



## Exploring the specific needs of an understudied group: Children with intellectual disability in residential child care



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### ARTICLE INFO

#### Article history:

Received 4 March 2013

Received in revised form 20 April 2013

Accepted 22 April 2013

Available online 11 May 2013

#### Keywords:

Intellectual disability

Child welfare

Residential care

Out of home care

Mental health

### ABSTRACT

Children and adolescents who live in out of home care in the child protection system are considered to be vulnerable to manifesting mental health disorders as well as other types of difficulties. This risk is greater in the case of children who display any type of disability. The aim of this study is to profile the state of health and well-being of a group of children presenting intellectual disability who live in residential care in a Spanish autonomous community and to compare these results with their non-disabled peers.

Two questionnaires filled in by the caseworker and key residential worker, respectively, were used and a screening test (CBCL) was administered to assess the children's emotional and behavioral status.

The results indicate that there are more vulnerability factors in this group of children comparing to their peers; in particular, a greater likelihood of having parents with a history of mental health and alcoholism and greater frequency of intellectual disability in their mothers. Likewise, they had a greater probability of having suffered physical abuse. The screening revealed the existence of greater alterations on the scale of social and thought problems, as well as a greater probability of being referred for treatment and greater use of psychotropic medication.

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### 1. Introduction

Over the course of recent decades, there has been growing interest in identifying and studying mental health in children who exhibit intellectual disability. However, few studies have addressed this issue within the child welfare system and more specifically, in residential child care.

In Spain, unlike other European countries, residential care is one of the most important child protection resources. According to the latest data available (*Observatorio de la Infancia, 2011*), approximately 69% of all new out-of-home placements in 2010 were referred to residential care and only 31% to foster care. The change in the profile of these children over recent decades has led to the specialization of Spain's residential care network in order to respond to the specific needs they have, including unaccompanied asylum seekers children, adolescents without a return to the family home being foreseen (for whom transition to independent adulthood programs are used), as well as those children and adolescents with serious emotional or behavioral problems (*Bravo & Del Valle, 2009; Del Valle, Sainero, & Bravo, 2011; Sainero, Bravo, & Del Valle, 2013*). Compared to other countries in Europe (particularly UK or Nordic countries) Spain shows a larger number of children in residential care (75% of whom are adolescents) with the main reasons for admission

being physical and emotional neglect (*Bravo & Del Valle, 2009; Colton & Hellinckx, 1993; EUROARC, 1998*).

Of these profiles, children and adolescents with some type of mental health disorder are particularly striking due to their high prevalence and the issues they pose in getting along with others in care at residential homes. In Spain, there is a paucity of studies dealing with their characteristics and the specific types of disorders they present and only recently has this issue been given any attention whatsoever, whereas internationally, much research has been devoted to this subject. Indeed, studies regarding children and young people in out-of-home care reveal that this is a population that is particularly vulnerable to displaying mental health disorders and alterations, as well as difficulties and delays in different areas of their development (*Burns et al., 2004; Clausen, Landsverk, Ganger, Chadwick, & Litrownik, 1998; Farmer et al., 2001; Landsverk, Burns, Stambaugh, & Rolls-Reutz, 2006; Pecora, Jensen, Romanelli, Jackson, & Ortiz, 2009*).

In our country, a recent study (*Sainero et al., 2013*) has shed some light on this reality, identifying the fact that a high percentage (44%) of children aged 6 to 18 years in residential care presented some kind of mental health disorder. In contrast, only 26% of the sample was being treated by mental health services, which calls into question the detection and referral criteria of these cases in the child care system, as already stated by other authors (*Burns et al., 2004*). These data point to the need for more research that will make it possible to profile these children's difficulties and to put forth a proposal for early detection and intervention when facing possible clinical disturbances.

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This vulnerability is even greater in the case of children with some kind of disability. Scientific literature has called attention to the high incidence of abuse presented by children with disability (including here all types of possible disabilities) in comparison with their non-disabled peers (Crosse, Kayne, & Ratnofsky, 1992; Sullivan & Knutson, 2000; Verdugo, Bermejo, & Fuertes, 1995). In some studies, this incidence rate is as much as threefold that of the general population (Sullivan & Knutson, 2000).

Neglect is the most commonly identified type of abuse in this group, approximately 20% according to Crosse et al. (1992), although the remaining types are also more common than in their non-disabled peers. Insofar as the more active forms of abuse are concerned, Sullivan and Knutson (2000) found a likelihood of 3.7 and 3.8 times higher of these minors having experienced physical and sexual abuse. In Spanish studies, these children have also been identified as being especially vulnerable to experiencing multiple forms of abuse (Verdugo et al., 1995) and a greater risk of manifesting various mental disorders than do their non-disabled peers (Dickens, 2000), in particular, conduct disorders, anxiety disorders, hyperkinesis and pervasive developmental disorders (Emerson, 2003).

The vulnerability of disabled children is even greater if we refer to those in the child welfare system since, in addition to having suffered abuse, they must also deal with the demands of adapting to new contexts when they are placed in family foster care or in residential care. Despite the high numbers of children with disability in child care, there is very little research describing their specific situation, their characteristics, and the type of care they receive. The figures being used are conditioned by the fact that they are not included specifically in any official statistics (Hill, 2012); the low rate of identification due to the lack of training for direct care professionals (Shannon & Tappan, 2011), and the difficulties involved with referring them to mental health resources (Burns et al., 2004; Farmer et al., 2001; Romanelli et al., 2009; Tarren-Sweeney, 2010). Moreover, the heterogeneity of the samples, methodology, and inclusion criteria used in research with these children must be taken into consideration, particularly when the type of disability referred to is not specified.

The research shows that children with disability have a greater probability of receiving interventions that involve separation from the family, especially residential care (Lighfoot, Hill, & Laliberte, 2011; Rosenberg & Robinson, 2004), and that they undergo greater instability in their itinerary through child care, with more interruptions and placement changes, in addition to remaining in the system for longer than their non-disabled peers (Chmelka, Trout, Mason, & Wright, 2011; Hill, 2012; Slayter & Springer, 2011; Trout, Hagaman, Casey, Reid, & Epstein, 2008). Likewise, they have been seen to present more problems associated with academic performance, higher likelihood of having various types of difficulties arise (Zetlin, 2006) and more mental health issues, especially higher scores (that reach into the clinical category) regarding social and attention problems, aggressiveness, and disruptive behavior (Casey et al., 2008; Tarren-Sweeney, 2008; Trout et al., 2009).

To the risk factors they share with other children in the child welfare system who do not exhibit these types of disability (history of abuse, separation familiar, placement change, etc.), adaptation and communication difficulties and self-protection deficits might also have to be added (Shannon & Agorastau, 2006). Consequently, intervention resources and strategies should be sensitive to and suit the specific needs of this group. However, very few studies have profiled these children's characteristics, demands, and specific needs in comparison with their peers in the child welfare system (Lighfoot et al., 2011).

This article seeks to contribute to this field, specifically analyzing the characteristics and mental health issues of the children who present an intellectual disability (defined as a DSM-IV-TR diagnosis of mental retardation) and who are in residential child care. If there is little research dedicated to disabled children in out-of-home placements, there is even less that specifically addresses children with intellectual disability. Some data indicate that about 10% of children in out-of-home placement

have some degree of intellectual disability (Hill, 2012; Lighfoot et al., 2011), a percentage that is remarkably higher than the rate estimated for the general population, which is around 1–2% (American Psychiatric Association, 2000; Maulik & Harbour, 2010). One of the few studies conducted with this specific group in residential care points out that, in addition to having more placement changes than their non-disabled peers, they have a twofold likelihood of living in residential care than in family foster care (Slayter & Springer, 2011).

In light of the data that highlight the importance of taking the special difficulties of intellectually challenged children into account when they are in residential child care, the aim of this article is to present a study that makes it possible to describe and analyze the specific needs of these children by comparing them to their non-disabled peers in residential care. To do so, research has been carried out regarding all children between 6 and 18 years who were in residential care in one Spanish autonomous community, identifying those who were diagnosed with some type of intellectual disability and recording a series of variables having to do with the intervention of the child protection system (incidence of abuse, history of protection, etc.), academic and training development, and, in particular, their mental health issues. Complications due to mental health in disabled children are not only common, but also pose significant impediments to the provision of proper care in residential child care; consequently, special detail has been focused on this specific aspect.

## 2. Materials and method

### 2.1. Sample

The study was carried out with the entire population of children between 6 and 18 years of age living in residential care in the Spanish autonomous community of Extremadura (N = 264) and who had been living with their educators for at least three months (this criterion was applied to meet the reliability demands of the screening test that will be presented below). Forty-eight (48) individuals were identified within this group who had a diagnosis of intellectual disability (according to DSM-IV-TR criteria); hence, we had a sample consisting of 264 participants subdivided into one group of 48 children–adolescents with intellectual disability and another 216-member group, without this disability.

### 2.2. Instruments and procedure

Variables were collected that referred to the family context of origin, the child him/herself, and to the protective intervention process that was underway. An information report form was created to collect the social–family considerations covering variables regarding the parents, such as age, the couple's status, number of children, and psychosocial problems (history of mental health, substance abuse, gender violence, etc.). To analyze the intervention process data were collected on the reason for protection, prior changes of placement, as well as the duration of the stay. This data collection was completed by the social workers in charge of the case in the child protection services.

Basic descriptive information was collected about the children, such as their age and gender, as well as their educational and health status, with particular emphasis on their mental health. For the identification of mental health problems, a report form was drawn up for completion by each child's key residential worker, requesting information about the medical history (physical illnesses, existence of diagnosed disability, etc.) and data about possible mental health disorders (referral for treatment, medication, diagnoses, etc.). A specific question was added regarding manifestations of suicidal behaviors, due to their severity.

The criterion for selecting the sample with intellectual disability was having received an official diagnosis by the regional service for disabled people. This information was reported by the residential workers.

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