Supports Intensity Scale for Children (SIS-Children)

**Aim:** To develop a field test version of a Supports Intensity Scale for Children (SIS-Children) **Method:** An item pool to assess the support needs of children was created through (a) selecting items from the SIS that were applicable to children, (b) reviewing literature regarding support needs and life activities of children, (c) placing potential items into potential domains of support needs, and (d) conducting a modified Q-Sort to provide content validity for items and domains. **Results:** A draft version of the SIS-Children was created which includes two sections. Part 1, the Support Needs Scale, consists of seven subscales: Home Living Activities (Activities completed as a function of living in a household), Community & Neighborhood Activities (Activities completed as a function of being a member of a community or neighborhood), School Learning Activities (Activities associated with acquiring knowledge and/or skills while attending school), School Participation Activities (Activities associated with participating in the school community), Health and Safety Activities (Activities that assure safety and health across home, school, and community environments), Social Activities (Activities that pertain to social integration with others, both children and adults), Self-determination & Advocacy Activities (Activities that are related to acting as a causal agent in one's life, making choices and decisions, and availing oneself of leadership opportunities). Part 2, Exceptional and Medical Support Needs, includes 17 items associated with medical conditions and 14 items associated with behavioral problems that require extraordinary supports to address. **Conclusions:** The draft version of the SIS-Children has sufficient content validity to merit a comprehensive field test in the Spring and Summer of 2008 to determine its psychometric properties.

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## AIDD and the Supports Intensity Scale™ Around the World

Anu Prabhala, American Association on Intellectual and Developmental Disabilities

This presentation will cover an introduction to the American Association on Intellectual and Developmental Disabilities (AAIDD), publisher of the Supports Intensity Scale (SIS™), as well as highlight of the way SIS is being used around the world. Since SIS was launched in 2004, 14 U.S. states have adopted it as the instrument of choice for planning services for people with intellectual disability.

SIS has been translated into 10 languages and is available in stand alone (SIS Venture) and web-based formats (SISONLINE™), in addition to the traditional paper and pencil test format. AAIDD is a 132-year old membership association of professionals in intellectual disability worldwide and does work in the niche areas of definition of intellectual disability, health, and supports. The Supports Intensity Scale is an extension of AAIDD's critical work in defining intellectual disability from a functional supports perspective, in the 1992 definition manual of AAIDD. SIS is a unique assessment tool that allows professionals to base service decisions on the *needs* of a person with an intellectual disability, rather than deficits. The presentation also briefly highlights future AAIDD/SIS initiatives.

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## **Evaluating Reliability and Construct Validity of the Supports Intensity Scale in a Dutch Sample**

Claudia Claes\*, University of Ghent

Geert Van Hove

Jos van Loon

Stijn Vandeveld

Robert Schalock.

### Aim

Up until now, the reliability of client versus staff judgments on the Support Intensity Scale has not been evaluated, although this is important because of the increasing consumer-driven approaches towards services. Additionally, the SIS' construct validity has not been studied yet in a non-English speaking sample, although the SIS has been translated into 13 languages.

Therefore, this study has two major purposes: (a) to determine the inter-respondent reliability of the SIS and (b) to evaluate the construct validity of the instrument, both in a Dutch-speaking sample.

### Method

Data were collected in two different studies, using the Dutch translation of the SIS and the Vineland-Z. (N=30; N=75)

### Results

The relationship between the mean scores of consumer and staff responses suggest significant differences in staff and consumer scores for all subscales. All correlations between the Vineland-Z domains and the SIS subscales are negative ranging from  $-.42$  to  $-.89$  ( $p \leq .01$ ).

### Conclusions

Analyses of the inter-respondent reliability point towards an increased confidence in information provided by clients. The significant negative correlations reflect that the SIS is measuring a different construct (needed support) than the Vineland (adaptive behavior). The results of the two studies provide additional support for the etic (universal) properties of the SIS.

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