

## INVOLVEMENT IN COMMUNITY-BASED ACTIVITIES OF PERSONS WITH PROFOUND AND MULTIPLE DISABILITIES

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### Abstract

In Portugal, regular schools embody the main context of learning of children with profound and multiple disabilities. Paradoxically the end of schooling – that aims to prepare the individuals for a full citizenship - often means a discontinuity on inclusion process, with less opportunities to be engaged in common contexts of participation. The Day Services or Centres for Occupational Activities comprise the main support services for youths and adults which complexity of disabilities prevents the access to employment. To value the individuals' social role and their involvement in the community encompasses the main principles of these services. In this study we examined to what extent the activities performed by individuals with profound and multiple disabilities – users of the Day Services - are based in the community and are of significance. Data was collected using a questionnaire that listed different categories of activities (within learning, communication, mobility, self-care, domestic, work, and recreation and leisure domains) that were identified in a previous study as characterizing the actions promoted by the Day Services. For each category, respondents were asked about the context of occurrence (i.e., inside the centre or in the community) and their significance for the users (with a 4-point scale varying from “low” to “a lot”). Respondents were occupational therapists responsible for planning and implementing activities held in 43 centres in the North of Portugal. From a total list of 19 activities, a mean of 5 were performed in the community and concern, predominately, to recreation and leisure category (including *shopping, tours and visits* and *laze*). Most activities were performed inside the centres, namely: the development of work tasks; training on domestic activities as preparing meals, and cleaning; and overall learning activities. Significance was judged? in a median of 4 – meaning “a lot” -, with exception to *audiovisuals* and *games and play activities* that, inside the category of recreation and leisure, were judged as having a reasonable significance. A rupture of traditional centre-based models, toward increased use of community resources and activities are discussed in terms of opportunities and challenges of an inclusive society.

**Keywords:** *Profound and multiple disabilities, community-based service, day services, social inclusion.*

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### 1. Introduction

Although the existing wide diversity of functioning profiles, the circumstances of profound and multiple disabilities are globally described by intense support needs resulting from severe cognitive and neuromotor disfunctions frequently accompanied by sensory impairments and medical problems (e.g., seizures, respiratory and/or digestive problems) (Bellamy et al., 2010). In Portugal, precise statistics over the prevalence of individual's with profound and multiple disabilities is unknown; being estimated, however, that during the school-age the number of children using specialized units within regular schools are around of 2.087 (DGEEC for the school year of 2015/2016). Although representing a relatively small and well-identified group, the development of responses aligned with the right of being included and of participating in the community (UN, 2007) has been an unaccomplished goal. As stressed by Maes et al. (2007) this group often experiences restrictions on the number and variety of developmental and leisure activities – resulting in repetitive and annoying routines; the time for leisure is predominantly spent inside institutions; the social network is commonly confined to professionals and family members; and their preferences and capacities are not sufficiently considered in the activities planning.

Based on the gap between the values/rights and the practical domain, the functioning model of support services – mainly represented by Day Services - has currently been under discussion in terms of significance and contribution for users' quality of life. As internationally documented adults with profound and multiple disabilities tend to spend around 7 to 10 hours in Day Services (Inspectorate of Health Care, 2005). Designed for persons which functioning circumstances prevent the involvement in a job – as

traditionally conceived – the Day Services, in Portugal, are defined by the intention of “*promoting quality of life through the engagement in social valued activities, whenever possible in the community, foreseen the development of skills as active and creative beings*” (Social Security Institute, 2007, p.2). Despite this definition, studies have been indicating that self-care, sensorial and group or passive activities are the activities predominantly experienced on these support services (e.g., Putten & Vlaskamp, 2011; Vlaskamp, Hiemstra, Wiersma & Zijlstra, 2007). The replacement of traditional approaches – merely dedicated to the occupation of time – by others centred on mediating the access and involvement in the community is a critical advance to achieve in terms of support’s organization. Modernization of these services entails, then, the need of developing activities for individuals’ empowerment, for social network enlargement and for the reduction of physical, social and intellectual barriers in the community (e.g., New Directions 2012-2016; Time to Move on from Congregating Settings: A Strategy for Community Inclusion, 2011).

Considering the need of developing strategies of support social participation of persons with profound and multiple disabilities in the community, this study intends to provide a description of the activities promoted by Portuguese Day Services, specifically in terms of their context of occurrence and of their significance.

## 2. Method

This study embodied a survey pertaining to a wide project that intends to map the nature and diversity of domains of Activity and Participation promoted by the Portuguese Day Services; and to understand which factors define the most satisfactory experiences.

### 2.1. Participants

A survey was administered to occupational therapists responsible for planning and implementing activities held in 43 centres situated in the North of Portugal. An incidental sampling was used for participants’ recruitment, starting by an invitation letter sent to occupational therapists working in different Day Services in the North of Portugal. The responding therapists had a mean age of 30.79 (SD=6.91), with 7 years as mean time of experience working in Day Services. The majority were females (n=40; 93.02%).

Therapists were working in Day Services that supported an average of 41.26 users (SD= 29.93). It is important to note, however, that a large diversity on the number of persons supported by the services was found, varying from 10 to 162 users. In total the services that participated in the study were serving 1 774 individuals. The majority was supporting individuals between 25-34 (n=67.4% of the centres) and between 35-49 years old (65.1%). Few services indicated also as target population individuals between 18-24 (18.6%) and between 50-59 (9.3%). Most of the centres were implementing supports to groups mainly composed by individual’s with intellectual disabilities. Other diagnoses were also represented such as cerebral palsy, down syndrome and autism.

### 2.2. Data collection

Data was collected using a questionnaire that listed different categories of activities (within learning, communication, mobility, self-care, domestic, work, and recreation and leisure domains), framed by the International Classification of Functioning, Disability and Health (ICF, WHO, 2001), that were identified in a previous study as characterizing the actions promoted by the Day Services (Nunes & Silveira-Maia, 2015). For each category, respondents were asked about the context of occurrence (1- inside the centre; 2 - in the community; 3 – inside the centre and in the community) and about their significance for the users (with a 4-point scale varying from “low” to “a lot”).

### 2.3. Procedure

Data was collected during 2018. The questionnaire was made available online through the software Lime Survey. Questionnaires were accompanied by an introductory letter and a consent form. Confidentiality and anonymity were maintained throughout the study development. A descriptive analysis was performed using the SPSS Statistics 23 software package.

## 3. Results

Most activities were performed inside the centers, being reported as main context of occurrence by most of the centers (table 1).

From a total list of 19 activities, five were assigned as being mainly performed in the community. Around a half of the centers developed in the community activities of *moving around* and *physical related-activities*. The majority (more than 79% of the centers) assigns/assigned? also to the community activities as *shopping, tours and visits* and *laze*.

Table 1. Predominant context of occurrence of the different categories of activities (number of centers; percentage) and median of significance (from “0 none” to “4 a lot”).

Categories	Main Context of Occurrence n (%)	Significance Md
Learning and applying knowledge (e.g., clubs of math)	Inside the center (n= 34; 79.1%)	4
Communicating (e.g., groups of conversation)	Inside the center (n= 40; 93%)	4
Using technologies	Inside the center (n= 32; 74.4%)	4
<b>Moving around (e.g., orientation and mobility training)</b>	<b>In the Community (n= 22; 51.2%)</b>	4
Manualities	Inside the center (n= 39; 90.7%)	4
Self-Care (autonomy training)	Inside the center (n= 23; 53.5%)	4
Eating and drinking (hour for tea/ lunch...)	Inside the center (n= 34; 79.1%)	4
<b>Shopping</b>	<b>In the Community (n= 34; 79.1%)</b>	4
Preparing meals (kitchen training)	Inside the center (n= 34; 79.1%)	4
Domestic Activities (cleaning training)	Inside the center (n= 33; 76.7%)	4
Preparing to work (e.g., carpentry workshops...)	Inside the center (n= 23; 53.5%)	4
Working activities inside the institution	Inside the center (n= 23; 53.5%)	4
Working activities for the community (e.g., laundry...)	Inside the center (n= 22; 51.2%)	4
Artistic and Creative Activities (e.g., painting...)	Inside the center (n= 31; 72.1%)	4
<b>Physical Activities (e.g., sports...)</b>	<b>Inside the Center and In the Community (n=20; 46.5%)</b>	4
<b>Tours and visits</b>	<b>In the Community (n=37; 86%)</b>	4
Audiovisuals (watching tv, listening music)	Inside the center (n= 38; 88.4%)	3.5
<b>Laze (e.g., going to coffees; restaurants, parties)</b>	<b>In the Community (n=35; 81.4%)</b>	4
Games and Play (e.g., board games)	Inside the center (n= 40; 93%)	3

Significance were judged in a median of 4 – meaning “a lot” -, with exception to audiovisuals and games and play activities that were judged as having a reasonable significance.

#### 4. Discussion and conclusions

The restructuring of Day Services towards a strategy based on accessing mainstream community amenities and facilities is an international trend (e.g., Simpson, 2007). From the perspective of the occupational therapists, this study provided information on the activities promoted by the Portuguese Day Services in terms of context of occurrence and of their significance. Data seems to confirm that the great diversity of the activities developed by Day Services are performed in institutional context. Exception was observed in areas as *moving around*, *physical activities*, *tour and visits* and *laze*, activities which were predominantly assigned as being developed in the community. It is worth to note that data also revealed that the work-related activities (including work activities for the community) remains encapsulated in the institutional context; contrasting with a modernization movement that conceives the employment as the maximum symbolic signal of participation in the community (Scottish Executive, 2003). Considerations should also be done on regard to the activities’ evaluation in terms of significance. The present study indicate that all activities were considered of great significance by the therapists. Nevertheless, we must be aware that significance evaluation should be primarily based on the satisfaction of the users (e.g., Simpson, 2007) – perspective not directly covered in this paper. Indeed, study findings seem to reinforce the need to increase the use of community resources and activities, which demands to rethink the way supports are organized and provided.

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