

## ADJUSTING SCHOOL ENVIRONMENT FOR CHILDREN WITH PROFOUND AND MULTIPLE DISABILITIES

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### Abstract

An “one track approach” has been defining the Portuguese policies and practices towards an education for all. Nowadays, more than 98% of children with disabilities is attending regular schools, including those with profound and multiple disabilities. This study aims to identify environmental factors supporting the inclusion of children with profound and multiple disabilities in mainstream educational settings. The Individualized Educational Programs (IEPs) of twenty-three children were subjected to a content analysis that used the International Classification of Functioning Disability and Health (ICF) for categorizing environmental facilitators. The examined IEPs were collected from ten schools of Porto district and were designed for children with significant impairments both on mental and neuromusculoskeletal and/or sensory functioning. Children had a mean age of 11 years old and were attending elementary and middle schools. Two co-researchers reviewed the categorization of the units of meaning into the ICF codes. A mean of 10 environmental facilitators were identified on students’ IEPs. Study findings report that 41.74% of the environmental factors comprised products and technologies, specifically the use of: adapted methods of communication (e.g., augmentative and alternative communication - Makaton, PCS and other symbol systems); adapted methods for education (e.g., time management; providing diversified sensory inputs; varied and ludic activities; segmentation of instructions; use of tangible concepts; structuring and anticipating routines/activities). Support and relationships embodied 40% of the facilitators, namely: providing physical and/ or verbal guidance; collaborative relationships between school-family and family-health professionals; positive reinforcement to students’ involvement and behaviors; choice-making opportunities; and tutoring support (identification and use of an adult and/or a peer of reference). The availability of services - such as transportation; extra-curricular activities; social assistance; medical and rehabilitation counseling (e.g., including genetics or neurology appointments) and the composition of a pluri-disciplinary educational team (including occupational and speech therapy) - was also found within students’ IEPs; embodying 9.57% of the identified facilitators. Others’ attitudes were also addressed in students’ IEPs in terms of promoting general acceptance and closeness to peers. Recommendations are outlined from the confrontation between the identified facilitators and the reported needs of students and families.

**Keywords:** *Profound and multiple disabilities, school inclusion, environmental facilitators, ICF.*

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### 1. Introduction

To provide every student the sense of belonging and a well succeed participation – including children and youth with disabilities - is the current challenge faced by European countries towards an inclusive education (e.g., EASNIE, 2018). Defined by the ability to respond to the diversity of pupil’ needs, inclusive practices depend on identifying and implementing environmental supports that enables the learning and participation of each and every one of the students (e.g., Rozenfelde, 2016; Silveira-Maia et al., 2017). The access to regular schools is an established reality in Portugal, being documented (CRPD, United Nations, 2016) that around 98% of the children and youth with disabilities are attending regular schools. A wide spectrum of functioning diversity is, then, found in Portuguese schools, including circumstances of profound and multiple disabilities. Beyond the access, the goal is now imposed on moving towards an increased participation, in terms of skills, relationships and membership (Blum, Gutierrez & Peck, 2015). This study intends to contribute in the path for environmental enablement, by describing the supports implemented in regular schools for children and youth which functioning profiles reports profound and multiple disabilities.

Pursuing an inclusive education, Portuguese legislation adopted a multilevel approach for implementing supports in regular schools. Three levels of measures are considered and mobilized according to students' educational needs and their response to intervention (DL No. 54/2018, articles 8<sup>th</sup>, 9<sup>th</sup> and 10<sup>th</sup>):

- (i) universal measures - mobilized for all students, including adjustments such as curriculum enrichment, promotion of pro-social behavior, differentiated instruction;
- (ii) selective measures - implemented when universal measures do not fill the needs for learning supports. Include, as example: non-significant curriculum adaptations, psycho-pedagogical support, tutorial support;
- (iii) additional measures - designed to respond to "intense and persistent communication, interaction, cognitive or learning difficulties that require specialized resources (...)" (art 10, point 1). Include: "the completion of the school year by subject"; "significant curricular adaptations", "individual transition plan" (designed to promote the transition to post-school life and, whenever possible, to a professional activity), "the development of structured teaching methodologies and strategies"; and "the development of personal and social autonomy competences" (art 10, point 4).

As found in a literature review conducted by Bellamy and colleagues (2010), within the diverse definitions of profound and multiple disabilities, consensual characteristics include "profound cognitive impairment, and social functioning, as well as more than one additional disability, usually including sensory or physical impairment, and may also include autism or mental illness or challenging behaviours or an associated medical factor" (p.225). Their complex needs commonly require educational interventions inscribed in additional measures of support which implementation is monitored by a multidisciplinary team, composed by: the school director (or an assisting teacher); a special education teacher; members of the pedagogical council; a psychologist; regular teachers; and other technicians (as an occupational and speech therapist) (DL No. 54/2018). Significant curriculum accommodations are commonly implemented, including objectives established in terms of knowledge and competences related with autonomy, personal development, and interpersonal relationships. At the end of the school pathway, according to the law, for those who followed a curriculum with significant adaptations, a certificate of completion? is provided describing the individual education program and the experiences promoted through the individual transition plan.

Although the legislation privileges the context of the classroom for implementing additional measures, along the years schools has been adopting a specialized unit model. Specialized units implement specific interdisciplinary intervention strategies aimed at building capabilities and strengthening skills that are necessary for enhancing those students' participation in classroom activities with their non-disabled peers (Sanches-Ferreira, Silveira-Maia, Lopes-dos-Santos & Santos, 2017). According to DGEEC, in the 2013-2014 school year, 3.19% of the students receiving special education services were being assisted in Support Specialized Units.

It is important to note that Specialized units have been subjected to substantial criticisms, being referenced as creating a new form of segregation within schools. As it is reported by Pinto and Pinto (2018), 57% of the students using the units spend less than 40% of the school time with their peers of the regular classroom. One of the responses to this criticism consisted on the intention – stated by the Portuguese ministry of education – of reconfiguring Specialized units into "Learning Support Centres", transforming that contexts in dynamic and plural spaces with human and material resources for promoting knowledge and experiences of all, and not only students' with profound and multiple disabilities (DL No. 54/2018).

Framed by this ideo-political context, this study aims to contribute on the path for the development of inclusive practices and cultures, by describing strategies, resources, as well as assistive devices that are used to support the learning and participation of children and youth with profound and multiple disabilities in regular schools.

## 2. Method

### 2.1. Participants

The Individualized Educational Programs (IEPs) of twenty-three children were examined. IEPs were provided by 10 schools of Porto District. Recruitment process entailed an incidental sampling, that started with a letter of invitation addressed to school principals of Porto district; followed by asking parents' authorization for consulting the IEPs. Inclusion criteria for the selection of IEPs considered the conditions of: (i) being designed for children with significant impairments both on mental and on neuromusculoskeletal and/or sensory functioning; and (ii) including significant accommodations in the curriculum.

The included IEPs were designed for students with a mean age of 11 years old, that were attending elementary and middle schools. Twelve (52.5%) were females and eleven (47.8%) males. A wide scope of diagnosis was found on their individual processes, including cerebral palsy, down syndrome, autism, fetal alcohol syndrome, intellectual disabilities, and global developmental delay.

IEPs were designed by interdisciplinary teams, predominantly composed by a special education teacher, regular teacher, parents, psychologist and therapists. The regular classroom and the specialized unit for multiple disabilities were the main contexts of students' participation and learning.

## 2.2. Data analysis

The IEPs were subjected to a content analysis that used the International Classification of Functioning Disability and Health (ICF, WHO, 2007) for deductively categorizing environmental facilitators. The ICF is a biopsychosocial framework that has been broadly used as a taxonomy supporting assessment and intervention planning in special education and inclusive field. The ICF incorporates a comprehensive list of environmental factors, organized into five chapters (table 1).

Table 1. Domains (WHO, 2007) considered for environmental categorization.

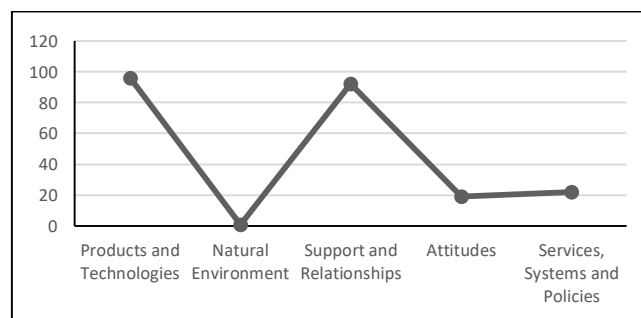
Environmental domain	Contents	Examples of corresponding meaning units and linkage to ICF codes
Products and technology	All references to "products or systems of products, equipment and technology in an individual's immediate environment"	"texture and diversity of food" (e1100-food) "adapted spoons with thickened cable" (e1151-assistive products for personal use in daily living)
Natural environment and human-made changes to environment	All references to "animate and inanimate elements of the natural or physical environment, and components of that environment that have been modified by people".	"Adjustment of light and sounds into different rooms" (e2400 - Light intensity; e2500- Sound intensity)
Support and relationships	All references to "people or animals that provide practical physical or emotional support, nurturing, protection, assistance and relationships to other persons, in their home, school or at play or in other aspects of their daily activities".	"Tactile kinesthetic cues" (e360-other professionals); "peer tutoring" (e325 - peers); "emphatic and secure climate" (e330-people in positions of authority)
Attitudes	All references to "attitudes that are the observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs".	"positive expectations"; "valuing progresses" (e430-individual attitudes of people in positions of authority)
Services, systems and policies	All references to provided "benefits, structured programmes and operations"; to "administrative control and organizational mechanisms"; or to "rules, regulations, conventions and standards established by governments"	"use of adapted services of transportation" (e540 - transportation services, systems and policies); "enactment of social assistance services" (e570-social security services, systems and policies)

Two co-researchers reviewed the categorization of the units of meaning into the ICF codes.

## 3. Results

A total of 230 meaning units were found on the 23 examined IEPs, representing a mean of 10 environmental facilitators specified in each students' IEPs. As shown in figure 1, most of support are described in terms of products and technologies (n=96; 41.74%) and support and relationships (n=92; 40%). An emergent reference to attitudes (n=19; 8.26%) and services, policies and systems (n= 22; 9.57%) was also verified.

Figure 1. Distribution of the meaning units according to environmental domains.



### 3.1. Products and technologies

In each IEP, a mean of 4 environmental facilitators was defined in terms of products and technologies. As we can read from table 2, a greatest diversity of factors was found on regard to products and technologies for communication and for education.

Table 2. Categories, subcategories and examples of meaning units found within products and technologies domain.

Categories of Products and Technologies	Subcategories	Examples of contents
Products or substances for personal consumption	Food Drugs	Diversity of food Pharmacotherapy
Products and technology for personal indoor and outdoor mobility and transportation	Assistive products and technology for indoor and outdoor mobility	Wheelchairs; lift for transfers
Products and technology for communication	Assistive products and technology for communication	Describing images/ situations, using gestures; using of the computer; using alternative and augmentative communication systems (SPC; Makaton; photos)
Products and technology for education	General products and technology for education  Assistive products and technology for education	Interactive board; using the computer/ specific software's; didactic games; using audiovisuals; correspondences Tasks segmentation; furniture adjustments; tangible and concrete instructions; involvement gradation in terms of time; sequencing activities; using different textures; routines predictability;
Products and technology for culture, recreation and sport	General products and technology for culture, recreation and Sport	Dynamization of parties, school tours; sports
Design, construction and building products and technology of buildings for public use	Design, construction and building products and technology for gaining access to facilities inside buildings for public use	lifts or elevators, ramps
Non-specified	.....	“Technologies/ assistive devices helps...”

### 3.2. Support and relationships

The environmental facilitators described in terms of practical physical or emotional supports registered also a mean of 4 references. Diversity of supports are defined on table 3.

Table 3. Categories, subcategories and examples of meaning units found within supports and relationships domain.

Categories of Products and Technologies	Subcategories	Examples of contents
Immediate family	.....	Involvement on educational planning; generalization of the strategies in home; economic investment; familiar stability; articulation with school
Extended family	.....	Involvement in students' educative life; emotional support; articulation with health professionals
Peers	.....	Support in routines management; protection; behavior modeling; tutoring support.
People in positions of authority/ Other professionals	.....	Positive reinforcement; monitoring; providing physical and/ or verbal guidance; encouragement; choice-making opportunities

It matters to highlight that several references to environmental factors did not specify, beyond the mention to the general environmental domain, which exact facilitators were mobilized for student's inclusion. Sentences as /“Technologies or assistive devices helps...”/ “The individualized support of the teacher is important for...” / “(...) with the support of the parents” / are often found in the IEPs, without further specification of the implemented supports.

General acceptance and closeness to peers represented the categories found within attitudes domain. Some of the references to services, policies and systems included transportation between school and rehabilitation centers, the availability of extra-curricular activities; economical support; social assistance support; technicians' interventions (occupational and speech therapy) and medical and rehabilitation counseling (e.g., including genetics or neurology appointments).

#### 4. Discussion and conclusions

The present study provides systematized data on supports implementation reported on IEPs of students with profound and multiple disabilities. Study findings show that *products and technologies*, as well as, *supports and relationships* – in terms of physical and emotional support - embody the major environmental adjustments addressed on students' IEPs. An environmental habilitation centered on *products and technology* seems to reflect the greatest emphasis of the literature on interventions towards: (i) communication, as working based on pre-intentional or intentional signals or with augmentative communication systems (e.g., Chadwick, Buell & Goldbart, 2018); and (ii) structured learning environments, with predictable routines, anticipation, repetition, sensory engagement, choice-making opportunities or use of objects of reference (e.g., Arthur-Kelly et al., 2008). 'Attitudes' was an emergent environmental domain addressed on students' IEPs suggesting that school community isn't yet considered as a target of intervention. As widely known, attitudes embody one of the greatest barriers faced by people who have profound and multiple disabilities (e.g., Safak, Muzeyyen & Kot, 2014). Thus, the low importance assigned to that domain contrasts with the need for a consistent implementation of the strategies already projected in terms of communication or learning, which highly depends on educating the staff for understanding and using that cues; along with shaping positive expectations and investment on students' progresses. Also, the integration of attitudes as targets of intervention is a critical factor for the accomplishment of meaningful and quality relationships; connecting with peers and with the community (e.g., Nijs & Maes, 2014).

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