

# **“That’s frustrating” - Stakeholder perceptions: provision processes, use, and future AFO needs for people with cerebral palsy**

Nicole L Zaino<sup>1</sup>, Momona Yamagami<sup>2</sup>, Kristie Bjornson<sup>3,4</sup>, Deb Gaebler-Spira<sup>5,6</sup>, Katherine M Steele<sup>1</sup>, Heather A Feldner<sup>3</sup>

<sup>1</sup>Department of Mechanical Engineering, University of Washington; <sup>2</sup>Department of Electrical and Computer Engineering, University of Washington; <sup>3</sup>Department of Rehabilitation Medicine, University of Washington; <sup>4</sup>Department of Pediatrics, Seattle Children’s Research Institute; <sup>5</sup>Department of Physical Medicine and Rehabilitation, Northwestern University; <sup>6</sup>Shirley Ryan AbilityLab

## **INTRODUCTION**

Cerebral palsy (CP) is a neuromuscular disorder caused by a non-progressive brain injury to the developing brain. CP is the most common pediatric motor disability in the US, affecting over 2 per 1000 live births [1,2]. Since CP affects gross motor function, individuals with CP require use of mobility aids throughout their lifetime. Ankle-Foot Orthoses (AFOs) are commonly prescribed for individuals with CP to allow for support or improve mobility [3]. AFOs can significantly impact alignment, quality of life, and participation interaction with peers. Successful AFO use relies on specific goals of treatment but also comfort, ease of use, and overall user acceptance, which has only been explored to a limited extent in rehabilitation literature.

The purpose of this study was to better understand the lived experience of people with CP and their caregivers regarding AFO access, use, and priorities for participation. We were particularly interested in exploring user experiences of the perceived purpose, provision processes, barriers/facilitators to use, and ideas for future AFO design and implementation across the lifespan.

## **METHODS**

Using a phenomenological research framework, a qualitative study consisting of focus groups and individual interviews was completed across four large metropolitan regions; Boston, MA, Chicago, IL, Los Angeles, CA, and Seattle, WA. All procedures in this study were approved by the authors’ institutional review boards, and written consent and verbal assent where appropriate was obtained by all participants prior to initiation of study procedures. Focus groups and interviews were audio-recorded, transcribed verbatim, and coded for analysis using constant comparison until themes emerged.

### **Participants**

74 caregivers and 68 people with CP participated or were represented by a caregiver in 20 different focus groups. 51 of these individuals specifically discussed having previous or current AFO experience during the focus groups. The represented age range of individuals with CP was: 10 [0-6 years], 18 [7-12 years], 19 [13-20 years], and 21 [21+ years].

### **Procedure**

The de-identified transcripts were analyzed and coded using constant comparison until themes emerged. Two authors (NZ & MY) completed independent content analysis using inductive coding using a hierarchical coding framework. Any differences in interpretation were resolved through discussion until a 100% consensus was reached. The codes were then consolidated into themes through discussion.

## **RESULTS**

Three themes emerged from the data:

- (1) *AFO provision is a confusing and lengthy process* describes how multiple appointments, frequent delays, and adjustment issues throughout the AFO provision process are common challenges for people with CP.
- (2) *Discomfort and difficulty can lead to abandonment* describes how individuals with CP recognize the benefits of AFOs, but challenges with heat, fitting into shoes, and difficulty donning/doffing the AFOs lead to decreased use or nonuse over time, especially in adolescence and adulthood.
- (3) *Despite challenges, AFOs can benefit mobility and independence* describes how individuals with CP and their families recognize the impact of AFOs in facilitating meaningful participation across environments and contexts, despite struggles encountered during daily use.

## **AFO provision is a confusing and lengthy process**

22 participants (4 users, 18 caregivers) discussed significant challenges with the AFO process; including getting a prescription, finding and interacting with orthotists, as well as fitting, modifying, and outgrowing AFOs. A total of 7 participants (1 user, 6 caregivers) said that finding the right orthotist was important for comfort and brace modifications. One caregiver said, *"finding somebody that can do really good AFO work [is hard]...we've been through a lot of providers before we got to our orthotist, who by the way I love."* The length of the process of receiving an AFO from prescription through casting to fitting and modifications was also a frustration mentioned by 7 participants (1 user, 6 caregivers), one of whom wished that they didn't *"have to show up in the clinic 17 times before [they] can get [their child's] AFO"*.

Another aspect of the process that caused frustration was insurance coverage with 11 participants (2 users, 9 caregivers) mentioning the cost and coverage of AFOs. In particular, 8 caregivers mentioned how quickly their child outgrows their AFOs and the challenge of managing insurance coverage. As one caregiver shared, *"to have to keep rationalizing to an insurance company, like my son has growth spurts, but yet he can't have new AFOs. And if the AFOs don't fit in the middle of his leg instead of closer to the top and his feet are hanging over, it doesn't matter. He hasn't used them long enough to do another [set]."*

Many participants proposed their own design ideas to address these challenges. One caregiver said *"...if it could even grow as they grow, [that] would be awesome."* Two caregivers noted a way to improve future AFOs would be quicker manufacturing, and 3 participants (1 user, 2 caregivers) said that AFOs should be adaptable.

Many participants experienced confusion and frustration during AFO provision. A total of 12 caregivers mentioned a time they were confused, uninformed, or wanted more education. Eight participants (2 users, 6 caregivers) mentioned the difficulty getting and fulfilling a prescription. One caregiver of an adult with CP provided insight that *"I can't find anybody to make these orthotics. I have a prescription, insurance is paid for and I keep hearing 'we only do children, we only do children, we only do children.' So, he's aged out of them."* Additionally, 10 caregivers noted that the reason for the type of AFO prescribed was often not understood or explained. One caregiver noted, *"I think when we first started with equipment, it was kind of passive with the PT [telling us what] we needed."* One caregiver noted they didn't understand the choice of AFO or why these choices changed over time, mentioning, *"It's solid. It's not jointed. It used to have a joint, but this is all one piece of plastic."*

## **Discomfort and difficulty can lead to abandonment**

The most common reason for abandonment of an AFO was due to discomfort. Four participants said discomfort was the reason for abandonment, which included skin irritation, pain, and heat. A total of 13 participants (3 users, 10 caregivers) mentioned the braces being hot. Five participants (2 users, 3 caregivers) noted that they did not use AFOs in the summer due to the braces being hot, uncomfortable, and causing skin irritation, with one parent discussing that a challenge is *"...how hot they get in the summer. He gets really uncomfortable in the summer and doesn't want to wear them as much."* Another caregiver suggested *"[the orthotists] should put vents inside of the AFOs."* One caregiver proposed that *"...every month you should come in just to see if they're doing okay. Are they rubbing up?"* to prevent skin irritation.

Difficulty of use broadly covered the inability of users to put their AFOs on unassisted, and the durability of the AFOs. A total of six participants (1 user, 5 caregivers) mentioned that the AFOs were difficult and time consuming to put on. One caregiver provided a future design idea to improve this problem, *"I think with the braces and shoes, if you could literally just have it open up together and be able to put your foot in and close and have it waterproof would be awesome."* A total of 10 participants (1 user, 9 caregivers) expressed their frustration with AFOs not fitting in shoes and 7 participants (1 user, 6 caregivers) mentioned the difficulty of finding shoes that accommodate AFOs, especially shoes other than sneakers.

## **Despite challenges, AFOs can benefit mobility and independence**

A total of 8 participants (2 users, 6 caregivers) said that AFOs were the most useful and beneficial device of their many supportive mobility devices, while 4 participants (2 users, 2 caregivers) said that AFOs were the least useful and beneficial device they had. A total of 11 participants (1 user, 10 caregivers) mentioned the AFOs provided support. Ten participants (2 users, 8 caregivers) said the AFOs improved walking ability, while only one user said AFOs decreased their ability to walk. One caregiver shared, *"She doesn't walk very well and she has got weak ankles and stuff so the AFOs have been really instrumental in helping her to walk at least a particular distance."* However, one individual with CP said that their least useful piece of equipment was, *"AFOs, they're totally painful."*

The use of AFOs also impacted psychosocial factors, with 4 participants (1 user, 3 caregivers) saying AFOs improved their (or their child's) independence and interaction with their peers. One caregiver shared that, *"He can feel close to his friends without having me around. I think he really enjoys feeling like he's included."*

## **DISCUSSION**

Individuals with CP who use AFOs and their caregivers experience many challenges including difficulty in obtaining AFOs, confusion in the acquisition process, and poor comfort and ease of use. However, AFO users and their caregivers expressed that there are benefits of AFOs. These perceptions highlight opportunities for improving AFO design, acquisition and use that can support mobility and participation among people with CP.

Finding an orthotist was a challenge for many caregivers. One solution is for providers to give suggestions on where and with whom prescriptions can be filled with greater transparency and clarity regarding insurance coverage. Additionally, participants emphasized the need for education and resources on transition once the individual with CP turns 18 years old, a challenge common to those with childhood disabilities. Maintaining pathways for acquisition and orthotic care throughout the lifespan is critical to support employment and quality of life.

The length of the AFO provision process, including casting, fabrication, fitting, and modifications, was another common complaint. A common suggestion among the participants to reduce the time required for this process was 3D printing. While 3D printing is in its infancy for orthoses there may be other ways to address the length of the process, while also providing lightweight and customizable AFOs [4]. Another idea provided by a caregiver was scanning the leg instead of the lengthy and messy casting process to increase efficiency. 3D scanning is a promising alternative that is being used with amputees; however, there are still variable results on the accuracy and reliability of 3D scanning compared to traditional methods of capturing foot and ankle morphology [5].

Participants' confusion and frustration with the process also suggest a knowledge gap that needs to be filled. Participants noted they did not understand why their AFO designs were changed. Participants also mentioned attempting to modify the AFOs themselves. Self-modification of the devices included not using the hard external AFO and just using the soft insert for added comfort. This suggests that there was a lack of understanding of the purpose of the components of the AFO, as the soft insert does not function and support the same way without the hard external AFO shell. This has significant clinical implications for both safety and long-term use. Providing additional education and clear communication to caregivers and AFO users is a simple way to address these concerns. This could include enhancing education about AFO selection, how an AFO will support function and participation goals, and how to address common challenges like pain or hot areas. Simple and clear standards for sharing information may not only address many of the frustrations expressed by the participants in this study, but also decrease rates of abandonment and support improved communication between often complex care teams.

One of the main limitations of this study was the small number of individuals with CP that participated in the focus groups relative to caregivers. It is important to acknowledge the difference in perspective from the lived experience of an individual with CP compared to a caregiver. One area where this difference was most visible was in the proposed ideas to improve AFOs in the future - caregivers focused on ways to improve the process and fabrication of AFOs and ease of use, while users focused on ways to improve ease of use and comfort.

## **CONCLUSION**

This research provides insights into the lived experiences of individuals with CP and their caregivers, highlighting perceptions of the AFO provision process, use, challenges, and benefits. The number of design ideas mentioned by participants highlights both current design limitations as perceived by users and families, as well as opportunities for design innovation. Future research should focus on collaborative design and engagement with individuals with CP across the lifespan and clinical teams to establish educational and functional processes and products that can support care, function, and participation across the lifespan.

To conclude, this caregiver perspective underscores the complex landscape of AFO provision and use: *"As difficult as it is to get and as expensive as it is to get, as cumbersome as it is, if all that stuff disappeared, he couldn't participate to the extent that he does. He couldn't experience life as he does, so there's lots to be critical of but it's also enabled a lot."*

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