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## Research in Developmental Disabilities



# Using the sis to better align the funding of residential services to assessed support needs\*



Climent Giné <sup>a,\*</sup>, Josep Font <sup>b</sup>, Joan Guàrdia-Olmos <sup>c</sup>, Anna Balcells-Balcells <sup>a</sup>, Judit Valls <sup>d</sup>, Maria Carbó-Carreté <sup>a</sup>

- <sup>a</sup> University Ramon Llull, c/ Císter, 34, 08022 Barcelona, Spain
- <sup>b</sup> CPT Estel, c/ Jaume I el Conqueridor, 19, 08500 Vic, Spain
- <sup>c</sup> University of Barcelona, Ps. de la Vall d'Hebron, 171, 08035 Barcelona, Spain
- <sup>d</sup> University of Girona, Campus Montilivi, 17071 Girona, Spain

#### ARTICLE INFO

Article history:
Received 18 October 2013
Received in revised form 30 January 2014
Accepted 31 January 2014
Available online 11 March 2014

Keywords: Resource allocation Intellectual disabilities Residential services Support needs

#### ABSTRACT

Resource allocation in social services has become an issue of the utmost importance, especially in these times in which budgets are tight. The aim of this study is to explore whether the SIS allows for the identification of groups of individuals presenting ID with different needs for support living in residential services in Catalonia, Spain, and if so whether or not a more efficient and fairer system of funding could be considered in comparison with the ICAP. The results show that the six categories of need for support resulting from this study could form the basis for better alignment the funding for those who live in this type of residence according to their assessed support needs.

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#### 1. Introduction

Over the last few decades, the standard of living of individuals with intellectual and developmental disabilities (IDD), has seen considerable improvements due to social and economic changes. The progress that has been made in research has led to significant changes in the understanding of these individuals and the way services intended for them are organized and provided (Kober, 2010; Schalock et al., 2012; Van Loon et al., 2013; Gómez, Verdugo, Arias, Navas, & Schalock, 2013). Acting in their respective spheres, international organizations, professionals, researchers, governmental agencies, and people with IDD and their families have all made critical contributions to the creation of new contexts and opportunities for the full development of these individuals and have helped enhance their quality of life.

One of the key elements in the transformation the IDD field is connected to the gradual international adoption of the support paradigm, stemming from the definitions set out by the AAIDD in 1992, 2002 and 2010. This paradigm is an approach to people with IDD that emphasizes their possibilities and what they are able to accomplish with the proper support, rather than focusing on the areas in which they are lacking.

According to this perspective, as Van Loon (2009) points out, all people should be viewed in light of the social, political and economic context in which they live, and when adequate support is available, people with IDD, who are so often at risk of

<sup>\*</sup> The EIS (Escala d'Intensitat de Supports) is Catalonia's adaptation and standardization of the Supports Intensity Scale (AAIDD, 2004).

\* Corresponding author. Tel.: +34 932533186.

E-mail address: ClimentGG@blanquerna.url.edu (C. Giné).

exclusion, should have access to the resources and opportunities that society can provide so that they are able to realize their dreams and live the kind of life they choose.

Therefore, public policies and organization practices should include as a critical and indispensable element a process to determine what patterns of support people with IDD need, and to ensure that they are accessible in all contexts of their lives.

Thus, it should come as no surprise that there is a growing interest, especially internationally, in linking the financing of services for people with IDD to the results obtained from an assessment of the support that these individuals may need throughout their lives (Schalock, Thompson, & Tassé, 2008; Smith & Fortune, 2008; Kimmich et al., 2009; Van Loon, 2009). This interest can be attributed to several factors, including a desire to achieve greater fairness when financing services for different individuals, meaning that resources should be assigned according to the real needs for the support of people with IDD. Another goal is to ensure a more efficient use of resources at a certain level of quality. Additionally, in some countries, a third goal is the creation of a mechanism to allow people and their families to directly purchase whatever services they choose (Smith & Fortune, 2008). But the most important has to do with the progressive adoption of the constructs of quality of life and support paradigm that lead to the redefinition of organizations and the services and supports they provide to persons with intellectual disabilities (Van Loon et al., 2013). Specifically, we refer to the importance of the quality of life-related personal outcomes and their consequences at the micro, meso and macrosystem level. All of this takes place in a context in which, as Kimmich et al. (2009) points out, it is necessary to reconcile an increased demand for services with a decrease in the budget of public agencies as a result of the worldwide economic crisis, whose effects have been especially severe here in our country.

This set of circumstances has led to a rethinking of the financing of services for people with IDD in broad terms, so much so that Smith and Fortune (2008) refer to a new "emerging framework" that is characterized by (a) prioritizing the individual and not the program or service when assigning financing, (b) developing financing systems based on the characteristics and needs of the person rather than on the service attending to the person, (c) admitting that if financing fails to meet the individual's needs, it will be impossible for him or her to make valuable progress, (d) taking into account the cost of the kinds of the support the person receives that are usually not paid for (including facilities for the family, among other things), and (e) accepting that payments to organizations that provide services should cover both the organizations' structural expenses and costs arising from the different levels of need for support of the beneficiaries.

This situation stands in contrast to the lack of studies and initiatives of this sort in Spain, even though the reality on the ground is very similar to that in other countries; both the associations, generally responsible for providing services, and public authorities who assume most of the cost, share the concern for funding more efficient, equitable and better adapted to the support profile of people with IDD.

Therefore, the time has come to carry out research projects, such as the one presented by this article. The study reported in this article was conducted along the lines of those conducted in other countries that serve to match resources with the real needs for support among people with IDD in Catalonia, with a special focus on new instruments of measurement, such as the SIS (Thompson et al., 2004) and its adaptation and standardization to Catalonia: EIS (Giné et al., 2007).

#### 2. The importance of the SIS for resource allocation

As Kimmich et al. (2009) point out, the key to attaining fairer and more efficient services for people with IDD is the gathering of reliable and accurate information on individuals' needs for support. Unlike other measurement tools in the field of IDD that either focus more on exploring disorders and difficulties or on measuring adaptive skills (ICAP), the SIS is an instrument with an enormous amount of potential (Kimmich et al., 2009) in that it attempts to identify the supports a person needs in order to fully take part in the activities of everyday life in different environments. Anyway it is worth remembering that ICAP has been widely used since the 90s in order to establish an individual's eligibility for the different services according to the rate of adaptive behavior and behavioral problems and, therefore, to guide funding decisions (Smith & Fortune, 2006; MacLean, Heath, & Carter, 2012). Since the SIS appeared, several studies have been conducted comparing the results between the two instruments that allow to conclude that ICAP and SIS measure different constructs and also respond to different conceptual models; while the ICAP is based on a person's independent functioning level (deficit approach) (MacLean et al., 2012) and aims at assessing adaptive behavior, the SIS has been built from the support paradigm and measures the intensity of support that a person needs to full participation in the community (Smith & Fortune, 2006; Whemeyer et al., 2009).

In this sense, according to Verdugo et al. (2010), the correlation coefficients obtained between SIS and ICAP scores ranged from –.498 and –.589; this significant negative correlation coefficients are consistent with other psychometric studies such as the one carried out by Whemeyer et al. (2009) who found a correlation between Total Support Needs Index scores and the ICAP Service Scores of –.49. Moreover Kimmich et al. (2009) argue that the ICAP comparing to the SIS shows the validity and flexibility of the SIS.

In the White Paper on SIS (Schalock et al., 2008), there is a description of two new possible ways of using the SIS: (a) the use of the scale to assign resources and (b) its use in the planning of individual support. The assignment of resources using the SIS is sure to give rise to several questions, some of which have been the focus of research over the last few years (Agosta et al., 2009). One of the most critical issue is to what extent is the SIS a good instrument of measure for use in assessing the support profile that a person with IDD may need throughout his or her adult life, and in broader terms, is it more sensitive to these needs for support than other forms of measurement? Whemeyer et al. (2009) recently carried out a study to explore the efficacy of the SIS for the measurement of needs for the support of individuals with IDD. According to the authors of the study, their results clearly show the SIS to be an effective instrument for the measurement of varying degrees of need for

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