ACCESS TO ASSISTIVE TECHNOLOGY DEVICES IN INDIVIDUALS WITH CEREBRAL PALSY AND COMMUNICATION LIMITATIONS

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Abstract

Introduction: Assistive Technology covers several areas and one of them is communication, with the development of strategies that make everyday actions accessible and allow to overcome difficulties, expand and facilitate inclusion and independent life. The individual with Cerebral Palsy has several limitations that can assume varying levels,

including motor and communication changes, these repercussions for those who need some type of assistance are diverse.

Objective: To evaluate the access and usability of Alternative and Augmentative Communication resources in individuals with Cerebral Palsy.

Method: A semi-structured questionnaire with open and closed questions was carried out to identify the scenario in which these individuals live and support with Assistive Technology resources, the interviews were conducted with professionals and caregivers of individuals with Cerebral Palsy.

Results: Findings indicate that assistive devices provide an adequate experience and offer independence and autonomy to individuals on the part of professionals. The responses of the caregivers indicate that there is little knowledge related to the Augmentative and Alternative Communication resources.

Conclusion: There is a gap to be filled between the communication of professionals who have knowledge about the Augmentative and Alternative Communication resources and families that do not understand their effectiveness during the therapeutic strategy, reinforcing the importance of clarifying the population about the existence of Augmentative and Alternative Communication.

Keywords: Self-help devices. Augmentative and alternative communication. Assistive technologies, Equity in Access to Health Services.

INTRODUCTION

The complexity of the relationships established in contemporary society poses challenges for the promotion of equity for people with disabilities. In this dynamic, for good coexistence, one cannot fail to observe the details that differentiate the individuals who participate and congregate in these spaces, people who have unique characteristics and are particularly related to politics, rights, access to information and their participation.

The possibility of accessing support resources for people with disabilities seeks to offer individuals to participate in social life and enhance their functionality to compensate for the observed limitation[1]. Assistive Technology (AT) and its numerous resources and devices are objects that seek to assist the individual with disabilities or the elderly who have reduced mobility, people who have some type of motor, cognitive and intellectual limitations for a certain executive function, very common in individuals with Cerebral Palsy[2,3].

From an epidemiological point of view, Cerebral Palsy (CP) is of great interest, since approximately 764,000 children and adults currently have CP in the United States. In this country, around 500,000 individuals under the age of 18 have CP, and about two to three children in every 1,000 live births have CP, about 10,000 babies born each year will develop CP and between 8,000 to 10,000 infants will be diagnosed each year and about 1,200 to 1,500 preschool children are diagnosed with CP each year[4,5,6,7]. It is estimated that in developing countries

like Brazil, this number is close to 7/1000 live births[8,9].

In Brazil (2007), the technical assistance committee of the Presidency of the Republic established rules for the adequate supply of these resources. The Technical Assistance Committee of the Secretariat of the Presidency of the Republic approved the term Assistive Technology as the most appropriate when dealing with all legal documentation and national production, thus seeking to encourage the use of the term and its dissemination in the training of human resources, research as its insertion in Brazilian theoretical references[10,11,12,13].

The limitation in communication in verbal expression can be compensated by the printed pictorial symbology, with internationally standardized graphic symbology boards, supplementary alternative visual graphic systems (BLISS)[14], the Picture Communication Symbols (PCS)[14].

Digitized systems for converting non-verbal codes to verbalized communication, available in electronic vocalizers (VOCA) or digital platform applications, electronic systems available on computers[15], smartphones and tablets offer the user the chance to communication, expressing your desire, feelings and wills, among other tasks of daily living and the possibility of establishing relationships[17,18]. These devices are tools that allow people with disabilities to integrate socially, learn and give meaning to the world[17,19].

This equipment and resources of Augmentative and Alternative Communication (AAC) are essential to stimulate the individual's learning, their practical activities of daily living, which contribute to the development and physical and mental well-being and in the process of cultural acquisition and social interaction[5,13,20].

There are great challenges to contemplate people with disabilities, special support and assistance are needed for social integration, an essential factor in the creation of systems and strategies for the evolution of these citizens[9]. Allow the participation of the social environment, guarantee their freedom of mobility and communication, health and education and provide means for them to have these rights respected[9].

Technological advances, with sophisticated design techniques and prototypes, offer solutions with higher quality for people with disabilities, in order to improve a specific functional action[1].

Motor and communication changes can take on varying levels, so their assistance needs can evolve according to the individual's degree of limitation and compromise motor functions in the lower and upper limbs with decreased distal movements, and find barriers to participation activities with autonomy and comfort[3,9,21-24].

Due to the disorder in their development, the individual with CP can use the auxiliary devices for communication and movement, to facilitate their participation activities, the AAC devices are alternative facilitators that encompass the range of AT options and allow the individual to interact and perform the tasks, everyday activities[25-31].

The effects of the application of AT resources in the activities developed by the individual with CP, with a special focus on the resources to aid communication to promote functionality due to the various degrees of limitation, we observe the general aspects of the

disability for a solution appropriate to their needs for participation activities[7,21].

Thus, the aim of this study was to identify whether there is access and usability of Alternative and Augmentative Communication resources in individuals with Cerebral Palsy.

METHOD

Case series study carried out with a semi-structured interview with parents, caregivers and professionals who work in the care of individuals with Cerebral Palsy (CP), and to identify if there is a communication aid resource in this population profile.

This work was carried out in the outpatient department of the neurology department of the Centro Universitário Saúde ABC - CUSABC. Data collection took place in an institution room, where individuals diagnosed with CP regularly attend, accompanied by a team composed of doctors and students from the multiprofessional residence.

This study involved caregivers, professionals who work with people with disabilities and individuals diagnosed with Cerebral Palsy (CP) with the severity level of motor limitation by the Gross Motor Function Classification System Scale[32] with levels IV and V[33,34,35] and according to the international classification of diseases and problems related to health ICD-10 in group G 80[36].

The sample was selected based on the following criteria: the individual had a GMFCS level 3 or higher and had changes in communication. The invitation to participate in the study was carried out at the outpatient clinic in an attached room. The exclusion criterion was applied to those who do not have changes in communication, that is, it was observed during the medical consultation if the individual had any type of change in the communicative process, such as not speaking, not presenting non-verbal responses, if walking or had any limitations or difficulty in interactive communicational processes.

To identify the individual's degree of communication, the Communication Function Classification System (CFCS) was used and the individual's communication performance level was observed[37], this evaluation generates a classification that has the Likert scale by parameter[38].

The issues are related to the use and access to Augmentative and Alternative Communication (AAC) resources, so it is expected to obtain an overview of the use of Assistive Technology and AAC resources. (Find it at: https://forms.gle/NqvUKznHruqnjUwh9)

Questions presented to study participants.

N1 Do you use, care for someone with disabilities or work with people with disabilities who use some kind of communication aid resource, (Augmentative and Alternative Communication Resources)?

N2 To get to know you better, which category are you in?

N3 What kind of Augmentative and Alternative Communication resource do you use?

N4 How did you acquire this communication aid feature?

N5 If the answer to the previous question was (Others), please describe how you acquired it.

N6 If there was a purchase, did the cost influence the acquisition of this AAC resource?

N7 How do you evaluate the efficiency of this communication aid feature?

N8 Is the AAC resource used appropriately, as was instructed?

N9 Is the use of this AAC resource satisfactory (do you like using it)?

N10 How do you evaluate the use of this resource?

N11 Where do you use this resource, what locations?

N12 Do you think the use of this resource is efficient?

N13 Have you ever changed AAC resources?

N14 Do you know of other features that could replace what you use?

N15 Is there adequate social interaction with the aid of this resource?

N16 With the help of this resource, you, the person you care for or accompany are able to carry out the activities of daily living (eating and ordering your favorite dish, choosing your clothes, ordering some cleaning and hygiene product, relating to other people) what shape?

N17 Do you participate in social events and attend alternative leisure environments (going to the cinema, parks and shows)? In what way?

N18 Does the form of the resource (the physical and visual characteristics of the AAC resource) that you use make your disability evident?

N19 If you want to share an opinion other than the answers to the previous question, this space is for you:

N20 Did using the resource make you more active and independent?

N21 Which region of the country are you from?

N22 Thank you very much for your participation, if you have any suggestions, opinions and are interested in sharing with us please leave your comment below.

The parents or guardians of the participants in this study received the free and informed consent form and the consent form with guidance on the objectives and ethical aspects. This study was approved by the research ethics committee of Centro Universitário Saúde ABC, under registration number 1,833,631.

RESULTS

In the total number of participants in this study, 28 individuals participated, who answered the question "Do you know assistive technology?". 08 face-to-face interviews were conducted with parents and caregivers from December 12, 2019 until March 6, 2020, of these participants who answered the questionnaire at the outpatient clinic, 07 participants had a negative answer, only 01 participant answering yes to the initial question. His knowledge of the Augmentative and Alternative Communication resources was explored, he responds to have knowledge about the resources and to try to use them, however he was not successful with the device experience and thus the use of the resource was given up.

The distribution of the cases observed at the outpatient clinic follows between the age group, sex and diagnosis and classification in relation to the Communication Function Classification System (CFCS).

Table 1: Distribution of study participants.

Participant	Age	Sex	Diagnóstico	GMFCS	CFCS
Part 1	7	Female	CP	4	2
Part 2	19	Male	Spastic CP	5	5
Part 3	11	Female	CP	5	4
Part 4	5	Female	Choreoathetoid CP	5	4
Part 5	21	Female	Spastic CP	5	5
Part 6	5	Female	Spastic hemiparesis Right Side CP	4	4
Part 7	4	Female	anoxia crural paraparesis CP	5	4
Part 8	6	Male	Neonatal hypoxia CP	4	5

Source: authors.

In the group of participants who responded via the internet, understanding that the starting question is "Do you know assistive technology?" and their answer to this question being “yes” obtained 20 participants who answered the questionnaire, mostly professionals (80%) who attend people with disabilities.

The following table shows the main answers in percentages, the questions were mostly conditioned to closed answers and two with open answers where the participant can state his opinion regarding the study.

Table 2: Answers to questions with closed answers.

Questions			
N2	A - 0	B - (5,9%)	C - (94,1%)
N3	A - (5,9%)	B - (17,6%)	C - (76,5%)
N4	A - (58,6%)	B	C - (41,2%)
N6	A - (15,4%)	B - (30,8%)	C - (53,8%)
N7*	3 - (5,9%)	4 - (52,9%)	5 - (41,2%)
N8	Yes - (88,2%)	No - (11,8%)	
N9	Yes - (88,2%)	No - (11,8%)	
N10*	3 - (11,8%)	4 - (41,2%)	5 - (41,2%)
N11	A - (13,3%)	B - (53,3%)	C - (33,3%)
N12	A - (33,3%)	B - (13,3%)	C - (53,3%)
N13	A - (56,3%)	B - (25%)	C - (18,8%)
N14	A - (94,1%)	B - (5,9%)	
N15*	3 - (23,5%)	4 - (41,2%)	5 - (23,5%)
N16*	3 - (11,8%)	4 - (17,6%)	5 - (52,9%)
N17*	1 - (23,5%) and 2 - (5,9%)	3 - (23,5%) and 4 - (23,5%)	5 - (23,5%)
N18**	B - (35,3%)	C - (47,1%)	D - (11,8%)

Note:* Likert Scale. ** the main answers were presented in the results table, in this question there was only one response in the deleted item. **Source:** the authors.

One of the open questions regarding the perception of the questionnaire, “If you want to share another opinion besides the answers to the previous question, this space is for you”

Two responses were obtained:

- "Responses based on patient experience"

- "You cannot attribute constraint to the use, because the use is made by users with serious compromises for the needs of daily life in school and family environment".

The question regarding the individual's independence: Did using the resource make you more active and independent? The results were: 82.4% - "Yes, with him I practice all my activities without prejudice and I have freedom and independence"; 11.8% - "No, I can do my activities without the resource" and 5.9% - "No, and using the resource has left me less active and has damaged my freedom and independence".

In this context, it is observed that there is a tendency to improve the subject's independence from the use of the Assistive Technology resource.

The distribution of participants in the territory and from which region of the country they answered the electronic questionnaire was identified, with 35.3% of participants from the southeastern region of the country, 23.5% from the southern region of the country, 17.6% from the northeast region and north of the country, and 6% of the central west region of the country.

DISCUSSION

During the study, a search for information related to the development of assistive technology (AT) devices and equipment was carried out in the literature, which makes a cut on diverse research to elucidate the limitations of individuals affected by CP.

Individuals with alterations that compromise motor functions in the lower and upper limbs with decreased movement, intellectual disability, convulsive conditions, communication deficit, some participants with dysphagia and problems in the sensory system as widely described in the literature and during observation studies that allowed to identify such characteristics, the literature review studies corroborate the observations, noting the individual's motor performance, observing his execution of uncoordinated movements and actions, in this individual profile it is possible to observe that there is a severe motor limitation that is an aspect of his pathophysiology in levels of the GMFCS IV and V scale[3,7,9,21-24,29].

Field observations indicate that the participants in this study have little or no knowledge about the term Assistive Technology and its communication resources, especially the Augmentative and Alternative Communication (AAC) resources. It is noted that the socioeconomic profile of families with lower income had a greater incidence in negative responses, which may be an indication for the little access to relevant information about resources and access to items that could favor the individual in their development.

The speeches were analyzed during the conversation with the caregivers as the relationship between care and how the need of children and adolescents is perceived. As the account of the mother of Part 3: “Listening to music calms her, but if the rhythm is very agitated she becomes uncomfortable, seeks to express herself through gestures, and expressions, such as a smile to indicate that she likes something, cries when she doesn't. he wants something, he screams to get attention and groans to indicate discomfort ”.

Other notes by caregivers are similar with regard to requests and as individuals express their desire and interests in the communicative process, we cannot say that there is no communication, but it is noteworthy that the repertoire is much to be expected in all age groups.

Part 1- seeks to point to what she wants, as an example: “to pee she points (SIC of the mother). He seeks to point to what he wants and does not speak.

Part 2- You are uncomfortable with very quiet and very noisy places, turmoil and abrupt changes. When he doesn't like something, he gets agitated and gets angry (SIC aunt). The relationship with the aunt and the cousin is different, so there may be differences in the interaction, Part 2 does not use AAC resources, it seeks through the interception of screams and facial and body expressions (mainly constant agitations) the interaction between the interlocutors is poor. The aunt reports the use of bullets to calm him down, talks about how to behave with him may or may not be easy depending on the specific moment and situation.

Part 3- Listening to music soothes her, but if the pace is very agitated she becomes uncomfortable, (SIC) seeks to express herself through gestures, and expressions, such as a smile to indicate that she likes something, cries when she doesn't want something, screams to call attention and moans to indicate discomfort (mother pump). The Mother reports that she knows the resources of Assistive Technology and that she has already used AAC resources, however she reports that it was frustrating, as she was not able to use it properly, as there was no adequate training, in a short time she abandoned the resource. Communication is more through gestures and expressions, but one can think of situations that are more of an attempt, the mother reports that the child cries or screams. Are you hungry or in the mood (to pee or poop). The mother says that "kick one of the two things, it is a trial and error".

This daily relationship provides a more intense bond and from that it manages to resolve these situations, however, the way the family routine is described and the relationship between the child and the mother indicates that there is no room for other interactions of Part 3 with the outside world. , Part 3 leaves only a few times, does not attend any special school or other environment, this reduces the repertoire of stimuli and experiences of the child who is segregated to the home environment.

Possibly the environment in which the individual participates inhibits his

possibility and potential for development, if it were possible to intervene with the professional Occupational Therapist could assist within an appropriate therapeutic strategy, by observing the individual in his entirety, considering his unique competencies and potentials and its context, an intervention would be possible for populations that did not have the opportunity to develop their skills and competences to the full, since the environment inhibits their development.

Part 4- The mother reports that Part 4 attends and chooses regularly and this helps in relationships and development. The mother reports that "she plays with the other children, and she understands everything and plays", this playing is not very clear however it is observed that there is a good interaction between Part 4 and her parents. Parents refer to the pattern of non-verbal communication as the most used by Part 4, through gestures and pointing out what they want, the mother says that verbal commands are understood, such as "yes and no", with the father what prevails it is mainly eye contact and gestures.

Part 5- Expresses your desires with some indications of looking and with denials with actions, with screams and gestures of denial with your head (no) or with a smile (it indicates yes). In the observation at the outpatient clinic, it is noted that, in a wheelchair, he presents repetitive movements (stereotypes) in balance, his expressions are poor and inefficient for interactions with other people or strangers.

Part 6- Main signs that Part 6 seeks to interact with other people is clapping hands with strangers, when you are not satisfied with something you are gnashing your teeth. From the CFSC evaluation, note that, as the sender is very inconsistent, as the receiver it is more efficient according to the caregiver. The caregiver reports that the codes established between them are very punctual, reclusive to physiological issues, actions related to ADL, reporting that their playing is poor and punctual, when offering two or three toy options "I put the toys in front of her and I leave it, if she wants some she takes it and soon loses interest and throws it away (SIC) ". The main way to request something or get attention is to clap your hands. The refusal is usually made by the refusal with the head (no). "When she doesn't want something for example food she turns her head to the side or grinds her teeth (SIC)".

The motor and language experience are intrinsic to their development, as the individual exercises and receives more sensory stimuli he is able to perform the movement and is able to express his desire.

Part 7 - Regarding Neuro Psychomotor Development (DNPM), she does not stand alone, only with support, does not speak, does not make eye contact, does not perform an object segment, possible low vision or blindness, altered gestural communication. poor gestures with few actions, babbling to indicate a request (hunger), grumbling, (negative and crying). (SIC). "I propose to her and expect some reaction, in fact I don't

really know what she wants. I don't know if she understands "(SIC mother).

The relationship between the child and the caregiver is poor in repertoire, as the caregiver does not understand whether the child really wants the object in question, be it a toy or another type of element available at the time of interaction, the mother has doubts if the child does not interacts due to low vision. Possibly an alternative with the use of glasses may assist in activities.

Since maturation and brain development of the individual is inherent to stimuli and their daily exercise in learning situations, for the development of executive functions. Thus, this section seeks to discuss aspects that may have an impact on the development of the individual, since physical, economic, social and intellectual barriers are the constituents of the image of the person with disabilities, whereas if we can make an effort to deconstruct such elements and removing these barriers individual may present with a disabled individual.

Part 8- Main forms of gesticulation with screams, smiles and crying (the main trigger for crying is to say goodbye to him, because the farewell leaves him crying). Performs dynamic movements to attract attention, when the hungry one grumbles and cries (SIC). "You get irritated with a lot of noise", the main notes: eye contact, gestural communication, facial expression and altered attention.

Individuals who have little information about access to resources available as aids to daily life may have greater limitations in carrying out their activities. For Rosembaun[39] (2007) until the most current observations on the aspects of the motor limitation and the interrelationships of the individual, it is noted that this issue is very important for the development and good performance of the individual in the family nucleus[40].

As people with disabilities are characterized as those who are prevented from full and effective participation in society on equal terms with other people due to the impediment due to barriers encountered in the environment, since to other individuals such barriers are not seen as obstacles[41].

This observation leads us to question what the disability is and its manifestation, as it arises only when the individual is prevented from carrying out an action. Certain that such an impediment does not occur, the individual is full and has equal conditions with other members of society.

When choosen of choice due to their physical or intellectual condition, which is enhanced by the environment inadequate to the full exercise of their desires and rights. Be it in access to public and private spaces, in access to information and in the possibility of identifying the objects and possibilities available for the execution of an activity, in the possibility of expressing your desire about a specific product or service.

The scientific community in many cases presents us with possible solutions to be tested with patients in more serious

conditions and more complex health conditions, with strategies for the development of social skills for individuals with intellectual disabilities, CP among others, with great advances in ADLs and in interactive processes[42]. This integration should also be done with parents and caregivers for appropriate training, an important competence of the Occupational Therapist at the heart of interactive processes[42,43].

Individuals characterized according to the GMFCS with level IV and V used an adapted wheelchair, few of them were able to get out of the chair or sit on it independently, from the observed individuals who used a walker to travel short distances, presented limitations, characteristic of literature reports[24,44-46], there is difficulty in communication, there is a wide variety of aspects of the relationship between the caregiver and the individual in which the participant (caregiver) stated that there were specific and intrinsic codes of the relationship between them, at one point a participant stated “But he does not communicate with me, I know what he wants because he makes a few groans and sometimes yells, when he does that I know he doesn't want to because he also refuses things ”(SIC Part 7).

The limitations encountered by individuals with CP can be used to propose solutions that seek to overcome barriers, with the development of product technologies at the service of people with disabilities. Such approaches contribute to the improvement of the individual's development process, using its functional residue, strengthening the relationships of trust and well-being among the people around them through the interventions of objects and environment[17,47].

Individuals with CP who have a high degree of motor limitation, as is the case with individuals with GMFCS V, may encounter barriers in interrelationships in the school environment, in activities and in communication due to developmental delay, do not accompany children in activities that require greater interaction, mobility and motor performance due to their clinical condition that characterizes the limitation of movements, which inhibits any chance of connection with the other nearby interlocutors[9,48,49].

In this perspective, the design of new products and the better suitability of objects can offer autonomy to the person with disabilities, with the application of universal design concepts in the development of products and services, which can assist their executive functions, motor functions, cognitive development for the relationship between the function of the object and the relationship with the environment, observing the potential of individuals and their unique characteristics, we can offer an alternative for socialization and in interactive processes[49-52].

The improvement in motor and cognitive performance that can be enhanced by these devices allows individuals with CP to have a more adequate perspective of social and family integration, with professional assistance, activity training, executive function training that intensely stimulate the individual to overcome

their limitations and be able to participate in the activities and relationships of the home[4,51].

In the educational context, the interactive process of individuals through Augmentative and Alternative Communication (AAC) technologies occurs gradually, adaptation and adequate training, with assistance to educators, including the family environment with guidance and assistance for the correct use of the therapeutic resource, the individual will be able to improve their skills associated with training stimuli that will improve neuropsychomotor, emotional, cognitive and psychosocial performance[16,17,48,51].

Associated with AAC and other therapeutic resources, mobility in the learning environment helps the individual, whether wheelchair or not, in neuropsychomotor development, with the search for teaching strategies and adapted activities that corroborate their development and social integration, these strategies provide a search for understanding of space and and relationships with their interlocutors[4,9,51,53].

Several authors agree that the application of various forms of technology and methods that assist the development of the individual with CP and can provide significant improvements in neurodevelopment, with interventions applied from early childhood and during the educational process, allows for better performance for the functions executives and ADL in motor and communication skills, in interpersonal skills[48,50,51].

Solutions with devices that improve the individual's performance, his posture in the wheelchair, in the AAC equipment and strategies that favor dialogue and improve social relationships are recommended, which provide better quality of life for the individual, are AT strategies promoting the development of individuals in helping to overcome limiting diseases[9,15,48,52].

However, socioeconomic factors can limit access to adequate resources, as observed in the profile of the population that attends the neurolgia outpatient clinic at Centro Universitário Saúde ABC, we realize that there is difficulty in accessing and even knowing the resources of AT and AAC, products and services available to assist their activities and interactions, which increases the distance between potential development and integration in society, observed in the reports of participants who do not have access to communication resources[9].

The ability to break barriers can be enhanced with the application of equipment and methods of inclusion, with appropriate environmental adaptations and with the monitoring and training of all actors responsible for the interaction and participation of people with disabilities, whether in the home, school and community, with low technology and low cost equipment providing greater autonomy, when exposed to new communication alternatives[7,9].

As the process of scientific and technological development is continuous in the field of AT, future researches will

be able to find more solutions and new proposals for innovation will be presented, with new relevant studies they will be able to expand our repertoire.

In this study, results related to empirical research on the aspects of communication with individuals with CP, access to AAC resources and the level of knowledge about ED were presented. We can observe the relationship between little knowledge about the availability of these alternatives in families, even assisted and accompanied by health professionals, their notes lead us to think that access to information is still limited, which makes the process of acquiring resources an even greater challenge for low-income populations, a fact that makes this more vulnerable citizen profile.

For Fraser[54] analyzing the thoughts and reflections on marginalized minorities within a socioeconomic context, he highlights the importance of calling attention to the socio-political circumstances that place people with disabilities in a situation of vulnerability, excluded subjects within a context of subjective marginalization.

The perspective of disability the criticism of the medical model in the light of the discussion in the field of health, in which the compartmentalized and specialized structure defines and sediments concepts of contemporary medical practice, especially in looking at the person with disabilities only as an individual with a certain defect in a part of your body, a disabled being or specific parts with a defect to be fixed or not.

However, this is not just a problem to be solved since this individual participates and has the same rights as the other participants in society, so the criticism for the observation of a social model of disability, as opposed to the so-called medical model as described by Fraser[54]. Furthermore "[...] the 'social model' that Ferreira defines as a" sociological understanding of the phenomenon of disability "excludes the medical focus on the body with disability, in favor of the emphasis on the limitations of the environment and the importance of changing attitudes social and institutional [...] "[54].

Assistive Technology in its philosophical foundation seeks to break the barriers built by society to promote to its citizens the right and access to any and all public goods, so that everyone can enjoy the right to participate in society[11,12]. In this perspective, we can even speculate the perception of these lines of thought, when one understands that the person with a disability must adapt to the environment, the other understands that the environment must be adapted to provide the subject with his full participation in social life.

Her proposal to promote resources and strategies for people's health and well-being removed the concept of disability in man, she is in the environment and in objects, as well as proposals that promote autonomy and mobility with inclusion strategies, environmental adaptations, communication systems non-verbal, AAC devices contribute to improving the exploration of the environment and to well-being, guidance and motor rehabilitation, such stimuli

assist cognitive development and improve the individual's relationship with the living environment[7,9].

Assessing the access and usability of AAC resources in individuals with CP provides us with indicators to direct future research on resource access by low-income populations and in situations of social vulnerability.

In a preliminary analysis, the lack of communication between professionals and caregivers could be limiting access to AT and AAC resources between caregivers and family members, therefore, identifying the level of knowledge about the acquisition of augmentative and alternative communication resources can help the individual with limitations in communication, once the information about the existence of resources is ignored, the family member will have little access to this public policy.

CONCLUSION

The results related to empirical research on the communication aspects of individuals with Cerebral Palsy, showed us the existence of a gap to be filled between the communication of professionals who have knowledge about the Augmentative and Alternative Communication resources and families who do not understand its effectiveness during the therapeutic strategy, so the families' usability and access to resources is otherwise unfeasible without the help of the health professional due to the lack of knowledge of the existence of the Augmentative and Alternative Communication resources.

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References

1. Hohmann P, Cassapian MR. Adaptações de baixo custo: uma revisão de literatura da utilização por terapeutas ocupacionais brasileiros. Revista de Terapia Ocupacional da Universidade de São Paulo. 2011; 22, (1): 10-18.
2. Leite ES, et al. Influence of Assistive Technology for the Maintenance of the Functionality of Elderly People : an Integrative Review. International Archives of Medicine. 2016; 9 (21): 1–13.
3. Monteiro CBM. Realidade Virtual na Paralisia Cerebral. São Paulo: 2011.
4. Assis-Madeira E, Carvalho S. Cerebral Palsy and Risks Factors in Motor Development : a. Cadernos de Pós-Graduação em Distúrbios do Desenvolvimento. 2009; 9 (1519–307): 142–163.
5. Freedman VA, Martin LG. Commentary: dissecting disability trends-concepts, measures, and explanations. International journal of epidemiology. 2006; 35 (5):1261–3.
6. Strauss D. et al. Life expectancy in cerebral palsy: An update. Developmental Medicine and Child Neurology. 2008; 50 (7): 487–493.
7. da Silva, AP et al. Low cost assistive technology to support educational activities for adolescents with cerebral palsy. Disability and Rehabilitation: Assistive Technology. 2018; 13 (7): 676-682.
8. BRASIL. MINISTÉRIO DA SAÚDE. DATASUS. Departamento de Informática do SUS, 2015. Disponível em: http://www2.datasus.gov.br/DATASUS/index.php?area=02
9. Cury VCR, Figueiredo PRP, Mancini MC. Environmental settings and families' socioeconomic status influence mobility and the use of mobility devices by children with cerebral palsy. Arquivos de Neuro-Psiquiatria. 2013; 71 (2): 100–105.
10. Bersch R. Introdução à Tecnologia Assistiva. Assistiva Tecnologia e Educação. Porto Alegre– RS, 2013.
11. BRASIL. Ministério da Saúde. Diretrizes de atenção a pessoa com paralisia cerebral PC. Disponível em:<http://bvsms.saude.gov.br/bvs/publicacoes/diretrizes_atencao_paralisia_cerebral.pdf
12. BRASIL, Constituição; BRASIL. Decreto nº 7.612, de 17 de novembro de 2011. Institui o Plano nacional dos direitos da pessoa com deficiência-plano viver sem limite. Diário Oficial União, 2011.Disponível em: <http://www.planalto.gov.br/CCIVIL_03/_Ato2011-2014/2011/Decreto/D7612.htm#art4
13. Queiroz FMMG. Tecnologia assistiva e perfil funcional dos alunos com deficiência física nas salas de recursos multifuncionais. Faculdade de filosofia e ciências de Marilia., v. 1, p. 1–18, 2015.
14. Mizuko M. Transparency and ease of learning of symbols represented by Blissymbols, PCS, and

Picsyms. Augmentative and Alternative Communication. 1987; 3 (1984): 129–136.

15. Geytenbeek, J. J. et al. Reliability and Validity of the C-BiLLT: A new Instrument to Assess Comprehension of Spoken Language in young Children with Cerebral Palsy and Complex Communication Needs. Augmentative and Alternative Communication. 2014: 31 (1): 1–15.
16. Geytenbeek, J. J. M. et al. Comprehension of spoken language in non-speaking children with severe cerebral palsy: An explorative study on associations with motor type and disabilities. Developmental Medicine and Child Neurology. 2015; 57 (3): 294–300.
17. Anderson, K.; Balandin, S.; Clendon, S. "He cares about me and I care about him." Children's experiences of friendship with peers who use AAC. Augmentative and alternative communication (Baltimore, Md. : 1985). 2011; 27 (2): 77–90.
18. Cockerill, H. et al. Speech, communication and use of augmentative communication in young people with cerebral palsy: The SH & PE population study. Child: Care, Health and Development. 2014; 40 (2): 149–157.
19. Passerino, M. L.; Bez, M. R. Comunicação alternativa Mediação para uma inclusão social a partir do Scala. 2015; 1. ed. Passo Fundo: Universidade de Passo Fundo.
20. Freedman, V. A; Martin, L. G.; Schoeni, R. F. Recent trends in diability and functioning among older adults in the United States: A systematic review. Jama. 2002; 288 (24): 3137–3147.
21. Brasileiro, I. DE C. et al. Atividades e participação de crianças com Paralisia Cerebral conforme a Classificação Internacional de Funcionalidade, Incapacidade e Saúde. Revista Brasileira De Enfermagem. 2009; 62 (4): 503–511.
22. Campos MAAD. Cadeira de rodas e acessórios para adequação postural na paralisia cerebral: Uma análise documental. Cadernos de Terapia Ocupacional da UFSCar. 2013; 21 (1): 43–49.
23. Goodwill, C. J. Mobility for the disabled patient. International rehabilitation medicine. 1984; 6 (1): iii–iv.
24. YI, S. H. et al. Validity of pediatric balance scales in children with spastic cerebral palsy. Neuropediatrics, 2012; 43 (6): 307–313.
25. Dahlgren Sandberg, A.; Smith, M.; Larsson, M. An analysis of reading and spelling abilities of children using AAC: Understanding a continuum of competence. Augmentative and alternative communication (Baltimore, Md. : 1985). 2010; 26 (9): 191–202.
26. Light, J. et al. The AAC Mentor Project: web-based instruction in sociorelational skills and collaborative problem solving for

adults who use augmentative and alternative communication. Augmentative and alternative communication (Baltimore, Md. : 1985). 2007; 23(3): 56–75.

27. Mccall, F. et al. Perspectives on AAC systems by the users and by their communication partners. European Journal of Disorders of Communication. 1997; 32(3): 235–256.
28. Mcconachie, H.; Pennington, L. Mother-child interaction revisited: communication with non-speaking physically disabled children. International Journal of Language & Communication Disorders. 1999; 34(4): 391–416.
29. Monteiro, Carlos B M; Jakabi , C M; Palma, Gisele C S; Torriani-Pasin, Camila; Meira Júnior, C. M. Aprendizagem motora em crianças com Paralisia Cerebral . Revista Brasileira de Crescimento e Desenvolvimento Humano. 2010; 2 (11): 250–262.
30. Morris, C.; Kurinczuk, J. J.; Fitzpatrick, R. Child or family assessed measures of activity performance and participation for children with cerebral palsy: a structured review. Child: Care, Health & Development. 2005; 31(4): 397–407.
31. Sutherland, D. E.; Gillon, G. G.; Yoder, D. E. AAC use and service provision: A survey of New Zealand speech-language therapists. Augmentative and Alternative Communication. 2005; 21(4): 295–307.
32. Gross motor function sistem. GMFCS. CanChild Centre for Childhood Disability Research Institute for Applied Health Sciences, Disponível em: <http://motorgrowth.canchild.ca/en/GMFCS/resources/PORTUGUESE_corrigido-FINALMay12.pdf> Acesso em 06 Jun. 2018.
33. Margre, A. L. M.; Reis, M. G. L.; Morais, R. L. S. Caracterização de adultos com paralisia cerebral. Revista Brasileira de Fisioterapia. 2010; 14 (5): 417–425.
34. RAGHAVENDRA, P. et al. School Participation and Social Networks of Children with Complex Communication Needs, Physical Disabilities, and Typically Developing Peers. Augmentative and Alternative Communication. 2012; 28 (1): 33–43.
35. Rolo, M. C. Perceção da Preparação do Envelhecimento em Adultos com Paralisia Cerebral Universidade de PEREIRA CARDOSO Adultos com Paralisia Cerebral. [s.l.] Universidade de Aveiro, 2013.
36. World Health Organization. CID-10: Classificação Estatística Internacional de Doenças com disquete. Edusp.1994; 1.
37. Hidecker, Mary Jo Cooley et al. Developing and validating the Communication Function Classification System for individuals with cerebral palsy. Developmental Medicine & Child Neurology. 2011; 53 (8): 704-710. doi: 10.1111/j.1469-8749.2011.03996.x, PMC3130799.

38. Likert, R. A Technique for the Measurement of Attitudes Archives of Psychology. Archives of Psychology. 1932; 140 (140): 1–55.
39. Rosenbaum, Peter et al. A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl. 2007; 109 (suppl 109): 8-14.
40. Bim RH, Vieira JLL. Developmental coordination disorder in children enrolled in part time and full time Public Schools. J Hum Growth Dev. 2020; 30(1):104-110. DOI: http://doi.org/10.7322/jhgd.v30.9959
41. OLIVEIRA AKC, Alves ACJ. Atividades de autocuidado em crianças com paralisia cerebral e a percepção dos cuidadores. Temas sobre Desenvolvimento 2011; 18-(103): 149-53.
42. American Occupational Therapy Association et al. The role of occupational therapy in providing assistive technology devices and services. 2015. https://www.aota.org/About-Occupational-Therapy/Professionals/EBP.aspx
43. Tilstra, Michele L.; Webb, Michelle L.; Groger, Sandra E. Instructing Students How to Use Evidence-based Technology Interventions with Older Adults. Journal of Occupational Therapy Education. 2019; 3 (4): 11. https://encompass.eku.edu/jote/vol3/iss4/11/ .
44. Chiarello, L. A et al. Child engagement in daily life: a measure of participation for young children with cerebral palsy. Disability and rehabilitation. 2014; 1–13.
45. MARIA, L. et al. Disability and Rehabilitation : Assistive Technology The influence of the flexibility of the chair seat on pressure peak and distribution of the contact area in individuals with cerebral palsy during the execution of a task. 2011; 3107 (11).
46. RAGHAVENDRA, P. et al. School Participation and Social Networks of Children with Complex Communication Needs, Physical Disabilities, and Typically Developing Peers. Augmentative and Alternative Communication. 2012; 28 (1): 33–43.
47. Simpson, R. C., LoPresti, E. F., & Cooper, R. A. How many people would benefit from a smart wheelchair?. Journal of rehabilitation research and development. 2008; 45(1), 53. DOI: 10.1682/JRRD.2007.01.0015
48. Deliberato D & Santos, VAA. Interação do aluno com paralisia cerebral sem oralidade frente a diferentes interlocutores. Revista Educação em Questão. 2015; 34 (20). http://ufrn.emnuvens.com.br/educacaoemquestao/article/view/3945
49. Rodby-Bousquet, E., & Hägglund, G. Use of manual and powered wheelchair in children with cerebral palsy: a cross-sectional study. BMC pediatrics. 2015;

10(1): 59. DOI: 10.1186/1471-2431-10-59

50. Palisano, R. J., Hanna, S. E., Rosenbaum, P. L., & Tieman B. Probability of walking, wheeled mobility, and assisted mobility in children and adolescents with cerebral palsy. Developmental Medicine & Child Neurology. 2010; 52(1): 66-71. DOI: 10.1111/j.1469-8749.2009.03454.x
51. Ragonesi CB, Chen X, Agrawal S & Galloway JC. Power mobility and socialization in preschool: follow-up case study of a child with cerebral palsy. Pediatric Physical Therapy. 2011; 23(4): 399. doi: 10.1097/PEP.0b013e318235266a
52. Liu, Wen-Yu et al. Postural alignment in children with bilateral spastic cerebral palsy using a bimanual interface for powered wheelchair control. Journal of rehabilitation medicine. 2014; 46 (1): 39-44.
53. Bunning K., Gona J. K., Newton CR & Hartley S. Caregiver perceptions of children who have complex communication needs following a home-based intervention using augmentative and alternative communication in rural Kenya: An intervention note. Augmentative and Alternative Communication. 2014; 30(4): 344-356. http://dx.doi.org/10.3109/07434618.2014.970294
54. Fraser B, Jiménez SG,'autor de minorías': la novela Angelicomio (1981) y el modelo social de la discapacidad. Bulletin of Spanish Studies.2013; 90 (8):1339-1356.