



A toolkit for raising awareness and overcoming physical, attitudinal, and communication hindrances for persons with neuromotor disorders in community settings

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Abstract. This work aimed to identify which barriers persons with neuromotor disorders face often to participation in community settings and to encourage all actors in society to become agents of inclusion in their social and professional circles. An online survey among persons with neuromotor disorders identified the diversity and barriers to participating in community settings. A focus group with nine adult persons with cerebral palsy discussed the relevance of the data, reflecting on their own experience as customers, employees, or just citizens in the frequency of community settings, providing contributions to the production of videos and written material. Finally, elements from ‘Era uma vez...’ theater group along with the creative writing group of the Cerebral Palsy Association of Porto provide the scripts and filmed different typical situations, illustrating problems faced by persons with disability and suggesting solutions to how to overcome them, especially at the attitudinal level. Results showed cultural activities as the least frequented service while the most were health services. The need for assistance for participation varied between 33.4% for stores and 54.4% for health services. From the creative phase, a practical guide for caring for and promoting the participation of persons with neuromotor disorders was published and the produced videos are available through digital platforms namely YouTube.com and APPC Facebook page. Providing tools for the community to raise their awareness about hindrances and barriers to the participation of persons with neuromotor disorders built through a co-creation process could facilitate the construction of an inclusive society.

Keywords: Neuromotor disorders, Community toolkit, Social participation.

1 Introduction

The United Nations (UN) Convention on the Rights of Persons with Disabilities 5th and 6th articles define the specific obligations of the State’s Parties to raise society's awareness of disability, combat stereotypes, and appreciate people with disabilities [1].

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Even before this structuring UN instrument, the World Health Organization proposed, at the beginning of the 21st century, a new approach to the concept of functioning, where participation emerged as the relevant focus. The social participation of people with disabilities has gained increasing significance in recent years, not only as a right but also to combat social exclusion, economic poverty, lower educational attainment, and poorer health outcomes. Participation is defined in the International Classification of Functioning, Disability and Health (ICF), as involvement in a life situation, is a crucial dimension for social inclusion, and is the result of the interaction of personal and environmental factors with the functions and structures of a person's body [2]. Environmental factors in ICF constitute the physical, social, and attitudinal aspects in which people live and conduct their lives [3]. If physical and architectural barriers seem easy to be recognized by the public, other types of hindrances like negative attitudes could lead to discrimination or too undesirable effects on those people that are impeached of participation. Thus, participation is context-dependent and may be predominantly influenced by environmental characteristics rather than individual characteristics, which is reduced in young persons with neuromotor disorders when compared to peers, which leads to conditioning their socialization, self-determination, and quality of life [4].

Most neuromotor disorders, like cerebral palsy, can be described as permanent disabilities since they start in childhood and persist throughout the lifespan [5]. With advances in medicine and economic development, many people with these health conditions have a life expectancy like that of the general population [6]. Trivial activities of everyday life could constitute a challenge for persons with neuromotor disorders like making a purchase, withdrawing money from an ATM, attending a concert hall, using transport, or using medical equipment during a consultation.

One of the premises for participation is the opportunity to be involved. The lack of opportunities can be multifactorial, but environmental barriers contribute to reduced social participation in different community services [7]. Facilitators of participation, on the other hand, are factors that mitigate the barriers posed by disability, enhance the level of functionality, and thereby promote increased engagement in society. Examples of such enablers are an accessible environment or access to technological devices, inclusive attitudes, and services that help in everyday life.

Given that legislative and political instruments such as the one cited above provide the framework and support for action, it is up to structures close to citizens to develop and implement strategies for change. In this sense, communities need, on the one hand, to be alerted to concrete problems experienced by people in vulnerable situations, and on the other hand, to be provided with the necessary tools to implement the desired change [8,9].

Co-creation as a strategy for involving people living with a health condition or disability in the process of developing new products has been increasing [10] and is being used in different contexts [11]. This involvement presents more interesting results in terms of product quality, consumer expectations, and needs [12]. The use of different communication media, namely videos broadcast through digital platforms, to raise awareness of issues relating to health [13] and people with disabilities among the public has shown positive results [14].

The lack of communication tools for the general population about the problems faced by adults with neuromotor disorders in the frequency of different services at the community level motivated the implementation of the project 'Eliminar Barreiras, Mudar Atitudes' (Remove Barriers, Change Attitudes).

The objective of this study is to identify specific barriers faced by individuals with neuromotor disorders in accessing and participating in community environments, focusing on different services. The research aims to encourage actors within the different community services to actively promote and contribute to the inclusion of individuals with neuromotor disorders in these environments."

2 Methods

2.1 Study design

The study was completed in three phases. The first phase, through a survey, intended to identify the diversity and which barriers occur to participation in community settings. The second phase included a focus group for discussion of the results of the first phase to contribute to the co-creation (the third) phase. The last phase produced informative and didactic material for different media in digital and paper support, which were developed under a co-creation methodology - a collaborative approach that allows researchers to build fruitful relationships with the creative team [15].

2.2 Participants

For each phase, a different group of participants was included. For the first one, were invited adults with neuromotor disorders attended services from the Rehabilitation Center of Cerebral Palsy at Porto-Portugal in 2021. For the next phase, were invited adults with cerebral palsy from both sexes with different functioning profiles, like using wheelchairs and/or augmentative communication devices, accustomed to attending community services. For the creative and the production phase, were invited elements of the theater and creative writing groups of the Associação do Porto de Paralisia Cerebral (APPC), which include people with and without disabilities.

2.3 Procedures

The first phase survey was made available online for two months and asked for information about gender, education level, age, self-classification of functional status (walking ability, hand manipulation, communication), and usual attendance of community services (stores, health services, restaurants, financial services) and the self-identification of barriers to participation (architectural, attitudinal, own barriers, no barriers). The diversity frequency of community services was calculated by the sum of each item (min=0; max=8). Additional information was collected about the use of public transportation services (like buses, metro, and taxis). APPC services were responsible for the dissemination of the questionnaire to potential participants.

The Focus group was conducted by health professionals with experience in dealing with persons with functional diversity. After the icebreaker, one of the moderators made a brief presentation of the results obtained from the phase 1 questionnaire. Then, the discussion addressed the relevance of the data, and reflected on their own experience as customers, employees, or just citizens in the frequency of community settings, providing contributions to the production of videos and written material.

Finally, elements from 'Era uma vez...' theater group along creative writing group of the Cerebral Palsy Association of Porto (APPC) provide the scripts and filmed different typical situations, illustrating the problem faced by persons with disability and suggesting solutions to how to overcome it, especially at the attitudinal level.

2.4 Data analysis

Survey results and website metadata were described using descriptive statistics indicators (like proportions for qualitative data, mean, and standard deviation for quantitative data), the Qui-square test, and the Spearman correlation coefficient for associations between variables, using SPSS Window version 25.0. Qualitative data obtained from the focus group were studied using a thematic analysis approach [16].

3 Results

3.1 Phase 1

Participants in the survey were 57 persons (57.9% male) with neuromotor disorders (68.4% cerebral palsy), a mean age of $35y0m\pm14y3m$ (61.4% have a secondary or higher level of education). Self-description of functional ability shows most of the participants walk without aid (59.6%), had no limitations in communication (63.3%), and handled objects without assistance (59.6%).

The diversity of frequency was high (median=8; $IQ1-IQ3 = [6-8]$). The least frequented services were indoor and outdoor cultural activities, and places of worship. The most frequented service was 'health services'. The need for assistance for participation varied between 33.4% for stores and 54.4% for health services, the service more used independently was stores and other similar commerce (Figure 1).

Street stores and restaurants along buses were mostly identified as having architectural barriers. For attitudinal barriers most frequently identified were street stores, cultural activities, and banking or insurance services.

Own barriers were frequently identified for the use of public transport. For the diversity level of participation, a correlation was found between education (Spearman $r=0.314$; $p < 0.05$), walking ability (Spearman $r=-0.283$; $p < 0.05$), communication (Spearman $r=-0.295$; $p < 0.05$). The diversity level of participation was different between those who use or did not use buses (7.5 ± 1.1 vs 5.8 ± 2.8 ; $p < 0.05$) or metro (7.7 ± 0.8 vs 4.6 ± 3.0 ; $p < 0.01$).

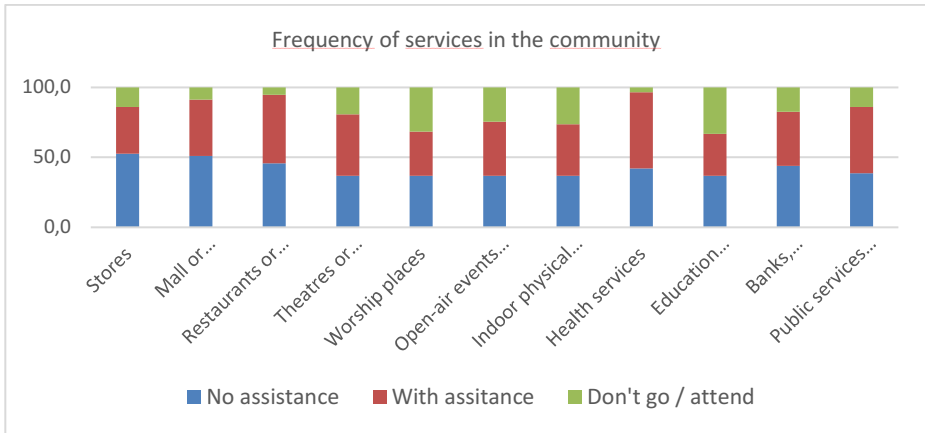


Fig. 1. Frequency of services in the community with or without assistance (Source: own elaboration)

3.2 Phase 2

Different themes were addressed during the focus group. The different experiences were particularly explored, where some of the behaviors and attitudes of other people were identified as common in everyday situations, including health professionals or public services. The following quotes are representative:

“The doctor doesn't look or speak to me. Just, to my wife, as if I don't understand what he means...” (Male, 47 years old)

“We get on the bus, there's no time to sit down, and I often fall on top of another person...” (Female, 25 years old)

“Sometimes I'm at the ATM, and as I'm slowly operating the system, other people start insulting me...” (Male, 35Years old)

The proposal for the elaboration of scripts for the elaboration of the films includes situations in the medical consultation, in restaurants, as a spectator of the sporting activity, using an ATM, parking cars on the sidewalk, and the emphasis on respect for individual choices from a perspective of self-determination.

3.3 Phase 3

Written, visual, and auditory information disclosure procedures were developed to provide relevant legislation and relevant sources of information, including simplified versions of legislative pieces. The written information was compiled into a practical guide for caring for and promoting the participation of persons with neuromotor disorders.

Each page of the guide provides a practical situation approaching possible everyday interactions with persons with limitations in mobility, communication, and interpreting

information due to sensorial or intellectual processing. A QR code is available for access videos, legislation, and other resources related to the theme.

The production of the eight videos was carried out in real contexts, and for the moments of oral communication, the respective correspondence in text and Portuguese sign language was introduced. In the first part, each video demonstrates a possible wrong approach to the person with a disability, then illustrates a possible way of acting appropriately to the situation. The videos are available through digital platforms namely youtube.com, APPC webpage, and Facebook page.

The guide and leaflet were downloaded 1 738 and 400 times, respectively, videos have 3215 visualizations, and more than 1 750 paper formats were distributed. References to this resource are available in a national newspaper and media agencies like Observador or Lusa, other local newspapers, and Antena 1 radio.



Fig. 2. Example of an illustration from the guide. (Source: https://www.appc.pt/_GuiaEliminarBarreirasMudarAtitudes/GuiaEliminarBarreiras.pdf).

4 Discussion

This study identifies relevant data about the diversity of participation in community services for persons with neuromotor disorders. The first note is for the high level of diversity of individual participation, covering most of the type of services possible to be found in the community, revealing that if the opportunities exist, they are used even in the face of possible barriers. The second note concerns the type of barriers identified depending on the type of services: architectural for transport, street shops, and restaurants; attitudinal for banking services, insurance, and again street shops. These barriers found in this type of service can be easily overcome if all the staff of these organizations has the possibility of accessing training in specific assistance to this group of people, not only regarding issues of mobility in the physical space but also in alternative forms of communication, highlighting the time available for service.

The functional profile has an influence on participation but environmental factors like access to adequate public transportation could play a major role in improving the level of frequency of community services [17]. If mobility issues, in the context of rehabilitation services, have been addressed as a priority over time, this work shows the

importance of communication skills for participation, like what has been proposed for other contexts of work for people with limitations on this activity [18,19].

If the perspective of evaluating participation includes the individual perception of interaction with other people, attitudinal barriers play a crucial role in its implementation. Indeed, the situations identified in different contexts reveal the difficulty that even trained professionals have in interacting with people with functional diversity [20]. Overcoming these barriers implies increasing the number of individual interactions with people with disabilities, in addition to introducing specific training, including for health professionals, in augmentative and alternative communication.

The results show adherence to different types of available materials. That corresponds to the initially foreseen objectives. The materials are described as useful, and easy to use, with simple and direct messages. The defined standard situations seem to be relevant and similar to those faced by other people with the same type of limitations as a result of other health conditions.

For the first phase of the study, the limitations of the study include a risk of selection bias and a risk of information bias. The risk of selection bias due to how recruitment was made, by the availability of the questions only in text format, and the response requiring precise movements (tick boxes size). The risk of information bias arises from respondents self-evaluating for the functional profile, and for lack of quality control of responses. Although an attempt was made to include participants with different characteristics, coming from only one region of the country could influence the experiences and changes the importance of some thematic areas. The website was developed for the Portuguese context which could be a limitation to using these tools in other countries even if they have Portuguese as their official language.

As a decrease in access to materials is expected over time, there are plans to diversify the contemplated situations, using a similar development methodology. Future work may address specific situations related to the main areas of life such as employment, training, and leisure.

5 Conclusion

The utilization of diverse methodologies to gather information about barriers and facilitators to the participation of individuals with neuromotor disorders serves to broaden the scope of situations and delve into potential triggering factors. Making these tools accessible through current online information dissemination mechanisms can extend their reach to audiences often distant from these issues.

Special attention deserves the need to increase training opportunities, including for professionals in the social and health sectors, on the impact of environmental factors on the level and diversity of participation of people with disabilities.

Empowering the community with tools designed to raise awareness about hindrances and barriers to the participation of individuals with neuromotor disorders, developed through a co-creation process, has the potential to facilitate the construction of an inclusive society. In this context, co-creation involves collaborative input from various stakeholders in the development of resources. Such an approach not only increases

awareness but also promotes understanding and empathy within the community, contributing to the creation of an environment that actively supports the participation of individuals with neuromotor disorders.

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