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Assessing Service Delivery Systems for Assistive Technology in Brazil using HEART Study quality indicators.

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Abstract. BACKGROUND: recently in Brazil, there have been investments and improvements in the service delivery system for assistive technology provision. However, there is little documentation of this process, or evidence that users are being involved appropriately. OBJECTIVE: to understand how assistive technology service provision currently functions in Belo Horizonte city, Brazil, in order to provide context-specific interventions and recommendations to improve services. METHOD: Qualitative research design, including visits to key institutions and semi-structured interviews with key stakeholders. Interview questions were divided with two purposes: 1) Exploratory, aiming to understand present service functioning; 2) Evaluative, aiming to assess staff difficulties in applying best existing best practices. RESULTS: Assistive Technology services in Belo Horizonte fall under the ‘medical model’ definition of service delivery developed by AAATE. It was also found that staff lack training and knowledge support to assess user requirements and involve them during the decision process. Additionally, there is no follow up stage after the device is delivered. CONCLUSIONS: The study clearly defines the service provision function and the staff difficulties at Belo Horizonte city, providing information for further studies.

Keywords. Service Delivery System, Assistive Technology, User Influence.

1. Introduction

This research aims to understand how assistive technology service provision functions in Belo Horizonte city, Brazil, in order to provide context-specific interventions and recommendations to improve the design of current assistive technology services.

Health care in Brazil is provided by a complex of systems and subsystems of public and private care [1]. Brazil is the only country with a population larger than 100 million inhabitants to declare healthcare as a duty of the State and a civil right [2]. The Brazilian national health service (Serviço Único de Saúde – SUS) is the only health service option for over 150 million Brazilians, nearly three quarters of the Brazilian population [3]. The service started providing assistive technologies (AT) as early as
2002 and, as recently as 2007, the orthotics and prosthetics department had a demand of 1,042,000 people waiting to receive a device [4].

Facing this scenario, in 2011 the government created the national plan for the rights of disabled people *Viver Sem Limites* (VSL) with investment estimates around US $3.04bn for the first four years of the program [5]. VSL articulates policies regarding social inclusion, access to education, accessibility and health care. Various resources were made available to promote AT acquisition and to the Service Delivery System (SDS) used to provide them. As a consequence, AT acquisition has boomed in Brazil since the start of the program. For example, 36,722 wheelchairs were delivered in 2011 compared to 19,890 delivered in 2008 [6]. It should be noted, however, that all these improvements are recent and there is a lack of research and data available, apart from government publications, regarding the functioning of these services. Also, there is lack of research and publication investigating whether user requirements and SDS’ best practices are being considered and implemented.

Europe has a long tradition in the provision of public health service and AT provision by means of SDS [6]. This research, classified existing delivery systems in Brazil, using European theoretical frameworks developed by the Association for the Advancement Of Assistive Technology In Europe (AAATE) and the European Assistive Technology Information Network (EASTIN) [7]. These were employed together with the user influence quality indicator (defined by the European Commission’s HEART Study [7]) to assess the current state of services in Belo Horizonte city, Brazil. The user influence is defined in AAATE and EASTIN [7] as:

“A service delivery system takes advantage of the user influence when it empowers, actively involves and makes the user participate in responsibilities in all decisional processes related to assistive technology interventions. The lack of user involvement exposes the process to the risk of wrong or ineffective intervention, abandonment of the devices provided and waste of resources. User influence indicators include the presence and strength of user organisations, the availability of juridical protection of the user’s rights, the involvement of users at a policy level, the user empowerment during the individual assessment, communication with the user in the service delivery process and the influence of the user on decisions in the process.”

The study comprises three main stages: an exploratory stage to understand the systems and identify a research focus; a preparatory stage to set the parameters for an intervention; and a testing stage to test and improve the intervention. This paper describes the exploratory stage.
2. Methodology

At this exploratory stage qualitative data were collected by: visiting major institutions providing AT services in Belo Horizonte city (n=5) and conducting semi-structured interviews with stakeholders directly involved in these services (n=28). Pilot interviews (n=7) were conducted and data analysed prior to the main data collection. The information collected was confirmed in a follow-up study in which participant observation (n=128) was carried out during a period of three months at three main public institutions providing AT services in Belo Horizonte city.

Data collected in the fieldwork were uploaded in the qualitative data analysis software NVivo, version 10.0. The audio recorded from interviews were transcribed and coded using a thematic analysis approach to identify key topics.

Ethical approval was gained from ethical committee departments of both Loughborough University and Belo Horizonte Municipal Health Office.

2.1. Design of Interviews schedule.

The interviews were designed to identify issues with the SDS, and to invite interviewees to evaluate their experiences of it. The interview schedule was therefore divided in two parts which were analysed using different methods. The first part enclosed questions with exploratory purpose and was analysed using an inductive approach, in which identified categories were strongly linked to data. Exploratory questions related to the functioning of the service, type of AT provided and staff difficulties and opinions towards service improvement. The second part of the interview included evaluative questions and was analyzed using a deductive approach, for which categories were defined prior to data collection. Questions were related to the implementation of the HEART Study recommendations, published in AAATE and EASTIN [7]. It was found that assessing the entire set of HEART Study’s quality indicators would undermine the study’s exploratory goal, due to the large amount of information necessary to be collected in order to cover all aspects of the service. For this reason this study focused assessing solely the “user influence” quality indicator.
3. Findings

3.1. Service Delivery System Functioning

The SDS for public AT provision in Brazil occurs by means of rehabilitation centres at the secondary level of care. AT for public provision can be prescribed by occupational therapists, physiotherapists, orthopaedic practitioners, physicians or physiatrists. Referrals are accepted from both private and public medical institutions. Nonetheless, every person is reassessed at SUS’s rehabilitation centres for the identification of an assistive solution, to be provided without any cost to the user. This assistive solution is limited to a list of devices called the SIA/SUS list, describing the device specifications and established price. The list contains 95 items, adaptations and substitutions (See Table 1).

It is worth mentioning that there are other AT items guaranteed by law [8] not included on this list, such as devices to facilitate education and work. This research focused on the ATs delivered at the rehabilitation centres by means of the SIA/SUS list.

Table 1. Types of Assistive Technology included on SIS/SAI list.

<table>
<thead>
<tr>
<th>Type of Assistive Technology</th>
<th>Variety</th>
<th>Type of Assistive Technology</th>
<th>Variety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cane</td>
<td>1</td>
<td>Orthotic used at the cervical region</td>
<td>2</td>
</tr>
<tr>
<td>Crutches</td>
<td>2</td>
<td>Orthotics used at the thoracic and back region</td>
<td>10</td>
</tr>
<tr>
<td>White Stick</td>
<td>1</td>
<td>Orthotics used at the upper limbs</td>
<td>3</td>
</tr>
<tr>
<td>Walking Frame</td>
<td>1</td>
<td>Orthotics used at the pelvic region</td>
<td>3</td>
</tr>
<tr>
<td>Shoes</td>
<td>5</td>
<td>Orthotics used at the pelvic and lower limbs</td>
<td>3</td>
</tr>
<tr>
<td>Inner Sole</td>
<td>4</td>
<td>Orthotics used at the lower limbs</td>
<td>12</td>
</tr>
<tr>
<td>Wheelchairs</td>
<td>5</td>
<td>Prosthetics for the upper limbs</td>
<td>12</td>
</tr>
<tr>
<td>Wheelchair’ Adaptations</td>
<td>8</td>
<td>Upper limbs prosthetic parts</td>
<td>4</td>
</tr>
<tr>
<td>Bath Chair</td>
<td>4</td>
<td>Prosthetics for the lower limbs</td>
<td>11</td>
</tr>
</tbody>
</table>

Assistive Technology provision in Brazil conforms to the ‘medical model’ of service delivery, as defined by AAATE, in which the prescription of an AT device is the responsibility of a qualified professional and AT eligible for public provision is usually regulated by a list of products or product specifications, with or without established prices or reimbursement thresholds [7].

3.2. User Pathways to access assistive technology

In Belo Horizonte city, SDS for public AT provision occurs by means of three SUS rehabilitation centres called CReab (an abbreviation for centro de reabilitação). A
user’s pathway to access the ATs after being referred to the CReabs was outlined during an initial interview with a member of staff coordinating the three CReabs in Belo Horizonte. Visits to each CReab institution with further interviews and participant observations were then used to confirm this information and to investigate the specific realities of each location.

The pathway was found to be similar in two centres (see Figure 1), which varied in some aspects from the other centre. One difference regards to the splints and upper limbs’ orthotics offered. In CReabs 1 and 3 this service is restricted to those users taking part in rehabilitation program at these centres. In CReab 2 there is no such distinction and splints and upper limbs’ orthotics services are offered to all users whom staff consider necessary. The main reason claimed by participants to explain such differentiation was that many types of splints and upper limbs’ orthotics are not included in the SIA/SUS list. In order to produce them, CReabs need to use a local fund different from the list, which seems insufficient to accommodate all users in need.

A further relevant difference between service pathways relates to hearing aid and cochlear implant services. All users in need of these services are referred to CReab 2.
There, the user will undergo an internal assessment to verify the need for the device and define the service characteristics. The user is then referred to a third-party clinic to receive the treatment and/or devices.

There are two possibilities when a piece of AT not offered on the SIA/SUS list is required and claimed by the user by means of referral. The most common seems to be users purchasing the equipment themselves. In this case, the staff is encouraged not to support the user on choosing equipment outside the list, as the user should receive no support from CReab service staff when this happens. Despite this fact, some staff commented that they provide guidance to users whenever they can, despite not being recommended to do so. The other possibility is by pursuing legal means. In this case users are referred to the Municipal Health Office (Secretaria Municipal de Saúde – SMSA) where each case is assessed individually and items are purchased directly by SMSA. Most participants mentioned that this process is bureaucratic and time consuming.

3.3. Exploring Service Staff Difficulties to Apply Best Practices

The main difficulties reported by CReab staff in applying the best practices recommended by AAATE’s user influence quality indicators are summarised in Figure 2. These are categorised according to the AT service stages suggested in EASTIN & AAATE [7]. The Swiss Cheese model for cumulative effects was used to organize and present the information. A Swiss Cheese model helps identifying cumulative failures in various stages of a process or complex system that can lead to accidents. The holes represent active failures and latent conditions. A bad outcome occurs when the holes in various layers, or stages, line up to permit a trajectory allowing an accident to occur [9]. In this case, the accident was interpreted as the risk of the AT not fitting the user profile.

It was found that the service still lacks important stages suggested as best practices, such as: testing the device before taking a decision, providing users with appropriate training with the device, and having feedback mechanisms regarding service evaluation and user self-evaluation.

The main difficulties staff reported encountering (in order of most frequently claimed) were: 1) inflexibility of the list; 2) lack of physical space; 3) access to training; 4) issues with the public-private partnership.
Regarding the inflexibility of the list, it was frequently commented that the list is incomplete and there is often demand for similar models or AT variations from those that are offered. One participant mentioned that these items do not necessarily cost more, but they are not listed or are not according to specifications, so they cannot be provided or contracted. The lack of physical space is an issue easily recognised as one can see various wheelchairs stocked through corridors of CReabs. The lack of physical space was said to directly affect a number of issues: the service queue, the contracted services, the implementation of new stages and the user’s comfort while at the CReabs.

The main issues with the public-private partnership reported had regard to: lack of AT suppliers at both local and national levels, variation between suppliers’ service quality, difficulty in guaranteeing the quality of AT delivered and to accommodating CReabs’ internal demand and supplier demands.

Figure 2 Swiss Cheese model of main AT failures in applying the “client-centred approach” at CReabs

Participants were also asked about changes they would like to see in the service. The three main categories that emerged from participant’s answers (in order of the most frequently claimed) were: 1) to have more knowledge/training support 2) to introduce a user follow-up stage and 3) to improve the physical space within CReabs.
Examples of reported training requirements related to: AT prescription, using existing assessment methods and knowing existing technologies. The term ‘knowledge supports’ refers to the use of standardised assessment and measuring tools, knowledge support from university and consultancy services, access to tools and training, and time available to study at work. To introduce a user follow up stage was also a great concern.

One participant commented:

“What is the point of giving expensive devices and not having a follow up? I think we are throwing money away by not accompanying these users… I think the follow up is the SUS’s great difficulty in order to function as whole. The user leaves the service with a prosthetic, use it once and put it inside the wardrobe because it hurts, instead of coming here and saying: I am not going to use that - and then he put it into the wardrobe, as we known it also happen with wheelchairs. So I believe that follow up is a big issue.” (Interview with staff member at CReab 1, author’s translation)

4. Conclusions

This study showed that Assistive Technology services in Belo Horizonte city, Brazil fit the ‘medical model’ of service delivery defined by AAATE. It was found that the service still lacks important stages suggested in best practices literature, such as testing the device before taking a decision, providing users with AT training and having feedback mechanisms. From the perspective of service staff, more knowledge support should be provided, a follow up stage should be introduced and rehabilitation centres’ physical space should be improved. The SIA/SUS list is considered rigid and the process of requesting AT not offered on the list bureaucratic and time consuming. Further studies aim to design participatory interventions with service stakeholders based on their difficulties in applying best practices.

References

