AN ACTOR-NETWORK APPROACH FOR REDUCING ABANDONMENT OF PRESCRIBED ASSISTIVE TECHNOLOGY

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Bachelor of Science in Biomedical Engineering

By

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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The World Health Organization (WHO) estimates that 1 billion people, roughly 14% of the global population, are in need of assistive devices (2018). Assistive technology (AT) devices, as defined by the US Technology-Related Assistance for Individuals With Disabilities Act of 1988, are “any item, piece of equipment, or product system, whether acquired commercially or off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities” (p. 1046). Some assistive technology device users are identified as having varying levels of motor impairment, which makes controlling limbs difficult or even impossible. Unfortunately, children are not excluded from living with such disabilities and disorders, which can include cerebral palsy, muscular dystrophy, and stroke aftermath, and may require the help these devices promise. Orthotics, which include splints, are a type of non-invasive assistive device for encouraging neuroplasticity or providing functional aid for stabilized or worsening conditions. Splints are medical equipment used for immobilizing parts of the body and provide protection and support. Thus, some children require splints for motor impairments.

The technical project concerns the creation of a dynamic and low-profile wrist splint designed for these children. Despite the abundance of available prescribed assistive technology, such as orthotics, there is a recognized issue of users, or patients, abandoning assistive devices. The Science, Technology, and Society (STS) paper examines if portions of a global call for AT provision standards have the potential to reduce abandonment when introduced into today’s health care system. Once the patient-prescribed device network is established with the Actor Network Theory (Law & Callon, 1982), the guidelines for provision standard are assessed separately before placement into the network. The STS topic is loosely coupled to the technical project; orthotic splints are a form of assistive technology, as orthotics aid mobility and

functionality. The STS section instead refers to a broader range of prescribed assistive technology. The foundation of the relationship involves the provision processes of assistive equipment, which is a form of technology with which the technical team has been challenged.

AT ABANDONMENT IN THE CONTEXT OF AT PROVISION

THE PATIENT-DEVICE NETWORK

Assistive devices can be referred to as low or high-tech products like mobility canes or motorized wheelchairs. The range of potential users includes diabetes, military, and accident amputees, as well as the aging population and 73,000 disabled children (U.S. Census Bureau). When such patients make the decision to abandon a prescribed device, potential benefits are lost. The term ‘abandonment’ within this research is akin to the concept of discontinuance, which is the act of rejecting a previously-adopted innovation (Rogers, 1983, Chapter 1). Nationwide survey data from Phillips and Zhao (1993) established that 29.3% of devices for 227 disabled adults were abandoned. Likewise, 53 U.S. college students together had abandoned 38% of owned AT devices (Riemer-Reiss & Wacker, 1999). Of course, the occurrence of device non-use is not restricted to the States; for example, devices had been abandoned by 17.9% of surveyed Italian National Health Service users (Federici et al., 2016).

Understanding the problem’s context involves ways in which a patient can receive these devices. The generalized diffusion of prescribed AT can be visualized using the handoff model (Carlson, 2013). As indicated in in Figure 1 on page 3, multiple people are involved in the diffusion of this technology from an idea, indicated by Star A, to the useful product, Star C or D, in the patient’s ownership. Each handoff is represented by an arrow. A researcher passes along their idea to a designer with evidence backing a difficulty caused by a condition. After taking on the idea and developing a design, the designer must convince manufacturing companies to

produce their design, Star B. What comes from the manufacturer, Star C, is the marketed product which may differ slightly from the designer's original plans if manufacturing constraints are identified.

Legend:

A = artifact idea
B = artifact design
C = manufactured artifact
D = modified artifact

Figure 1: Handoff Model Representation of Prescribed Assistive Technology: Each separate person or entity involved in this process, represented by a differently-colored rectangle, procures a version of the artifact, as indicated by the stars. Each player receives the artifact version through a handoff, represented by the arrows (Adapted by Hannifin (2019) from Carlson, 2009).

The healthcare provider seen by the patient either modifies the marketed product, creating Star D, or decides the device is suitable 'as-is', a decision imparted before the last handoff. The provider is generally a specialist the patient has been referred to by their physician. The specialist needs the education and insight necessary to identify which available product is best for matching to the patient. In addition, the specialist needs training for performing any modifications to the product, such as selection and creation of different programs for hearing aids, or adding cushioning support or grip material on an orthosis. Finally, the patient receives a device, either Star C or D, that is believed to be the best option for them. As the end user, the patient holds autonomy over the product and decides if they will use it and for how long.

The final handoff of the device from a healthcare provider to the user is of particular importance. Figure 2 expands the handoff into a simple network using Law and Callon's Actor Network Theory (1982). Human actors and their one or two-way relationships are represented by

the blue circles and arrows respectively. Non-human actants are represented by the green rectangles. Question marks indicate that unknown changes will be made by the inclusion of the chosen missing actant, which ideally alters the course for device abandonment.

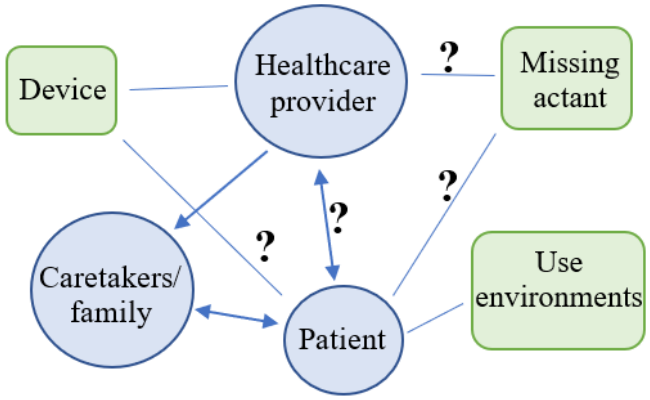


Figure 2: Prescribed Assistive Technology Actor Network with Variable Actant: The introduction of a non-human actant has the potential to impact the essential provider-patient relationship and the technology use. Relationship changes are subject to the missing actant, as represented by the question marks (Created by Hannifin, 2019).

Device abandonment can result in losses for all actants involved; the patient can lose potential health benefits otherwise gained from incorporating the device into their life. Both the patient and involved family members also risk losing financial investments. It is also possible that levels of independence are strained for the patient. They might need more assistance from caretakers and family or can no longer participate in desired life activities as easily (Scherer & Glueckauf, 2005). The healthcare system itself ultimately wastes insurance coverage investments and early design and research funding. Additionally, abandonment may be "seen as a failure for the team, as well as having a potentially negative impact on the healthcare team-patient relationship" (Verza et al., 2006, p. 89). The missing actant must modify the relationships and connections between both human and non-human actants in order to mitigate the action and ill effects of device disuse. Through this research, it is proposed that portions of assistive technology (AT) provision standards are best suited to fill the role of the missing actant and to improve future adoption rates of assistive devices.

EXAMINING PROPOSED AT PROVISION STANDARDS

The current research identifies the missing actant in the network of the previous figure as selected guidelines for AT provision standards. These new additions to the network, shown in Figure 3 on page 6, stem from a 2018 position paper. In this document, de Witte et al. emphasized the need for an international assistive technology provision standard by providing possible approaches to solving identified issues (2018). Provision in this context is defined loosely as "everything that is needed to assure that a person with disability who might benefit from AT actually obtains it and obtains the most appropriate AT solution for that individual" (Elements of Assistive Technology Provision section, para. 1). The position paper was discussed during and altered following the 2017 Global Research, Innovation, and Education in Assistive Technology (GREAT) Summit. Held at WHO headquarters, the event served as a collaborative space for AT users, designers, and researchers invested in encouraging development of global research and policies to give those in need access to proper devices (www.who.int/phi/implementation/assistive_technology/great_summit/en/). In this specific document, de Witte et al. emphasized the need for an international assistive technology provision standard by providing possible approaches to solving identified issues (2018).

Though the authors' intentions were to increase global accessibility through approaching international provision standards, the current research applies the discussed concepts to decreasing prescribed AT within the United States. When the missing actant is replaced by aspects of the aforementioned provision standards, the actor network proves visually complex and is best represented using Pacey's Triangle, shown in Figure 3 below. Pacey's diagram maps out technical, organizational, and cultural components, serving as a visual for "orderly view of . . . technology-practice" (1983, p. 5).

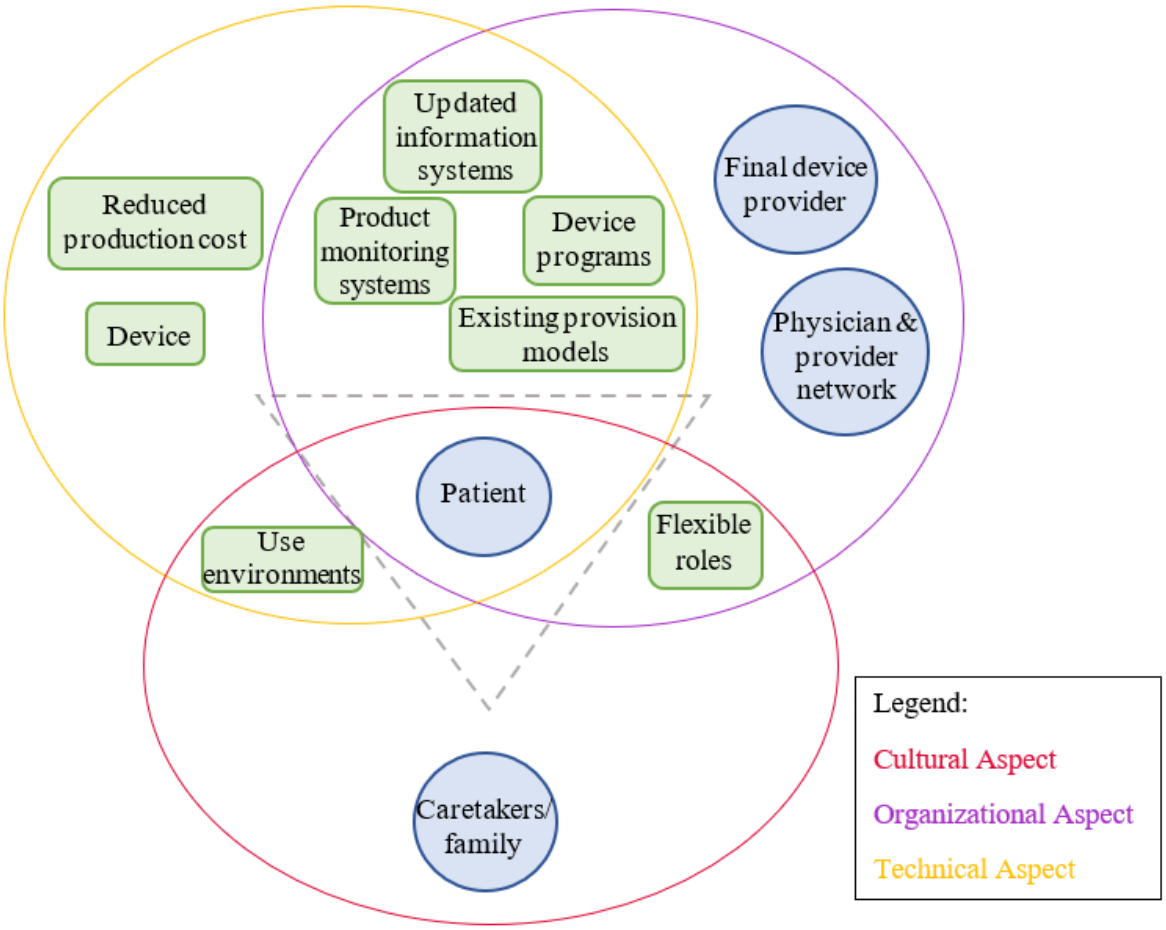


Figure 3: Final Network as Depicted by Pacey's Triangle: Each component for the three aspect vertices are representative of the expanded Actor Network, where the missing actant is replaced by parts of AT provision standards. These new actants are not necessarily restricted to one type of aspect categorization, as indicated by the legend. The patient is the most important actor and is connected to all components, which together can reduce instances of AT abandonment (Created by Hannifin, 2020).

As with before, the human actors are blue and all non-human actants are green. The original 'healthcare provider' actor is split into distinct 'physician & provider network' and 'final device provider' actors to account for instances where multiple professionals are involved with the same case. Finally, the patient is in the center of the triangle and has connections to all components, indicative of the idea that prospective patients must always be in consideration for actions and ideas stemming from all three domains. Within the remainder of this research, each of the GREAT Summit paper's elements of provision are separately discussed: availability,

information systems, professional services, advice, and support, eligibility and funding mechanisms, and infrastructure for maintenance and repair. For each section, specific suggested guidelines are analyzed to determine if and how they are applicable to the issue of device abandonment and their potential outcomes.

Availability of Affordable High-Quality Assistive Product

Not all people who could benefit from AT have access to such aid due to financial contexts. High production costs and high retail prices of AT automatically places certain populations at a disadvantage. Additionally, patients enabled with health insurance are generally regarded as having no "direct purchasing power" (para. 2) due to narrow insurance coverage, which can have a greater effect on more expensive items. Companies were encouraged to follow lowest-cost production processes, while still maintaining high quality, for items on WHO's Priority Assistive Products List (de Witte et al., 2018).

Lowering production costs could have a substantial effect. Availability barriers may prevent the patient from even receiving a device, or they may receive one that is not suitable or high-quality as others on the market, which could influence the decision to abandon in the future. Insurance is discussed later, but barriers stemming from device cost include total reimbursement caps and out-of-pocket payments (Institute of Medicine Committee on Disability in America, section 9). In fact, a 2001 survey showed that 37% of all devices in question were paid personally (Carlson & Ehrlich, 2005, Sources of Payment and Funding for Assistive Technology section). Reducing upfront costs in turn reduces the financial struggles patients and families may face. Removing these initial availability barriers also promotes social justice by increasing fairness of resource distribution and does not strip patient autonomy. Though a seemingly obvious approach for a solution, only relying on manufacturing changes is not the perfect solution; Phillips & Zhao found a positive correlation between easily accessible equipment and

abandonment (1993).

Information Systems

Countries that have widespread accessibility to the internet still lack sufficient AT product information systems that could increase awareness of possible devices. Therefore, de Witte et al. emphasize the need for them to be updated, include unbiased research-backed data, and rely on user-based experiences (2018). One such insufficient information system is the United States' AbleData website, in which these aforementioned vital additions are missing; pages present basic product descriptions and links to manufacturer websites, but there is no additional research data and one can click a 'thumbs up' or 'thumbs down' without any explanation or user verification.

Unfortunately, the idea that device awareness is critical for patients assumes that these potential users are motivated to conduct their own forms of research and invest substantial time. Given that motivations exist, the benefit of giving potential users the opportunity for detailed product awareness might be seen in the clinical setting, especially among communication with providers about products. A device failing to fulfill expectations has been a reported reason for disuse (Phillips & Zhao, 1993, Wielandt & Strong, 2000, Scherer & Glueckauf, 2005). If a patient has access to updated user-based data and informative product details within one place, especially when paired with a provider who is aware of product successes and failures, it is possible to mitigate unrealistic device expectations and in turn increase the chance of selected device adoption.

Professional Services, Advice, and Support

De Witte et al. argued that there are not enough professionals in the health care field, excluding occupational therapists, prosthetists, and orthotists, with the knowledge of available devices and the capability to assess patient needs. To address these concerns, "[core]

competencies should be embedded in [educational and training standards]" wherever possible in the field (2018, para. 4). Additionally, those involved in the provision process should also have "clearly described roles and responsibilities" (2018, para. 4).

Literature on the topic of device dissatisfaction stress that patient-device matching is critical for provision, so it would be vital to improve the quality of existing and future providers. Standardized competency within the field would involve the consistent use of any existing provision models that are person-centered, such as the Matching Person and Technology model which assesses the client's needs, environments in which the technology will be used, and desired device functions (Scherer & Federici, 2015). Because of the numerous existing models, universal application of the same ones proves difficult, if not impossible, and it should not be expected that one model fits every situation. Furthermore, established specific roles and responsibilities would be subject to change in practice anyway; responsibilities can shift if multiple professionals are involved in a patient's case. Another dynamic is added if those involved have different levels of expertise with respect to devices, an occurrence explained by an experienced certified orthotist in the University of Virginia Health System:

> I often get a prescription for a certain brace and determine after my evaluation that a different kind would be more appropriate for [the patient]. I then notify the physician that I evaluated, found x/y/z, and the patient would do better with a [different] brace instead . . . The physicians aren't experts in [prosthetic and orthotic] devices and don't know what's available or possible . . . Usually the prescription or referral sent over is the most generic one they come across so they just choose something. It's my job and my duty to give the patient the best, most functional, and most appropriate brace for them. (M. Bryant, personal communication, March 3, 2020)

As for roles, providers play an extensive part in promoting adherence and should evolve their roles with each patient, hence the inclusion of 'flexible roles' within the network. When examined against the case of prescribed medication regimens, patients prescribed assistive technologies encounter the same concept of adherence. Based on interviews within a diabetes

clinic, Lutfey concludes that practitioners take on multiple roles to promote regimen adherence, such as an educator, a salesman, and, rarely, a policeman (2005). In the context of the current research, these roles can and should be implemented; patients should be taught about their afflictions and guided through technical skills necessary for managing their prescribed device within environments, thereby driving motivation for adherence. The providers must facilitate communication and identify patient constraints to achieve the best levels of use possible. Additionally, actions of a 'salesman' make the patient aware of the benefits to reap through assistive technology (AT) use. Policing, even if to correct bad habits early, is generally discouraged as it can create a lack of trust and general resistance in the future (Lutfey, 2005).

If a provider forces a passive patient stance, their relationship can suffer from similar outcomes and AT abandonment could occur. Lutfey and Wishner propose that imposing an authoritative role shifts the intended adherence towards compliance (1999). Patients may feel they are not heard and do not have a choice in the device-choosing process, and might be dissatisfied with the outcome. Indeed, discontinuance has been linked to users feeling they have minimal say in equipment decisions (Phillips & Zhao, 1993, Riemer-Reiss & Wacker, 2000, Wielandt & Strong, 2000). Different roles have the potential to reduce non-use and should be implemented in various ways. As patients and their needs vary, providers must find the right type of position to take without harming the relationship or reducing client autonomy. In addition, these health care professionals must be appropriately trained to handle various patients and to communicate effectively with other providers in the patient's own medical network.

Eligibility and Funding Mechanisms

Eligibility criteria and financial support are heavily intertwined, as the former influences the latter. The position paper reported that accessibility is hindered by eligibility requirements for AT equipment and extent of funding; these issues can possibly be mitigated by establishing

specific budgets and de-centralization of the medical model (de Witte et al., 2018). Instead, the current research proposes that proper documentation knowledge and device programs are suitable related efforts for reducing abandonment.

Eligibility and coverage barriers include varied medical necessity interpretations, service provider restrictions, and incorrect documentation of medical cases (Institute of Medicine Committee on Disability in America [IMCDA], 2007, section 9). As a result, the patient runs the risk of receiving AT deemed incompatible for their needs, which is a relatively significant reason for abandonment (Riemer-Reiss & Wacker, 2000, Verza et al, 2006, Wielandt & Strong, 2000). Public health plans rely heavily on 'medical necessity' criteria for AT coverage, particularly when concerning orthoses, prostheses, personal mobility ATs, and devices needed for activities of daily living (IMCDA, 2007, Table 9-1, section 9). The GREAT Summit position paper's emphasis on transforming the medical model into more of a generalized decision model is not a favored approach; modifying eligibility would require higher insurance costs and documenting effectiveness of technologies, which in turn increase research costs (IMCDA, 2007, section 9). Some of the aforementioned barriers can be minimized when the final providers have appropriate knowledge of and double-check case documentation; physicians have to provide detailed documentation for insurance and Medicare concerning why a certain prescribed AT is needed, but do not typically know how. Therefore, within the case of a prosthetic and orthotic (P&O) clinic, the P&O provider "is responsible to make sure the [physician's documentation satisfies] the policy and [receives] insurance coverage of the device" (M. Bryant, personal communication, March 3, 2020).

Financial support for AT could influence device use as cost is a highly valued product attribute for adoption by the elderly population (Ahn et al., 2008, p. 254). Though funds are

sometimes available, such as those from the federal Assistive Technology Act, funding for each state is not directly aimed at providing for provision services (IMCDA, 2007, section 9). Just as with the production-based affordability discussed previously, existence of used-device loaning and trial programs could decrease financial investments and chances of abandonment. These programs would give potential users a chance to see if the specific AT is right for them for the intended environments of use. If the equipment is ill-suited for them, then patient and insurance spending is not wasted on devices abandoned within the first year (Phillips & Zhao, 1993, Verza et al., 2006).

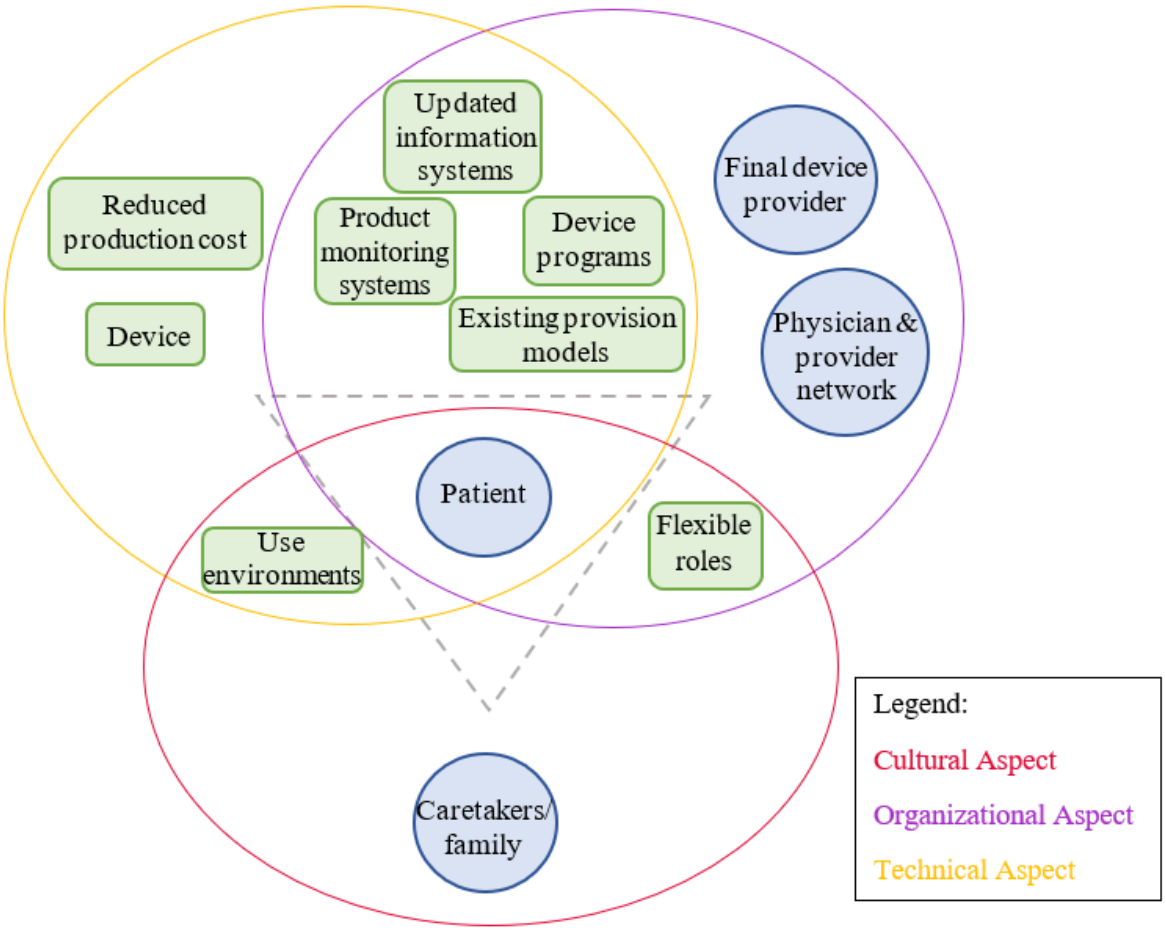
Infrastructure for Maintenance and Repair

Finally, de Witte et al. asserted that infrastructure is needed to "ensure that products . . . continue to meet the needs of the user" (2018, para. 1). Addition of a product monitoring system to the network reduces chances of abandonment by addressing device quality and functionality changes. Following through with a patient-device match benefits all parties involved; user feedback and maintenance reports serve as useful information for the equipment manufacturer. Additionally, the user can inform the provider or health care team on the case of any health or circumstance changes that shift the usefulness of the product, thereby allowing for the opportunity to receive a different AT and training for using the new item in desired environments (Wielandt & Strong, 2000). Consistent incorporation of such a system places heavy emphasis on direct and indirect product monitoring, which are "essential" for product engineering (Martin & Schinzinger, 2010, p. 79).

HOW PROVISION STANDARDS SHIFT THE NETWORK

THE IDEAL SYSTEM

In summation, specific suggestions from the position paper were chosen to replace the missing actant in the patient-device network, as shown again in Figure 3 below.



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The authors discussed important shortcomings of and associated suggestions for AT provision, specifically applying their guidelines to generating more global AT accessibility. Here, the same principles were applied in the context of abandonment of prescribed devices.

The provision elements believed to hold the most promise for addressing abandonment

are device programs, lowered manufacturing costs, and professionals' flexible roles. As previously mentioned, device programs give users the opportunity to determine if that type of AT is right for them and their lifestyle goals. The ideal outcome is for the patient's level of independence and ease of activities to increase through the use of a compatible product. Reduction of upfront product costs may be more easily achieved when compared to the complexity of public health plans; funding changes enacted by insurance policies appear unlikely, especially in the near future. Finally, the team members involved in the patient's case should play a large and evolving role to provide assistance in every step of provision. In addition to the heavy stigma surrounding those with disabilities, people are hesitant to adopt technologies that appear to validate their disability (Verza et al., 2006). Not only must medical practices be carried out ethically, but providers must also adapt to help patient's overcome psychological barriers and influence adoption by implementing role flexibility.

FUTURE CONSIDERATIONS

Though the WHO position paper identifies an immense global need for increasing accessibility of assistive equipment, it is unlikely that one specific provision model will be the perfect fit for all patients and communities. In efforts to eventually reach that ideal, the general field of assistive devices could benefit from more standardized methods of assessing abandonment in order to make more appropriate changes for each community. There appears to be a lack of consistent abandonment rates reported which may be due to varying survey methods, questions asked, and the differing communities in question. Information vital to the field also includes the demographics of users and non-users, such as age, race, gender, economic status, disability, and geographical area. Despite these differences and challenges, of highest importance is using a patient-centered approach to device provision whenever possible even without all provision standards implemented; not every ideal change to the existing system will be

physically or economically feasible, a view shared by Wielandt & Strong (2000). Additionally, if no financial or systematic support comes from federal or state governments, the issue of device adherence might benefit instead from community-based solutions.

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